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Studies of caregivers of children with disabilities have historically assumed a deficit or disease model, while at the same time relying heavily on quantitative measures of stress and maladaptive behaviors. There is a dearth of qualitative and constructivist research into caregivers who are successfully thriving while caring for children with significant physical and cognitive disabilities. The purpose of this dissertation is to use parent/caregiver narratives to provide a fuller picture of how the experience of raising a child with disabilities might in fact be positive and transformative. Eight caregivers and caregiving couples who self-identified as resilient, hopeful, and as advocates for their children are interviewed in both school and home settings, with the goal of giving medical, educational, and therapeutic professionals a fuller, more intimate picture of these lived experiences. A post-critical, ethnographic framework—putting the interviewer and interviewee in conversation with one another while preserving the textual integrity of the participants' stories—is central to the research methodology. Internal and external systems of caregiver support are examined, as well as the privileged concept of normalcy which acts to thwart full societal acceptance and inclusion. Implications for caregiver and community responses through advocacy, an ethic of care, and public policy initiatives are proffered.

MEETING DISABILITY WITH RESILIENCY, HOPE AND AGENCY:

A NARRATIVE STUDY OF CAREGIVERS OF CHILDREN

WITH COGNITIVE AND PHYSICAL DISABILITIES

by

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To my study participants—moms, dads and foster parents—who are caring for children with profound disabilities. Their steadfast love for their sons and daughters and fierce dedication to procuring for them the best quality of life possible is beyond telling. I am grateful that these busy people extended to me the gift of their time, so that I might better understand the caregiving experience. To be privy to their hopes, fears, and joys was a profoundly illuminating experience that I will carry with me always.

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To my bright and energetic mother, who has been my champion and cheerleader throughout my life, this latest chapter no exception; her generosity of spirit has never wavered. And to my birth and step-fathers, both now deceased—they would have been so proud of my efforts. I owe my parents a debt of gratitude for their abiding confidence in me, their own thirst for learning, and their unconditional love.

Last, to my husband Jack, childhood sweetheart lost and reclaimed after a three decade hiatus. One of the first things he said to me when we reconnected was this: “Wait . . . you’re not *Dr. Kirby*? What’s up with *that*?” He set about making sure that I could indeed become *Dr. Kirby*, giving me space (literally and figuratively) to read and write, making it possible to survive my demanding day job as a public school principal and my “night and weekend job” immersed in this second labor of love. My dear Jack, sometimes there really are fairy-tale endings; you are mine.

APPROVAL PAGE

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PREFACE

How many of us have looked away, in a store or on the street, from a mother pushing a young child with severe disabilities in her wheelchair? We are distressed and unhinged by the sight of tubes, wires and equipment. We avert our glance from a child who may not fit the visible norms to which we have become inured. Most of us would admit to experiencing these moments. We have held our breath, perhaps attempted a wan smile, and have gone on with our lives—untouched (“thank goodness,” we think secretly to ourselves) by what we perceive as grave hardship.

The stories of how these mothers, fathers, and other caregivers navigate in an ableist world, how they advocate for their children, and how they are not merely coping, but in fact thriving, remain veiled from the mainstream. There is a need for researchers to explore these stories, privilege them, and make them explicit for the majority culture, a culture in which most children are healthy of mind and body.

There are caregivers with the power to upend and disrupt our ill-conceived notions of pity and discomfort. I hope you will join me in listening to their stories.

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CHAPTER I

INTRODUCTION

Overview

Much educational research on parents and other caregivers of children with disabilities has focused on a deficit or “disease” model (Guetzloe, 1991; Maes, Broekman, Dosen, & Nauts, 2003; Michelson, 2001; Parrish, 2010; Pipp-Siegel, Sedey, & Yoshinaga-Itano, 2002; Trute, Hiebert-Murphy, & Levine, 2007). Medical and educational professionals and researchers have propagated the meme that brands these families as diminished or damaged by the experience of raising a child with disabilities. Surveys and rating scales used by the authors cited above have meticulously gauged families’ levels of unhappiness, stress, alcohol and drug use (and abuse), and incidence of divorce. Through the privileged lens of the able-bodied, those who care for children with disabilities are imagined as leading lives devoid of the joys accorded “normal” families. Thus, there is a pressing need for qualitative research into the flip side of this phenomenon, studies exploring *what is working* for caregivers of children with disabilities.

Qualitative research is a multi-faceted field; narrative inquiry is one of those dimensions. As detailed by Clandinin and Connelly (2000), narratives go beyond reductive storytelling, often embracing multiple data sources such as autobiographies,

journals, letters, conversations, field notes, and visual media. And beyond mere rote recitation of the data, the authors insist that narrative inquiry must also transfer this knowledge to others, placing the onus of responsibility upon the researcher and eventual readers to immerse themselves into the process, creating subtexts unique to personal interpretation. This challenge is echoed in the work of Goodall (2000), who presents the process of narrative inquiry through the metaphor of researcher as detective:

The detective story is all about learning to read and to follow the clues that get you to—and through—the storyline. Learning to read clues into the weave of contexts. Learning the histories and conversational flows of a discipline. Figuring out how things add up. Being a good detective is about using observations and interviews to elicit information and then using the information to establish motives, patterns, and connections. (p. 24)

While Goodall's advice may seem simple and straightforward, what he suggests requires thoughtful data collection and methodical analysis. Learning the "conversational flows" of the culture of disability is an imperative; the white noise of privileged (read: able-bodied) positionality must be set aside. A framework drawing upon narrative inquiry subsumes the gravitas accorded the able-bodied population and their presumed right to define "normalcy" for others. Authentic voices (in the form of first person oral narratives) of parents and other caregivers raising children with disabilities must be honored and amplified if a substantive cross-cultural conversation is to take place.

Significance of the Study and Intended Audience

A qualitative approach that foregrounds parental/caregiver voices and perspectives expands the body of research begun by the first wave of quantitative researchers. Richly textured narratives provide valuable insights for professionals whose lives intersect with children with disabilities and their families. A quote from Brown's (2009) memoir *The Boy in the Moon* captures this rift between the able-bodied and the disabled world:

Raising Walker was like raising a question mark. I often wanted to tell someone the story, what the adventure felt like and smelled and sounded like, what I noticed when I wasn't running through the darkness. But who could relate to such a human anomaly, to the rare and exotic corner of existence where we suddenly found ourselves? (p. 10)

Physicians in a multiplicity of disciplines (pediatrics, orthopedics, neurology), therapists (speech/language, physical, occupational), and educators (classroom and resource teachers, administrators) all benefit from a deeper understanding of the children they serve and the caregivers who support them. Families raising children with disabilities can learn from one another's stories, finding common ground while also discovering novel strategies to incorporate into daily living. Beyond reading the narratives of fellow parents, some caregivers might be stirred to share their own stories of dealing with disability through oral (support groups) or written (blogs, published works) modes. Research that actively involves the parents of children with disabilities can become a lodestone, attracting others within the community to join the "talk."

Berube (1996) expressed this need for tolerance in his plea for inclusion and acceptance for his son, Jamie. He made clear the need for the sharing of stories—everyone’s stories—so that we may better understand and care for one another. Berube puts forth the precept that each member of society is a valuable, contributing constituent—a part of the aggregate.

The ideal of social justice is founded on a collective dialogue—or, more precisely, polylogue—in which all social actors contribute their notions of individual and collective good . . . We would be well to seek the ground for human justice in our capacity to communicate with one another, regardless of whether we have sustained hearing loss in one ear, regardless of whether we are capable of uttering proper names, regardless of whether we mumble, regardless of whether we communicate by ASL. (p. 244)

Placing this call within the social justice realm is not an original idea; many before Berube have found congruence between the community of disabilities and other disenfranchised groups. But when this petition comes from a caring father, seeking a place in the world for his son, it has great urgency. Researchers, medical and educational professionals, and even legislators all have roles to play in insuring that children with disabilities are not forgotten. But it is parents and caregivers who have the most intimate knowledge of critical needs, and the passion to see that those needs are met.

Paradigm and Theoretical Framework

Defining the various paradigms or theoretical frameworks from which researchers can approach their work is a compulsory step toward clarifying the

individual researcher's preferred approach to any study. But as Hatch (2002) reminds us, even the word paradigm itself is a foggy notion:

Paradigm is one of those words that is overused to the point that its meaning has been lost. Writers of popular books about everything from business to gardening use the notion of a paradigm shift to sell the importance of their products or ideas. I've heard television preachers use the term, seen it on the back of trucks going down the highway, and read a brochure that touts a new paradigm in termite control. (p. 11)

Paradigm as a catch-phrase has been overused and commodified, to be sure. But by pulling back from the worlds of advertising and self-help and delving into more academic loci, a more carefully-crafted and philosophical meaning can be studied.

Drawing upon seminal work of Kuhn (1970), which bucked the heretofore existing belief that all science was innately objective, Hatch and others (Bettez, 2010; Glesne, 2011, Lichtman, 2010; Reitzug, 2010) have defined paradigms as multiple ways of looking at the world. More precisely, paradigms are "sets of assumptions that distinguish fundamentally different belief systems concerning how the world is ordered, what we may know about it, and how we may know it" (Hatch, 2002, p. 11). It is critical, then, to first drill down below questions of mechanics ("What or who do I want to study?" "What research questions do I want to answer?") to delineate my own philosophy on how the world "works" by examining competing world views or paradigms.

Traditional research paradigms lay claim to a clear Truth—an objective, unchanging reality that is waiting to be uncovered or discovered. Early research work in

the field of the social sciences drew upon these ideas, often labeled as positivist or modernist thought. Those who adhered to (and continue to cling to) this paradigm believe that the researcher and the research subject must maintain a distanced, hierarchical relationship, and that studies should be untainted by bias or opinion. This clinical approach can no doubt have merit for scientific studies requiring rigorous methodologies and controls. But when applied to the study of human behavior and cultures, a positivist underpinning places the researcher in the role of judgmental colonizer. As Denzin, Lincoln, and Smith (2008) warn, it is “a way of controlling the foreign, deviant, or troublesome Other” (p. 4).

As post-positivist ideas began to take hold in the years following World War II, some researchers embraced a multiple-methods approach resting upon the philosophy that a static, consistent reality or Truth did in fact exist, but at best could only be approximated. Still insisting on rigorous adherence to disciplined data collection and analysis, these researchers “subject[ed] truth claims to close critical scrutiny in order to maximize chances of apprehending reality as closely as possible—but never perfectly” (Hatch, 2002, p. 14). While post-positivism represented an expansion of the ideas that came before it, the philosophy remained wedded to the modernist notions of control, fixed identity, and generalizations induced from patterns or commonalities in the data set.

These two paradigms “dominated the field of research in education until the 1980s” (Lichtman, 2010, p. 8). Yet increasingly, researchers began to challenge the

status quo, welcoming multiple truths, acknowledging the positionality and subjectivity of the researcher, and even incorporating calls for action and participatory roles on the part of those studied and those in the academy. This new post-modernist paradigm was not so much concerned with statistical validity and reliability—quantitative measures—but with rubrics of fairness, trustworthiness and authenticity. Thus, what Seale (1999) calls “a sometimes bewildering variety of new concepts arose” in what he names as “an endeavor whose guiding philosophy often stresses creativity, exploration, conceptual flexibility, and a freedom of spirit” (p. 171). A post-modernist, anti-foundational philosophy was born. Qualitative inquiry began to blossom, first covertly and as a “second-class” form of research, then as a respected methodological collective in its own right. Lichtman (2010) shares a succinct rationale for the shift toward acceptance.

There are several reasons for the increased interest in qualitative research that began in the 1990s. First, the opening up of the educational research field to women and people of color led to alternative sensibilities and alternative voices. No longer were quantitative studies (developed by white European men) the only choice of research methods; other ways of knowing might be considered just as legitimate. Second, there was a growing dissatisfaction with educational research findings based on quantitative studies alone. Educational research findings were often vague, subject to many problems in implementation, poorly disseminated, and often irrelevant. The public school community made decisions based on many factors other than research results. Third, teachers demanded a larger role in the design and conduct of research and were drawn more to action research projects. Finally, publishers broadened the base of their offerings, and methods drawn from many disciplines were disseminated to a much greater extent than previously. (p. xv)

My head and heart tell me that this post-modern paradigm and its qualitative tools are the only authentic way in which to approach my work with parents and caregivers of children with disabilities. But even within the parameters of post-modernist philosophy there exist multifarious though not entirely discrete tacks. Critical, Feminist, Constructivist, Post-Critical, Post-Structuralist, and Black Feminist frameworks all hold to this “new paradigm” model, striving to look behind the curtain of “the ‘imaginary real’ of history” and “risking an engagement with the difference of the other” (Merriam, 2002, p. 411).

From this wealth of new traditions, Lincoln and Guba’s (2000) explanation of constructivist theory most closely resonates with my vision for conducting narrative inquiry with caregivers. When the authors speak of “new paradigm inquirers . . . concerned with the single experience, the individual crisis, the epiphany or moment of discovery, with that most powerful of all threats to conventional objectivity, feeling and emotion” (p. 179), I recognize connections to my research aims. The parents of children with disabilities are plunged into “crisis” experiences with the births of their children. Yet for numerous parents, this life-changing occurrence is wedded to a positive transmogrification, a redefining of self and purpose. My hope was to create an open space for verbal exchange with my research participants. The parents and other caregivers of disabled children are perhaps by necessity constructivists themselves; they deal on a daily basis with the need to accept undefined realities, with truth as a fluid and emerging *construct*, not a given. In a world defined by the parameters of the non-

disabled community, a narrative, open-ended conversation is needed, allowing the parents of children with disabilities to share (and at the same time, construct) their realities. Constructivist theory, then, matches my own perspective on how to approach my study participants and the research process itself.

While constructivist theory is a touchstone for unpacking my views on how to approach research, other theories can also contribute to a better grasp of the underpinnings that guided my study. Like Lincoln and Guba (2000), I maintain that “there is great potential for interweaving of viewpoints, for the incorporation of multiple perspectives, and for borrowing or *bricolage*, where borrowing seems useful, richness enhancing, or theoretically heuristic” (p. 167). Hence, while I embrace constructivist theory’s focus on allowing each individual to make sense of his or her singular life experiences, my research design drew upon other theoretical frameworks as well. Post critical ethnography, as defined by Hytten (2004), “stems from the felt need to make research more socially relevant and more influential in efforts at social reform” (p. 95). Hytten’s account of post critical ethnography describes it as a means to effect social transformation and to reject research methods that “seem to benefit only the researcher (i.e., in the tenure process) or that serve to unproblematically reproduce the status quo” (p. 95). This viewpoint is particularly relevant to research into the lives of caregivers of children with disabilities, as the “status quo” for them is filled with barriers to full inclusion into community. Hytten asks the researcher “to let the voices of marginalized groups speak,” to promote “reconstruction and representation of their

voices in ways that subvert efforts to sustain their powerlessness” (p. 98). Research that centers upon narratives of parents of children with special needs is in accord with this post critical line of thought. We are called by Hytten to “to change the material conditions of oppressed peoples’ existence in emancipatory and empowering ways” (p. 98). The world of disabilities is laden with hindrances to acceptance and power. A post critical ethnographic framework, like that outlined by Hytten (2004) “alter[s] the traditional relationship between the researcher and the researched such that the research subjects’ voices, problems, and concerns become the focus of the research,” with the *participants* (which I prefer over Hytten’s choice of the more clinical descriptor “subjects”) claiming “legitimacy and authority to produce socially useful knowledge” (p. 101).

Denzin et al. (2008) speak of the “nonindigenous scholar” who must learn “how to dismantle, deconstruct, and decolonize traditional ways of doing science, learning that research is always already both moral and political” (2008, p. 3). Darder and Miron (as cited in Denzin et al., 2008) submit an outright audacious yet compelling argument: that love is the grounding force in our efforts toward understanding one another through the research process. They call love

An essential ingredient of a just society . . . love is a political principle through which we struggle to create mutually life-enhancing opportunities for all people. It is grounded in the mutuality and interdependence of our human existence—that which we share, as much as that which we do not. This is a love nurtured by the act of relationship itself. (p. 3)

By initiating my research with these goals gleaned from both post critical and constructivist thought as my framework, I entered into relationship with caregivers and parents, approaching the work in ways that honored the participants' voices. I allowed meaning to be constructed through dialogue, with the hope of reaching for Lincoln and Guba's (2000) "epiphany or moment of discovery" (p. 179), and the loving interdependence that Darder and Miron hold up as the gold standard.

Research Questions

- What proactive strategies do families (mothers, fathers, grandparents, and other caregivers) of children with disabilities use that enable them, when faced with challenging circumstances, to remain resilient and hopeful?
- What stressors are common to the lived experiences of families of children with disabilities? When families *are* successful in building lives (or perhaps moments) of hope and resiliency, what ameliorates their stressors?
- How do families navigate the dominant cultural stereotypes of "normal" behavior, intelligence, or able-bodiedness? For families that succeed in redefining normal, what are their strategies for replacing a "deficit" mindset with a paradigm of inclusion, acceptance and even celebration of the diversity of human ability and disability?
- What specific advocacy strategies do families employ to move the needle of acceptance in the local community (neighborhood, school, medical settings) for their children with disabilities? How do parents lobby for fuller

acceptance and inclusion of their children with disabilities into the mainstream of society in broader terms (social justice work, state and national advocacy groups, political/government action)?

Positionality as a Researcher

My desire to explore these research questions is framed within my own personal and professional story. I am a 55-year-old White, married, middle class, heterosexual woman, holding an undergraduate and two master's degrees. I have worked in public education for 34 years in a variety of roles: first- and second-grade teacher, reading teacher, curriculum coordinator, and school administrator.

Currently I am the principal of a joint public/non-profit school for children (age birth through eleven) with physical disabilities, chronic illnesses, and severe cognitive and developmental delays. I have spent the last 13 years of my career at this particular site, working closely with families as they navigate the cleave that exists between the world of disability and the mainstream culture of the able-bodied. I enjoy the privilege of working alongside these families, coordinating specialized instruction and therapies, acting as a facilitator for access to non-profit and government-based services, and perhaps most importantly, developing relationships with these caregivers as we strive to help their children reach their highest potential academically, physically, emotionally and socially.

My professional life affords an emic view into the world of special needs, yet my personal journey thus far has been free from the immediate impact of disability. My

three children and two step-children, all in their twenties and thirties, are able-bodied, as is my granddaughter. (My youngest son, born with a unilateral multicystic dysplastic kidney, functions just fine with one healthy kidney.) My spouse and I enjoy good health. But there have been encounters throughout my adulthood that have no doubt led me to both my professional concentration and my research topic. Kilbourne (2006) agrees that “it is appropriate to comment on one’s own biography as it relates to the study because this too is an issue of perspective—personal perspective” (p. 546). Caveats rightfully exist about the risks of sliding into self-indulgency (Glesne, 2011; Kilbourne, 2006). Researchers of a traditionalist bent might view the introduction of self into the mix as a risky venture, likely to contaminate data analysis. Yet I would make the case along with Glesne that our own history “can help [us] make use of personal passions and strengths” (2011, p. 159). Here are three bellwether events from my own history:

1975: During my freshman year of college, my grandfather, 69, had a massive heart attack and stroke. He survived, partially paralyzed on his left side, but never regained the ability to speak. He communicated through non-verbal utterances, gestures and facial expressions. My grandmother was his caregiver, and showed an amazing ability to find the positives in their trying circumstances. With her encouragement, my grandfather began to ride an exercise bike to strengthen his left leg and arm. When he had pedaled 24,902 miles – *the circumference of the earth* – their retirement home threw him a huge party. He kept riding that bike until he died, at age 89, a full twenty years after becoming disabled.

1986: In my seventh year of teaching, I was assigned a second grade student with Spina bifida. She was the first child with physical disabilities mainstreamed into my classroom, and I was apprehensive. Sandra was bright, funny, and determined to do everything that her classmates did, even though she used crutches (and occasionally a wheelchair) for mobility. She was a confident and

headstrong pupil, commanding the respect of even the rowdiest students. Her parents held high expectations for her, refusing to treat her differently from her older, able-bodied brother. Since Sandra lacked bladder control, she catheterized herself during the school day. I would find a colleague to watch the rest of my class while Sandra and I sat together on the floor of the bathroom, chatting and giggling like girlfriends while this tiny child nonchalantly went about her medical procedure. Sandra and I have remained in touch for a quarter-century. She is now a successful young woman with a college degree.

1998: When my friend Carly and her husband Bob discovered that they were expecting twins (after many fertility treatments and miscarriages), they were overjoyed. Everything changed when Carly went into pre-term labor. Abby and Madison were born at 23 weeks, 4 days gestation. (Babies at that time were not considered “viable” until 24 weeks.) Abby died after a five day struggle. Madison survived crisis after crisis, and after four months was finally released to go home, tethered to an oxygen tank, heart monitor, and apnea alarm. Other than Carly’s mother, I was the only person trusted to stay with Madison when her parents took a rare break. The doctors held out little hope that she would ever walk, talk, or eat by mouth. In February of this year Madison celebrated her fifteenth birthday, and while she faces hurdles (profound hearing loss, learning disabilities) she is a smart, beautiful teenager who *does* indeed walk, talk, and eat . . . as well as read, write, play piano, swim, and “text” prolifically with her girlfriends . . . and with me. I have the honor of being her godmother.

I came to understand fortitude and resiliency from my grandparents. Sandra tested my preconceptions and fears about teaching students with disabilities, and her parents taught me to set lofty expectations. As godmother to Madison, I have gained an understanding of the power of hope, and the ferocity of parental love. I present these three vignettes to situate my voice as an integral part of my study. I place myself as a co-participant in the research, rather than as a detached observer. Lincoln and Guba (2000), writing on the importance of sound qualitative processes, ask researchers in the field, examining the lived experiences of others, “to ‘locate’ themselves deliberately and

squarely within their texts” (p. 183). To that end, I included my most essential personal intersections with disability in an attempt to transform the etic subject/researcher relationship into one of co-travelers. Untying the Gordian knots surrounding caregiving and disabilities is a job best accomplished with all hands immersed in the work; disengaged onlookers or bystanders need not apply.

Chapter Summaries

This first chapter sets forth the case for an inquiry into the lives of caregivers of children with severe disabilities who experience resilience, hope and agency. I posit that a turn towards both qualitative study and a focus on those who are successfully navigating their caregiving roles is warranted. The theoretical frameworks which inform my research design are summarized. I offer preliminary research questions, and outline my own positionalities and most pertinent experiences in relation to disabilities.

In Chapter II, I provide a succinct précis of the current disability studies literature as it relates to the caregiving role. (Much additional research is cited in Chapters VI and VII to more tightly imbricate the data from my eight caregiving stories with past study outcomes.) In Chapter III I take a look back at how our country has dealt with disability over the last century and a half, specifically honing in on how parents and caregivers have manned the front lines of the disability rights movement as it has developed from its infancy to the present day.

Chapter IV covers the methodology and design of my research study, and the particulars of how it was implemented. Highlighting personal narrative and caregiver

voice, my study design rested heavily on the recruitment of participants that self-identify as hopeful, resilient, and proactive. With a relatively large amount of aural and eventually print-based data to process, a lucid plan for organizing and analyzing interview and blog material is delineated. Because of my position of authority in a disability-focused work environment and my membership in a variety of privileged groups, issues of trustworthiness are explored.

Chapters V, VII and VIII provide the nucleus of the study; interviewee data is first presented in stand-alone parent stories and is then mined for insights into discrete aspects of the caregiving role. Beginning in Chapter V, parents' narratives are presented anecdotally, offering the reader a soupcon of day-to-day life as a caregiver of a child with a severe disability. ("Birth stories" are a consistent part of these accounts.) Verbatim passages are preserved whenever possible to maintain authentic story flow. Chapter VI then delves into multiple systems of internal and external support, touching upon community agencies, family systems, spiritual convictions, and more, once again putting caregiver voice on center stage. In Chapter VII I explore personal and societal dynamics at work in the zeitgeist of caregiving and disabilities: resiliency and advocacy, normalcy, cultural obsessions with "the body," and junctures between disability and race, gender and class.

Chapter VIII looks at how topics addressed in the data might prompt an examination of larger societal, political, and ethical mores surrounding disability. (Are segregated spaces places of power or of marginalization for those with disabilities?)

Should a “cure” mentality be fully discarded? Will a culture and a political matrix that increasingly pays inordinate fealty to individualism and power cease to undergird its weaker, more dependent members?)

The concluding chapter examines ways in which this research study may have fallen short of the mark, whether in planning, execution, or in the “messy” business of working with unpredictable human subjects. I recommend areas for further study in the sphere of disabilities and caregiving, so that others in the field may continue the work of “writing in the gaps” (Lunenburg & Irby, 2008, p. 155) that has yet to be explored.

A Few Words about Language

People with disabilities have long been labeled as Other. Words such as “retarded” and “invalid” were once accepted medical terms, later became abusive epithets (Charlton, 1998), and are now, thankfully, memento mori. The disabilities community is accustomed to enduring, but is not hardened to, slurs still present in the common lexicon. M. Johnson (2003) provides a laundry list of actual headlines containing verbal slights to the disabled:

“Legally Blind on the Hudson,” “Hard Times Cripple a Football Legacy,” “Copyright Fine could Cripple MP3.com” . . . “Strikers Threaten to Paralyze Seoul,” “Irate Cuban-Americans Paralyzed Miami” . . . “Focusing on the Few, Blind to the Many,” “Genetics: Blind Spot in Medical Training,” . . . “Zimbabwe was ‘Deaf to Calls for Fair Elections’” (p. 136)

In an audacious move, disabilities activists now claim such words as “crip,” “gimp” and “freak” for their own, using their shock value as a badge of honor while defusing the

power of these terms to wound and control (Biklen, 1992). These innovative ways of naming belong only to those within the culture itself. Shapiro (1993) summarizes the conventional wisdom on the topic of naming this way:

Disabled has become the usage of choice, replacing “handicapped” in recent years and becoming the first word to emerge by consensus from within the disability community itself. More acceptable still is “person with a disability” (or “who is deaf” . . .) since it emphasizes the individual before the condition. (p. 33)

Shapiro’s description of preferred usage is now commonly referenced as “person-first” or “people-first” language.¹ I will adhere to this construction throughout my study. Since the terms “disabilities,” “special needs,” and “exceptionalities” are all currently in usage in government and academic settings, I use them interchangeably. While at times it can become syntactically cumbersome (sacrificing concise writing in the service of current political preference), I trust that the reader will concur with the person-first philosophy, and forgive the glut of prepositions!

A final remark concerning word choice: because all of the caregivers in my study were also parents or foster parents, I used the terms “caregiver” and “parent” interchangeably in the interest of narrative flow. Caregivers were also referred to on occasion by the descriptors “participant,” “volunteer,” “mother,” or “father” (but never “subject”). I have faith that my readers will appreciate this wordsmith’s attempt to avoid monotonous language, and will be able to follow the text with minimal confusion.

¹ For an excellent overview of this concept, see <http://www.thearc.org/page.aspx?pid=2523>.

CHAPTER II

REVIEW OF THE RELATED RESEARCH LITERATURE

Introduction

According to figures from the 2010 United States Census, more than 4.2% of American children age six through 15 are living with a significant disability, whether cognitive, physical, or crossing both domains. Nearly .5% of families in our country are raising a child with a disability so serious that total assistance is required with “activities of daily living.”² For those of us living in the able-bodied world, these challenges are hard to imagine. “The parents of these children face the complexities of balancing normal parental tasks with treatment programs, additional physical duties, and needing to adjust emotionally to their child not living up to their expectations” (Paster, Brandwein, & Walsh, 2009, p. 1337). This sizable segment of our population merits the close attention of researchers, as there is tremendous potential to positively impact the lives of these children and the families that raise them if we take time to “unpack” their lived experiences. William James said that “a chain is no stronger than its weakest link, and life is after all a chain.”³ Perhaps this “four percent”—the families of children living

² See http://www.census.gov/hhes/www/disability/sipp/disab10/figure_2.pdf for a breakdown of disability prevalence by age and severity.

³ <http://www.1-love-quotes.com/quote/1778>

with disabilities—are in point of fact our *strongest* elements, and we, the other 96%, have much to learn from them.

Deficit Model of Disability

Researchers in a number of fields (education, psychology, nursing, etc.) have devoted considerable time and energy toward examining families that include a child with a disability. In general, these researchers have held to what could best be described as a deficit archetype, namely, measuring children by their variance from what is termed to be “typical” or “normal” for the majority population, that is, those who live in an able-bodied world, or who vary little from cognitive and behavioral norms. Scholars such as Valencia (2011) continue to examine and deconstruct the pervasive idea that fault lies within the individual when educational or societal norms are not met. Yet we find that there is a hefty corpus of research which accepts that parents, siblings and even extended families are somehow diminished by the experience of caring for a child with special needs. Trute et al. (2007) state that “the family practice and research literature has tended to dwell on the deleterious effects of childhood disability on family life, highlighting parental sorrow, marital discord, and family instability” (p. 1). Words and phrases such as *stigma*, *depression* (Michelson, 2001), *stress* (Pipp-Siegel et al., 2002), *caregiving burden* (Maes et al., 2003), *depression*, *suicide* (Guetzloe, 1991), and *grief process* (Witcher, 1989) appear with abiding regularity in the existing literature. The overriding calculus derived from these studies is that a child living with a disability is literally and figuratively broken, and somehow less

than fully human. The family of such a child, under this cock-eyed theory, is negatively impacted by the aberrant family member. (And do note the irony of this colloquialism. “Cock-eyed” was a pejorative previously hurled at those with vision deficits.) We see a uniform insensitivity borne out in a number of other language choices commonly made, even today, to describe people with disabilities: “She *suffers* from Multiple sclerosis,” or “He is a *victim* of Spina bifida.”

The most glaring flaw in this past pool of research focused on deficits in individuals—both those with disabilities and their caregiving families—is that it presupposed that a perverse pathology resided in the *person*, not within the system itself. Societal attitudes and prejudices were not examined; systemic discriminations, so pervasive as to be invisible, were accepted as status quo.

Quantitative Measures

It bears mentioning that parents and caregivers in the cases above were evaluated using quantitative surveys and rating scales. Data were assembled using such measures as *The Family Impact of Childhood Disability Scale* (Trute et al., 2007), *The Reiss Screen for Maladaptive Behaviour* (Maes et al., 2003), and *The Center for Epidemiologic Studies Depression Scale* (Michelson, 2001). The findings of these metrics-based quantitative studies contributed to the body of research, and no doubt led to greater recognition of the trials faced by parents of children with exceptionalities. We can be appreciative that much time and attention was indeed given over to this “four percent” by quantitative researchers. Yet I would argue that ephemeral emotional

states such as grief, anger and sorrow might be more humanely explored through qualitative study. Adding depth and shadow to the picture painted using quantitative instruments by introducing qualitative methods (interviews, focus groups, and observations) can add rich and colorful layers to this growing field of inquiry.

Discovering Outliers: The Shift towards “What Works”

Clearly it can be discouraging to review disabilities research from the last half-century, skewed, as it is, towards viewing these particular families as damaged goods. Yet a growing anthology of discourse is aiming to ferret out “what works” in families with disabilities. There are, thankfully, a number of research studies that focus on parents’ *positive* coping strategies (while still unfortunately still using only quantitative methodologies). Pitchlyn, Smith-Myles, and Cook (2007) looked specifically at the role of religion and spiritual beliefs in the lives of parents with adolescents with cognitive disabilities, finding these factors to be mitigators of stress. Paster et al. (2009) compared 112 suburban, White, wealthy (\$100,000+ yearly income) families, half of which had a disabled child, and found little difference in levels of dysfunction when the families of children with disabilities reported strong systems of support. Fallon and Russo (2003) concluded, after surveying 253 United States active duty military members with disabled children, that adaptation, resilience, and healthy coping strategies were actually *the rule* for this specific group, rather than a deviation. Pipp-Siegel et al. (2002) hypothesized that their sample of 184 mothers of young children (6 to 67 months) with hearing loss would report greater stress when compared to demographically similar mothers of

hearing children. Yet these mothers scored *lower* on a parental distress subscale than the control group. Trute et al. (2007) reported that other researchers also began to turn away from “the tendency to dwell on the negative effects of childhood disability on family life” - a “pathogenic focus” (p. 1) - and began to center their research on questions that might yield proactive answers for families.

Hope and Positive Strategies

As the twenty-first century began, a number of researchers commenced an exodus from the deficit model of disabilities; there was also an effort to study specific subgroups within the disabilities community. While a wheelchair logo is commonly used as the synecdoche for handicapping conditions, cognitive impairments, often called developmental disabilities (DD) or intellectual disabilities (ID), in actuality affect more children and their families.⁴ Lloyd and Hastings (2009) examined *hope* as a factor of resiliency in mothers and fathers of children with ID. They defined hope as both agency (a perception that goals could be reached) and pathway (finding the means to reach these goals.) Lloyd and Hastings also spoke of the growing trend towards “positive psychology, which is a focus on adaptive, rather than maladaptive functioning, and on strengths and abilities, rather than weaknesses” (pp. 957–958). As predicted by the authors, hope proved to be a chief psychological resilience factor in the mothers and fathers in the study group. Yet once again, we find that parents were analyzed using six

⁴ The 2010 Census has plentiful data on the topic of children and disabilities in the report “School-Aged Children With Disabilities in U.S. Metropolitan Statistical Areas: 2010” http://www.cdc.gov/Features/dsDev_Disabilities/index.html

different *mailed questionnaires*; no emotional or physical connections were made between the researchers and their subjects.

Lloyd and Hastings were not unique in their desire to illuminate what works for families of children with special needs. Glidden and Natcher (2009) also studied families of children with cognitive disorders, pointing out that “parents of children with developmental disabilities (DD) may face many decades of caregiving responsibilities” (p. 998). They examined 68 married couples, 33 of whom had knowingly adopted a child with DD. Their participants were asked to complete five questionnaires which were, again, returned by mail. (This study proved particularly interesting, as the authors had polled this same cluster six years earlier.) Glidden and Natcher’s longitudinal work found that coping strategies had not changed markedly over time; the researchers also confirmed that those who use problem-focused coping strategies (actively controlling or amending the stressor sources, seeking social support) were better able to cope than those who used emotion-focused strategies (denial, escape, and avoidance). While cognitive disabilities may pose challenges that vary from the negative forces facing those with physical disabilities, this growing compilation of work points towards a fresh focus on hope and positive problem-solving for this particular subset within the disabilities community.

Resiliency

The world of disabilities is quite diffuse; while Lloyd and Hastings along with Glidden and Natcher honed in on parents of children with compromised cognitive

function, other researchers have examined other subgroups. Autism, for instance, is “a chronic disability that appears in all racial, ethnic, cultural and social backgrounds around the world and is more common than childhood cancer, cystic fibrosis and multiple sclerosis combined” (Greeff & van der Walt, 2010, p. 347). It stands to reason that researchers have turned their attention to children with autism, and the concurrent challenges encountered by their families. Both Bayat (2007) and Greeff and van der Walt (2010) focused on *resilience* in families that include a child with autism, mining for features that invigorated the family unit. Bayat’s study, combining quantitative (survey and rating scales) and qualitative (written responses to open-ended questions) methods, identified a number of common threads in resilient families, such as finding positive meaning, mobilizing resources, uniting as a family, cementing spiritual bonds, and appreciating daily life. Greeff and van der Walt set out on a similar quest to unravel the reasons behind families’ resiliency, choosing to distribute seven self-reporting questionnaires to 34 families. Their findings revealed six factors common to families coping well with a life that included a child with a disability: professional help, positive outlook, social supports, a sense of normalcy, family unity, and a faith community or center. Even though the two researchers used dissimilar approaches and were even working on different continents (Greeff and van der Walt in Western Cape, South Africa, and Bayat in Chicago), the factors of resiliency they identified were remarkably parallel.

Parent Voice/Agency

Sadly missing in most of the current research on families that have a child with exceptionalities are *voices*: the voices of parents, siblings, grandparents, caregivers, and the children themselves. Goodall (2000) says that voice “is the sound of the ethnographic world being called into being” (p. 140). If voice is a way of representing ourselves to the world, then speaking out becomes an act of power and privilege, something long denied to those living with disability. Goodall goes on to say that what he calls an “original” voice “speaks to your heart, because you haven’t heard it before, and because you closely identify with it” (p. 141). The work of Kaplan (2010) is one researcher’s refreshing attempt to draw attention to participants’ original voices into her work. She traveled to Russia to do 20 semi-structured interviews with mothers of children, ages 3 through 11, with physical and/or mental impairments. Through a translator Kaplan was able to listen to these mothers as they shared their stories. Finances, social support, future planning, treatment options, transportation, structural barriers, and cultural obstacles emerged as major concerns. Strnadova and Evans (2007) interviewed parents of fifteen school-aged children with special needs in Sydney, Australia, looking at coping strategies, future expectations, and the role of the school and other related services. Mothers and fathers spoke of building support networks, utilizing respite services, attending to self-care needs, and building strong relationships with relevant school and medical personnel. Schumacher Dyke and Bauer’s (2010) research is yet a third example of qualitative methodology in action. They interviewed

members of twelve families of children with disabilities; participants were asked to share their advice for “a happy, healthy life for all members” (p. 21). The participants’ opinions included many of the factors previously identified by both Bayat (2007) and Greef and van der Walt (2010): acknowledge grief, shore up the family, seek out professional help, be proactive, access financial and respite supports, practice self-care, and include the child with disabilities in the larger world.

While these three researchers all conducted semi-structured, individual interviews and asked open-ended, reflective questions, their actual published research, disappointingly, contained few direct quotes. What are most plainly heard in these studies are *the voices of the researchers*, interpreting and analyzing the voices of the parents. The researchers talk; the parents themselves are barely heard. Their voices are “lost in translation,” so to speak. Verbatim quotations are an entry point, but not entirely sufficient; as Goodall (2000) reminds his readers, voice is “an ongoing conversation with the world . . . the confluence of the many voices and personal stories that have constructed you” (p. 140). Parents must be provided occasions to have these conversations, and to tell their stories.

Some researchers are beginning to tiptoe around the idea that parent voices can be shared in their unadulterated form. Hartshorne introduced his 2002 article with full-length email messages left on parent support electronic bulletin boards. These postings, rich with parental hopes, dreams and fears, were sadly just a “teaser” for the full text, which devolved into a recitation of previous quantitative studies. (How ironic that

Hartshorne wisely and intuitively knew that parent voice would immediately attract the reader in his introduction, but failed to see these authentic and unfiltered postings as valid grist for scholarly discussion throughout his work.)

Parents Tell their Stories

If we delimit our quest for research that centers on parents of children with disabilities to peer-reviewed journals and scholarly works, perhaps the most authentic resources are left on the shelf unread. Over the past century a number of parents (some authors by trade, some not) have been moved to put their experiences to paper as both an act of personal catharsis and as an aid to others who might walk similar paths. Of course, those with celebrity status found ready publishers of a hagiographic bent, and a rapt audience even in eras when speaking of disability was quite taboo. Buck (1950), a widely-read author of the mid twentieth century, wrote about her experiences raising a daughter with disabilities. A popular non-fiction book from that same era was written by Evans (1953), also known to the public as Dale Evans and wife of Roy Rogers, as a tribute to their daughter, born with Down syndrome. Perhaps two of the most eminent mothers touched by disability in the first half of the last century were Yvonne DeGaulle and Rose Kennedy. Both matriarchs of wealthy political families, they were mothers of children with exceptionalities at a time when these children were hidden from view. Anne De Gaulle, born in 1928 with Down syndrome, traveled everywhere with her iconic parents, and her mother established a nationwide charity for children with disabilities. Rosemary Kennedy, born in 1918, was sequestered by her renowned family; historians

remain divided as to whether she had cognitive impairments or perhaps a mental illness. Even in seclusion she became the inspiration for Special Olympics (Shapiro, 1993). Both mothers chronicled their devotion to their children in copious diaries and letters.

Unlike these writers from the last century, who tended to speak in idyllic, euphemistic terms about disability, contemporary writers have chosen a leitmotif grounded in frank realism. While author and editor Kamata (2008) was still reeling from the news that her daughter was born profoundly deaf, she reported

I was looking for deep and sustaining stories to guide me on the long path ahead, and while I found many cheery volumes offering hope and inspiration, that wasn't exactly what I wanted. I needed to know that others had felt the same kind of pain, fear, and anger that I was feeling, and I wanted a better idea of how my daughter's disability would affect my marriage, my son, my work, and other aspects of our lives. (p. ix)

Kamata did search for and eventually unearth the stories of other children and families, gathering them into an oeuvre that speaks graphically and unflinchingly about how disability can wreak havoc and at the same time buoy the human experience. Her cache of twenty-plus gritty short stories and poems does not look away from the "dark places" and troublesome questions. Other authors are adding to this body of contemporary work; Berube's (1996) autobiography chronicles life raising a son with Down syndrome. Yet another father, Canadian writer and editor Ian Brown, laid bare the experiences of his family as they raised Walker, born with a devastating genetic mutation. Brown's

memoir (2009) provides an unblinking, loving portrait of parenting a child who needs assiduous care. These and other parents are part of a different breed of writer, zealous emissaries and guides for the “rest of us” who move about in the world untouched, or only tangentially impacted, by disability.

Sometimes it is siblings, friends, or those with disabilities themselves who “tell the story.” A non-fiction tale of deaf culture (L. H. Cohen, 1994) was authored not by a parent, but by the child of the superintendent of the Lexington School for the Deaf in Queens, New York. Her experience growing up immersed in the deaf culture inspired her writings. People with disabilities can certainly speak on their own behalf. Chris Burke, who has Down syndrome, co-authored his life story with great humor and unflinching openness (Burke, 1991). (He might be best remembered as the actor who played Corky on the television series “Life Goes On.”) Ben Mattlin, financial writer and frequent contributor to NPR and the New York Times, chronicled life with spinal muscular atrophy (and the resulting quadriplegia) in a critically-acclaimed biography which interwove his own history with that of the disability rights movement (Mattlin, 2012).

Occasionally researchers turn the lens on their own families and friends. Lawrence (2008), in the Department of Communication Studies at the University of Denver, is herself the mother of a daughter with a profound disability stemming from a genetic disorder. She published an article that included her own story, woven in with anecdotes of three other parents, chronicling the intricacies of navigating public spaces

with a child who has a severe disability. Lawrence stated the power of personal narratives thus:

These stories express each mother's private and public experiences raising a child with a disability. I listened to these mothers' stories of caregiving and impairment. Despite differences in disabilities and family situations, we share similar emotional experiences. Narratives facilitate our understanding of these experiences and emotionally bind us together, helping us to overcome some of our isolation and alienation. (p. 538)

Portraits of disability have even entered the realm of contemporary fiction; Palacio (2012) crafted a novel for young adults which told the story of a boy with acute craniofacial abnormalities struggling for acceptance in his peer group. By alternately writing from the perspective of the child with a disability, his parents, a sibling, and a friend, she illuminated multiple perspectives on the family and community impact of being marked by difference in a society which values conformity.

Family Support

While some researchers have looked at how caregivers may (or perhaps may not) experience resilience, hope, and advocacy, others have focused more specifically on the nature of the supports that can contribute to these qualities. Cowie, Quinn, Gunning, and Gunning (1998) were interested in how school staffs support families of students with disabilities. They opted for a narrow aperture, choosing one student and his caregivers for a case study. The school counselor, psychologist, and social worker were all listed as powerful agents for supporting a family (in this case, one grieving at

the sudden onset of serious disability when their child was in middle school). Given the age of the study by Cowie et al., the framework of a “disease” or crisis model rather than a transformative social model does not surprise.

Canary (2008) chose to sift through relevant studies to create a compendium of the current research on support systems, including 103 peer-reviewed articles from 1996 through 2005. She found, during that time span, 52 studies using quantitative methods, 33 studies employing qualitative techniques, and 18 with mixed methodologies. Coding for frequency, Canary found that informal (familial, social) and formal (professional, intervention programs, religion) assistance was reported with great regularity. Many studies highlighted the effects of socioeconomic factors, culture, and minority status as they related to levels of support. Last, she noted that public policy (macrostructures and micropractices) is increasingly an area of interest, as research on disability begins to bleed into the political domain.

Brett (2004), like Canary, explored areas of support for caregivers of children living with profound disability. In the study that most closely resembled my own, she selected six families from a purposeful sample in a special school setting, conducting in-depth interviews. Brett framed her study in phenomenology, placing the act (or acts) of support as “events” to be described and explored in the context of the interviews. While she claimed to be searching for the “essence” of this phenomenon, she instead closed with the refreshing confession that her mission became an “unraveling of the multiple layers of the parents’ experiences” and that it had “no clear end point” (p. 18). Even

though Brett relied on interviews as her data-gathering technique, direct quotes from parents were never longer than a phrase or sentence; parent voice was not central to her work.

Conclusion

Important factors for family resiliency, hope and agency have been identified and confirmed through multiple studies, along with channels of family support. In the last decade there has been a nascent shift towards greater inclusion of qualitative research in the study of disabilities and family dynamics. Turnbull, Turnbull, Erwin, and Soodak (2006) structured their textbook on professionals' family partnerships around the narratives of four diverse families dealing with a child with special needs, emphasizing that these stories provide "a real-life context for the theory, research, and best practice" (p. vi). Yet the majority of the qualitative research studies uncovered were conducted half a world away from the United States. Surely if almost four percent of our families here in the United States have a child with a disability, there are many voices waiting to be heard within our own borders.

Engaging, authentic narratives are on the shelves, but these are often self-published memoirs, anthologies, or short stories—inherently valuable, but not generally granted full credit and authority without the imprimatur of the academy. Narrative research—research that respects the true mavens (parents and other caregivers), allied with the synthesis that the researcher can bring to the table—is a field still only tentatively explored. If we ask families of children with disabilities to share their stories

and then honor their personal narratives through careful analysis, we can begin to sketch an image of authentic lived experiences. It is only then that we can take the next step; we can build fledgling communities that deconstruct barriers to inclusive practices. Then research is no longer about examining “subjects,” but about providing a conduit for visceral voices to be heard and privileged. Turnbull et al. (2006) provide a model for this partnership:

There are abundant opportunities . . . for professionals to understand families and their children with disabilities; people possess extraordinary skills to become trusted and trustworthy partners. Beyond opportunities and skills lies the quality that we call the empathetic imagination; often that quality responds to the need for justice in our schools, community and society. More than that, partnerships, trust, and the empathetic imagination are twice blessed: They bless those who seek them and those who are sought by the seekers. (p. 306)

Turnbull et al. have captured the import of possibility in not only the parent/professional relationship, but in the parent/researcher connection as well. And lest we hold to the hubris that we are “helping” or “uplifting” these parents and children, the authors also remind us that we are the ones who will be richer and wiser for our encounters. By developing an “empathetic imagination” honed by listening to parents’ stories, researchers can become not only learners, but perhaps also fulcrums of social justice.

This initial review of previous research provides an overview of past efforts in the field, documenting the gradual but incomplete shift from quantitative, deficit-model studies to qualitative approaches that begin to recognize caregiver voice. In Chapters VI

and VII, as I discuss aspects of parent support along with agency, hope and resiliency, further studies are provided to enrich the information gathered in the interview setting.

CHAPTER III

PLACING DISABILITY IN HISTORICAL CONTEXT

Introduction

A brief “walkthrough” of disability and its place in the American psyche helps to ground the research in historical context. This is only necessary because, unlike other marginalized groups, those with disabilities cannot boast of a well-worn, shared primer of familiar yarns and heroes. Quiz a handful of Americans on the civil rights movement, and you are likely to elicit shout-outs of “Rosa Parks,” Dr. Martin Luther King, Jr.,” and perhaps even “March to Birmingham.” Query them about women’s rights, and a few will respond with “ERA” or “Gloria Steinem.” An esoteric handful might even be able to cite Harvey Milk or the Stonewall Riots if you ask about the fight for gay equality. Yet mention disability, and the room will most assuredly fall silent; quizzical looks, wrinkled brows, and blank stares will rule the day. No leaders, no legislative action, no seminal, watershed events will spring to anyone’s lips. In fact, the fight for the rights of those with disabilities in America has transpired wholly beneath the general public’s radar. Most citizens who pride themselves on attention to politics, history, and societal transformations would be forced to admit complete ignorance of a critically important movement which was quietly fomenting in their midst for over half a century.

How could the narrative of such a group—replete with iconic leaders, ground-breaking legislation, and compelling stories—a movement rich with examples of both hard-won victories and disappointing failures—be so obscured? Brueggemann, White, Dunn, Heifferon, and Cheu (2001) speak of the paradoxical “invisibility of disability,” stating that

Many of us “pass” for able-bodied—we appear before you unclearly marked, fuzzily apparent, our disabilities not hanging out all over the place. We are sitting next to you. No, we are you. As the saying goes in disability circles these days: “If we all live long enough, we’ll all be disabled. We are all TABs—temporarily able-bodied.” (p. 369)

Those with disabilities (and their ongoing struggles for equal rights) have remained largely concealed and disguised for a variety of reasons: their ability to “pass,” their lack of social and economic capital, and, perhaps most telling, the desire of “TABs”—those who are temporarily able-bodied—to look away from that which is feared. Disability, Shapiro (1993) reminds us, “is the one minority that anyone can join at any time, as a result of a sudden automobile accident, a fall down a flight of stairs, cancer, or a disease” (p. 7). To compound the ambiguity, there is not even a modicum of consensus as to what constitutes disability. But regardless of the means of measurement, “even at the lowest estimate, disabled people could be considered the nation’s largest minority group” (p. 7).

Over the last 50 years, battles have been waged by, and on behalf of, this vast yet amorphous body. While at times people with disabilities themselves have been at

the forefront of change, often it is the parents and caregivers who have worked tirelessly for inclusion, acceptance, and full rights for their sons and daughters. These two groups—disabled activists and caregivers of children with disabilities—have not always utilized identical strategies, nor even pursued similar goals. But most specifically, in the realm of educational reform, parents and other caregivers came into their own as vocal advocates for their charges, often borrowing strategies from the disability rights activists’ “playbook.” Caregivers as advocates receive a more comprehensive treatment in Chapter VII; this chapter, then, serves to draw awareness to others’ efforts to bring those with disabilities into the mainstream.

20th Century, Part 1: Asylums and Ugly Laws

A comprehensive treatment of the history of disability and disability rights would require a traispe through ancient civilizations; it would necessitate an exploration of how, over time, varied religious traditions and cultures have both rejected and venerated bodies and minds deviant from the norm. I will pick up the thread of the American story of disability relatively late, during the great wave of migration after the Civil War and into the early 1900s. The notion that the “national stock” could and should be improved was popular in the waning years of the nineteenth century. Witness this account by Longmore and Umansky (2001) of common immigration practices:

Medical exclusions on the basis of “poor physique” and “lack of physical development” began to appear . . . The immigration service defined it as covering individuals who have frail frame, flat chest, and are “generally deficient

in muscular development” or those who are “undersized—markedly short of stature—dwarf.” (p. 49)

Americans were expected to be strong, capable, and free of aberrations from the norm. In a nation on the brink of industrialization, “standardized” bodies and minds that could succeed in the workforce were prized. Shockingly, “ugly laws” were passed so as to protect the able-bodied from even enduring the spectacle of the infirm, effectively legislating those with disabilities into invisibility. A Chicago statute specifically forbade persons “diseased, maimed, mutilated, or deformed in any ways so as to be an unsightly or improper person to be allowed in or on the public ways or other public places” (Garland-Thomson, 2001, p. 338).

A short historical digression is in order, by way of explanation. This stance of intolerance toward those with disabilities had its pseudo-scientific roots in France, where Adolphe Quetelet developed the discipline of statistics and, chillingly, applied this new field of study (conceived as an industrial metric) to *human variations* (Davis, 2006a). The use of Quetelet’s bell curve to demarcate those with disability was seamlessly exported to England, where Darwin’s wildly popular theories on natural selection were feeding a frenzy to eliminate “defectives, a category which included the ‘feeble-minded,’ the deaf, the blind, the physically defective, and so on” (Davis, 2006a, p. 7). The eugenics movement, subsequently fueled by Darwin’s cousin Francis Galton, pushed the envelope of small-mindedness even further, seeking to “improve the inborn

qualities of races and classes of people” (J. D. Smith, 2003, p. 105) through sterilization and even selective elimination of newborns deemed flawed.

These misguided notions of “perfecting” humanity crossed the Atlantic and found a fertile home in the minds of notable American citizenry such as Alexander Graham Bell, Oliver Wendell Holmes (Shapiro, 1993), and, surprisingly, even Helen Keller, who “supported eugenic and euthanasia policies to prevent the birth and sustenance of children with significant disabilities” (Longmore & Umansky, 2001, p. 282). Keller’s sympathetic 1915 cant detailing the case of a doctor who withheld treatments to save a disabled newborn, labeled by her as “a poor, misshapen, paralyzed, unthinking creature” (J. D. Smith, 2003, pp. 81–82), is stunning in its callousness. She wrote, “Our puny sentimentalism has caused us to forget that a human life is sacred only when it may be of some use to itself and to the world” (Longmore & Umansky, 2001, p. 282).

By 1927 sentiments such as Keller’s on eugenics and euthanasia were rampant, and the U.S. Supreme Court upheld Virginia’s state law allowing sterilization of “those judged to be psychologically or socially incompetent, and who were considered likely to genetically transmit their ‘deficiencies’ to their offspring” (J. D. Smith, 2009, p. 27). This case, *Buck v. Bell*, set the stage for the sterilization of more than 50,000 Americans over the next fifty-plus years. (North Carolina is currently weighing a plan to financially compensate those sterilization victims still living.) Nazi Germany would in fact crib heavily from the language of the *Buck v. Bell* case when designing a “race hygiene”

program of its own. And so, our nation's attempt to paint Hitler as the original mastermind of racial purification is mythology, plain and simple; Hitler drew his rationale from his American neighbors, expanding the scope to include *two million* sterilizations and, of course, mass exterminations.

Thus, in the early 20th century, American children born deaf, blind, “mongoloid,” or epileptic—those with any offensive physical or mental aberration whatsoever—were considered sub-par, human detritus. Considered an embarrassment to families, they were often parceled off to one of the newly-formed asylums, some run by private religious or charitable groups, some government-supported (Scotch, 2001). Shapiro (1993) reminds us that “these people—with disabilities that were not fatal—were segregated in isolated institutions. There they lost control of their lives and their liberties, solely by virtue of their disability . . . cut off from their families” (pp. 158–159). These sites provided food, shelter, and sometimes vocational training, but in fact neglect and even abuse (physical, sexual, emotional) were frequently the rule rather than the exception (Scotch, 2001; Shapiro, 1993). J. D. Smith (2009) summarizes the isolation inherent in the institutional model:

There is a very good reason why most mental retardation institutions have their own graveyards. People who lived in these institutions for most of their lives were at high risk of outliving their connections to the external world. When they died there was no one to claim them, no one from the outside world to grieve for them . . . It is no accident that most of the large mental retardation institutions were built in out-of-the-way places. The facilities were not intended to be a *part* of society. They were intended to be *apart* from society. (pp. 55–56)

20th Century, Part 2: The Charity Model, and Glimmers of Activism

So, as America entered the mid-point of the 20th century, the plight of those with disabilities was bleak. Shame and segregation were the watchwords if a citizen was unfortunate enough to have physical or cognitive incapacities not easily shrouded. A. Johnson (2005) speaks of this “socially constructed reality” in which any privileged group—in this case, the able-bodied and able-minded—has the power to define “normal,” and can wield that power to label the disabled as

Little more than needy, helpless victims who can't take care of themselves and whose achievements and situation in life depend solely on their physical or mental condition and not on how they are treated or the physical or attitudinal obstacles that are placed in their way. (p. 22)

While there were certainly voices raised championing the disabled, these were not calls for equal rights or accessibility, but paternalistic pleas for largesse. Efforts such as the March of Dimes campaign or the Jerry Lewis MDA telethon cast the disabled person as the “cute and courageous poster child . . . brave, determined, and inspirational, the most innocent victim of the cruelest whims of life and health” (Shapiro, 1993, p. 12). To be disabled in America at mid-century was to live in an aporetic netherworld—highly visible and marked by one’s deviation from the norm, while at the same time a non-entity, lacking the rights and rewards of full citizenship.

Yet, in the 50s and 60s, tectonic shifts *were* indeed brewing for other minorities. The civil rights movement and later the women’s movement began to challenge the

status quo in legal, political and cultural arenas. Through the courts, civil disobedience, and grassroots community organizations, hard-fought changes were accomplished in the realms of employment, voting, education, and access to public spaces, culminating in the Civil Rights Act of 1964 (Friend, 2006; Shapiro, 1993). But these newfound rights afforded to everyone regardless of “race, color, religion, or national origin”⁵ were *not* extended to people with disabilities. They remained a “hidden, misunderstood minority, often routinely deprived of the basic life choices that even the most disadvantaged among us take for granted” (Shapiro, 1993, p. 11). Who would be the leaders—the counterparts to King, Milk, and Steinem—of this unsung struggle? What would be the aspirations of this movement, and what strategies would be employed in service of these goals?

If there was to be a movement for disability rights, it would have to develop bereft of the broad-based institutional supports made available to other minorities. Whereas women, African Americans, the poor, and other marginalized groups had garnered media, political, and community sympathies, M. Johnson (2003) says that

The American Civil Liberties Union was rarely quoted supporting access. Access wasn’t an agenda item for any of the dozens of other progressive policy groups that could usually be counted on to speak out on a panoply of public issues from gay bashing to hate crimes to gender disparity in salaries Jabs, slurs condemnations of and bigoted comments about disabled people and their movement’s goals encountered almost no public outrage. No articles in *Harper’s* or *The New York Times* or *Mother Jones* examined the tenets of disability rights. No reporters delved into the issues from the disability rights perspective as

⁵ Text of the Civil Rights Act can be found at <http://www.ourdocuments.gov/doc.php?doc=97&page=transcript>.

though they might offer cogent lessons for society. Public debate, in the true sense of the word, was virtually nonexistent. (p. 127)

The public simply couldn't conceive of people with disabilities as a cohesive band of oppressed citizens. Those with disabling conditions were, in the collective mind of the "TABs" (temporarily able-bodied), unfortunate individuals who were patiently hoping for a "cure" for their medical condition. Garland-Thomson (2006) further clarified this misguided mentality, stating that "the ideology of cure directed at disabled people focuses on changing bodies imagined as abnormal and dysfunctional rather than on exclusionary attitudinal, environmental, and economic barriers" (p. 264). That is not to say that reducing illness and suffering is not a worthy goal. But this singular focus on an illness/medical model served to excuse society at large from asking tough questions about the multitude of roadblocks erected to thwart those with disabilities from full inclusion in the human experience. M. Johnson (2003) quoted Martin Luther King, Jr.'s insightful words: "the greatest tragedy of this period of social transition was not the strident clamor of bad people, but the appalling silence of the good people" (p. 127). Although King's oft-quoted statement referenced the struggles of African Americans, the admonition rang just as true for the disabilities community. Otherwise "good people" saw no need to defend their brethren with disabilities' appeal for comity.

There were, however, intermittent and isolated examples of disabilities rights legislation, even in the first half of the twentieth century. The Smith-Sears Veteran's Rehabilitation Act of 1918 established vocational training for returning World War I

veterans with injuries; two years later the Smith-Fess Act extended this vocational rehabilitation training to *all* citizens (over sixteen years of age) with disabilities who had the potential for gainful employment (Scotch, 2001). As far back as the 1930s, local and state ordinances protected “the right of access to public places by blind people using white canes, or service dogs” (p. 383). Yet these programs were still predicated on the premise that deficiencies resided within the disabled themselves; the mentality of disability as a pitiable and “lesser” state of being remained unchallenged.

Emergence of the Social Model

The first true standard-bearer for the fledgling disabilities movement was a college student. Shapiro (1993) avers that “the disability rights movement was born the day [Ed] Roberts arrived on the Berkeley campus” (p. 41). As a post-polio quadriplegic denied his high school diploma (until his parents protested) because he was unable to pass driver’s education or physical education classes, he learned of the power of the press when his junior college contacted the local paper to protest his exclusion from scholarship funding for higher education. Monies were subsequently granted, and he was greeted by the headline “Helpless Cripple Goes to School” (Shapiro, p. 45) upon his arrival at UC-Berkeley in the 1960s. Living first in a segregated hospital ward which doubled as a dorm, Roberts was soon joined by other students with disabilities who were energized and emboldened by his success.

By the time Roberts entered his doctoral program, “there were twelve severely disabled students living in Cowell. They called themselves the ‘Rolling Quads’” (Shapiro,

p. 47). Taking on the city council over issues of campus accessibility, the tight-knit cadre eventually won their tenacious fight for “curb cuts” throughout the city, the first such accommodation in the U.S. for people with disabilities. The Rolling Quads morphed into the Physically Disabled Students’ Program (PDSP), a hard-hitting, politically active alliance that tackled issues such as bus transportation, housing, and wheelchair design. Their methods were borrowed directly from the civil rights movement: sit-ins, community organizing, non-violent protests, and lawsuits. Interviewed years later, Roberts remembers the excitement and momentum of the times:

So much of the good that has happened to me and the good I’ve done has to do with being in Berkeley in the sixties. There was such energy, so much optimism. We were the generation that could and would change the world. There were all sorts of alternative living experiments and new ideas. Like everybody else, I just got caught up in them. Fortunately, there were other people with disabilities who were also affected. We were together at the right time at the right place. (Charlton, 2000, p. 131)

Like Roberts, others became activists because of their personal vision of achieving parity in the classroom or workplace. Judy Heumann (a student at Long Island University who used a wheelchair) was denied her teaching certificate after successfully passing her speech therapist exams, but flunking a required medical screening.

The testing physician questioned whether she could get to the bathroom by herself or help children out of the building in an emergency. Heumann quickly slapped the Board of Education with a lawsuit, charging discrimination. Then she went to the local newspapers, which were happy to tell the story of a qualified teacher up against a coldhearted bureaucracy. (Shapiro, 1993, p. 57)

Heumann won her battle, received her teaching certificate, and went on to found the group “Disabled in Action,” which employed overt political protests in service of change. She organized a Lincoln Memorial demonstration in 1972 to protest “Richard Nixon’s veto of a spending bill to fund disability programs” (Shapiro, 1993, p. 58), later leading a takeover of the Nixon reelection headquarters in conjunction with Vietnam veterans with disabilities.

With protests, lawsuits, sit-ins, and even the subversive co-opting of language (see Chapter I—“A Few Words about Language”), disability activists worked to swing the public’s mindset away from charity and pity. They began moving the needle from “medical model,” which assigns fault to the individual—to “social model,” which places the responsibility for change squarely on a society constructed for the comfort and convenience of the able-bodied. Hahn and Belt (2004) aptly captured the ideology of the disability rights movement:

Many disabled citizens now regard living with their disability as a valuable experience that can yield a positive source of personal and political identity instead of viewing their disability as a negative defect or deficiency that results in a loss or decline of bodily functions. (p. 453)

But perhaps the biggest victory of the 1960s and 1970s came not through the arduous work on the part of activists, but, ironically, through the quiet, uncontested passage of Section 504 of the Rehabilitation Act of 1973, a “legislative afterthought” which “made it illegal for any federal agency, public university, defense or other federal contractor, or

any other institution or activity that received federal funding to discriminate against anyone 'solely by reason of . . . handicap'" (Shapiro, 1993, p. 65). Without hearings or debate (as 504 was at the time considered an empty platitude to placate an interest group), sweeping civil rights reform for those with disabilities became the law of the land. When the Carter administration grasped the scope of this new law and attempted a furtive rewrite, activists rose up in dissent, staging confrontations such as the sit-in at the Health, Education and Welfare offices in San Francisco lasting twenty-five days. When HEW secretary Joseph Califano finally caved to activists' pressures and signed the regulations into law, one disabled picketer captured the euphoric sentiments of many:

I used to know what I would wish for . . . I wanted to be beautiful. I wanted to stop being a cripple. But now I know I am beautiful . . . We all felt beautiful. We all felt powerful. It didn't matter if you were mentally retarded, blind, or deaf. Everybody who came out felt, we are beautiful, we are powerful, we are strong, we are important. (Shapiro, 1993, p. 69)

While the story of the disability rights movement has never been widely told, clearly there were numerous leaders who, during the 1960s and 70s, cribbed time-tested methods from other oppressed groups and used these strategies to transform public policy, if not always public opinion. These activists were by and large college-educated and disabled themselves. Beyond individual efforts, numerous groups were spawned to draw attention to particular issues or populations. ADAPT used, and continues to use, confrontational tactics to address wrongs, particularly in the areas of transportation and health care reform. Centers for Independent Living (CILs) number

in the hundreds throughout the U.S. and Europe, addressing such issues as housing discrimination and personal assistance (Charlton, 2000). As Charlton (2000) attests, “for the first time in recorded human history politically active people with disabilities are beginning to proclaim that they know what is best for themselves and their community. This is a militant, revelational claim” (p. 4).

Conclusion

So, while those with disabilities may not have a shared chronicle that is widely known, that history does exist, and lays claim to a pantheon of champions who have paved the way for continued growth towards an inclusive society. By driving small wedges into closed spaces—college classrooms, public transportation, and job interviews—these activists readied the stage for further progress. Ugly laws, asylums, and eugenics policies have been eradicated; accessibility and opportunities, while still insufficient, are vigorously pursued daily under the banner of ADA. Parents and other caregivers, though (in general) not disabled themselves, have always been at the front lines of this push for fuller acceptance and equity; my research participants are no exception. Since the children in their care are nonverbal and non-mobile due to the severity of their disabling conditions, this willingness to act as proxy becomes even more indispensable. Chapter VII will marry the storied history of parental activism over the last half-century with current efforts being put forth by the caregivers interviewed for this study.

CHAPTER IV

RESEARCH DESIGN AND IMPLEMENTATION

Methodology Selection

I put forth my beliefs in a post-modernist, anti-foundational world view, both personally and as my research philosophy, in Chapter I. I alluded to my faith in qualitative versus quantitative tools for this particular work as well. While the benefits of exploring these questions by embarking on a qualitative study might seem obvious, my rationale for rejecting quantitative methodologies deserves at least brief explanation. Hatch (2002) challenges researchers to “unpack their ontological and epistemological beliefs [and to be] introspective about their world views” (p. 2) before choosing to use a qualitative approach. My own philosophy of education (and of research) most closely aligns with the underpinnings of qualitative methodologies, which assume the nature of existence and knowledge to be not linear and closed, but divergent, and open to individual interpretations and the nuances of culture. Because my goal is not to prove any foregone conclusions or to test a hypothesis, but rather to honor the voices of a particular sub-group of individuals, qualitative methods can best guide my research practices. If, as Glesne (2011) suggests, qualitative researchers “seek to make sense of actions, narratives, and the ways in which they intersect” (p. 1), then I believe my dissertation study can be well-served by exploring a variety of *qualitative*

approaches to find one that might best provide a conduit for the voices of parents of children with multiple disabilities.

Since my intent is to explore the lived experiences of parents of children with severe disabilities, the case study is one research approach within the qualitative tradition that is worthy of examination. Case studies have long been standard practice in other disciplines, such as medicine and business; The University of Chicago School of Sociology first pioneered the method in the United States during the first three decades of the 20th century, studying issues of poverty and unemployment with groups of immigrants (Tellis, 1997). Columbia University sought to discredit the approach and called for a firm adherence to the scientific method, successfully squelching the case study method for a time. But as qualitative studies have become customary practice in educational and sociological research, the case study has once again gained broader acceptance (Lichtman, 2010).

The case, or subject for study, is a “bounded system, a single entity” (Merriam, 2002, p. 178), finite in terms of time, space, or participants. Rather than drawing from a large number of subjects, sites or events, the case study allows the researcher to keenly focus his or her lens on the complexities and unique qualities of (usually) just one subject. Whether the “case” under study is a large public high school with a diverse student body (Enomoto & Bair, 1999) or an academically gifted minority student in rural Alabama (Hebert & Beardsley, 2001), there is in-depth and prolonged engagement with the case in question. Like all qualitative research, the case study involves a “search for

meaning and understanding, the researcher as the primary instrument of data collection and analysis, an inductive investigative strategy, and the end product being richly descriptive” (Merriam, 2002, p. 179).

Within the tradition of case studies, there are a number of design options, depending on the intent of the researcher. Lunenburg and Irby (2008) provide an excellent synopsis of the variety within the case study approach. Case studies can be *single-case*, in which just one individual or bounded group is studied, or *multiple-case*, in which the researcher chooses to “target multiple individuals and the same phenomena or . . . various communities related to a similar phenomenon” (Lunenburg & Irby, 2008, p. 96). Cases studies involve purposeful sampling, unlike quantitative research methods, which typically involve randomly-selected subjects.

Lichtman (2010) lists three types of cases: the *typical*, the *exemplary model*, and the *unusual or unique*, while Lunenburg and Irby (2008) delineate *typical*, *extreme*, *critical*, *convenience*, and *politically important* as case designs. Even though labels may differ, the definitions parallel one another; Lunenburg and Irby simply add the *convenience* (the weakest of designs, based on the availability of participants) and the *political* (which could meld case study with action research) to the mix. When the researcher strives to study an individual, site or event that closely resembles the norm or average for the larger group, he or she might choose the *typical* case study model. The *exemplary* model seeks to highlight the best or most outstanding member of a particular group, be it a gifted fourth grade teacher or a successful performing-arts high

school. The *unusual, unique* (Lichtman, 2010) or *critical* (Lunenburg & Irby, 2008) case study is concerned with exploring a particular trait that is atypical or groundbreaking in some way. These cases are often referred to as *outliers*. No matter the particular type of case study, all draw the reader into the “world” of the case through rich description and mindfulness to detail.

Creswell (2007) reminds those new to qualitative research that “it is important that studies being conducted go forward with rigor and attention to the procedures developed within approaches of inquiry” (p. 223). What, then, are the implications of employing a case study approach when examining the lived experiences of parents of children with multiple disabilities? First, this approach would impact the selection of study participants. The scope of the researched group would be narrowed to one or perhaps two parents, versus a much larger group. The participant selection process itself would need to be clearly defined; would the goal be to find a parent participant who is successfully navigating in the “ableist” world—an exemplary model—or would the “average” (whatever that means!) parent be courted for participation? Perhaps two diverse cases would be explored so that differences in parents’ lived experiences could be parsed for meaning.

Second, the methods used to obtain data would be circumscribed somewhat by choosing to follow a case study approach. Lunenburg and Irby (2008) stress that case data

may include, but not be limited to: (a) basic demographic information about the individual that is written in narrative format, (b) family history (or if the case is about a program or organization, it would relate to the program's or organization's history), (c) document analyses relating to the individuals or programs, (d) interview data, and/or (e) observational records. (pp. 96-97)

Therefore, choosing to explore a parent's (or parents') experiences in raising a child with multiple disabilities through a case study tradition would entail the careful gathering of a variety of data to enrich and support the study's findings. It might denote the need for a comprehensive demographic/family history questionnaire, interviews in a setting that could most fully inform the study (the home, perhaps), and possibly an examination of relevant documents (IEPs, school/home journals, family photographs) that could contribute to a comprehensive case study. Third, a case study approach requires that the researcher invest in the participant(s) for the "long haul;" should I choose to utilize this approach to studying parents' experiences, one or two sittings could not provide more than a simplistic take on the subject. A case study would necessitate prolonged and meaningful encounters with parents—a substantial and mutual commitment of time and energies on the part of the researcher and the researched.

Armed with a working knowledge of the case study approach as well as a feel for the methods that would best facilitate its execution, what do I perceive to be the strengths and shortcomings of case study in the pursuit of my intended dissertation topic? There are number of reasons why the case study would provide a strong framework for exploring my topic. To dive below the surface level of engagement with

just one, two or three parents offers opportunities for amassing rich data. Even with the safeguards of IRB approval in place, parents might feel uncomfortable sharing their innermost thoughts, fears and wishes about their children with a near-stranger in a single encounter. The protracted interactions built into the case study could aid in breaking down this potential reticence. Second, the variety of data (interviews, observations, documents from school, home, and medical sources) paints a nuanced picture of the family's life experiences raising a child with disabilities. While no researcher can completely become "the fly on the wall," the case study presents multiple avenues for access into meaningful discourse with the study participants. This ideally leads to a restructuring of the hierarchy between the academic and the "subject," a chance to

alter the traditional relationship between the researcher and the researched such that research subjects' voices, problems, and concerns become the focus of the research. Such research builds from the premise that research subjects have legitimacy and authority to produce socially useful knowledge. (Hytten, 2004, p. 101)

Conversely, are there reasons to shy away from the case study method? If we recall Brown's description of the "rare and exotic corner of existence" that is life with Walker, his disabled son, we might hesitate to focus on just one or two families when building an accurate picture of the experience of living in the ableist world with a child with disabilities. Each family's journey is unique; the case study approach would preclude the prospect of exploring this rich variety. The community of disabilities knows

no boundaries of race, ethnicity or socioeconomic status. A case study could not capture the experiences of a wide cross-section of society. Another drawback to the case study method, while purely practical in nature, is nonetheless relevant. As a school principal, the workload of my profession is such that extended home visits and lengthy observations are not logistically possible. The hazards of “backyard research” (Glesne, 2011) are also magnified due to my professional role in the case study method. Glesne states “both you and those around you may experience confusion at times over which role you are or should be playing” (p. 41). As an authority figure in the eyes of families, I run the risk of gathering data that may be skewed by parent perceptions of my power in the educational and political realms, and a desire on the part of parents to present family life in a particular light, for my benefit.

Given the positives inherent in the case study tradition, it cannot be dismissed as a potential dissertation approach. Yet it is wise to look closely at alternate methods before beginning the study; time front-loaded in this endeavor should pay off in a more meaningful research process and final product. A second possible approach, the phenomenological method, “focuses on how multiple individuals experience a phenomenon, the meaning it has for them, and the commonalities in their experiences and meanings” (Reitzug, 2010, p. 1). In other words, what can I as researcher (and thus my readers) learn from how others have experienced a *particular human life event*? This method is immediately intriguing; without doubt the experience of raising a child with

multiple disabilities can be couched as an uncommon and remarkable phenomenon—a human life event of the highest order, by any reckoning.

Phenomenology is “both a philosophy and an approach” (Lichtman, 2010, p. 77). When its tenets are used to guide research, it can be used to explore “gaps in the discipline, those areas that previously were not considered important to research” (Lichtman, 2010, p. 78). Edmund Husserl (1917/1981) is generally credited as being the “father of phenomenology,” although Lichtman notes that the Greek term was first familiarized by Kant as early as the mid-1700s. Husserl, followed by Heidegger, Merleau-Ponty, and other European writers and philosophers, championed this alternative to the scientific method. Lunenburg and Irby (2008) state that Husserl

was concerned with the study of ‘experience’ from the perspective of the individual, and believed that the researcher could approximate those experiences through intuiting and rigorous examination of the subjects, objects, or people’s lived experiences, behaviors, or actions. He believed that researchers could gain subjective experience, essential realities and insights into a person’s or persons’ motivations and actions . . . the researcher is concerned with clarifying the specific and recognizing phenomena through the eyes of the participants. (p. 90)

A phenomenological approach, then, seeks to foreground the experiences of the participants in relation to an event or series of events. The intent of the researcher is not to begin with a preconceived, overriding hypothesis or paradigm; the essence or essences of the study flow from the voices of the participants themselves.

It is no mistake that Lunenburg and Irby also mention rigor in their summary. A phenomenological study can utilize a variety of methods to insure that data is rich and relevant. Interviews are often key, and can be structured, semi-structured, or unstructured in nature (Merriam, 1988). Focus groups provide benefits akin to interviews, with participants' interactions adding depth to the data, through the counterpoint of their exchanges. On-site observations, photographs, artifacts, journals and diaries can enhance the data, as can newer, virtual avenues such as (secure) blogs and wikis that capture written communications and interactive dialogue, whether participant/participant or participant/researcher. Hatch (2002) even includes the examination of poetry, novels, stories, plays, biographies and works of art as a means to uncover experiential descriptions from others.

“Phenomenological research emphasizes the lived experience not only of the research participants but also that of the researcher . . . This, I believe, is one of the trickiest aspects of semiotic-phenomenological research for beginning researchers to master” (Merriam, 2002, p. 117). This declaration by Merriam should be heeded as both a warning and an invitation. If qualitative research in general and the phenomenological approach in particular are embodied processes that value self-reflection, and I believe that they are, then the researcher cannot help but bring his or her own life experiences to the table. At the same time, the researcher has a responsibility to make explicit his or her prejudices, biases, and assumptions. This process, called bracketing, epoche, or eidetic reduction (Hatch, 2002; Lichtman, 2010; Merriam, 2002) is *not* an attempt to

completely set aside one's personal history, but instead a conscious effort to place these experiences "in suspense" (Lichtman, 2010, p. 80) for the duration of the study, while acknowledging the unavoidable impact of one's own history on interpretation and analysis. Peshkin's (1988) confession of subjectivity is particularly relevant:

By monitoring myself, I can create an illuminating, empowering personal statement that attunes me to where self and subject are intertwined. I do not thereby exorcise my subjectivity. I do, rather, enable myself to manage it—to preclude it from being unwittingly burdensome—as I progress through collecting, analyzing and writing up my data. (p. 20)

I relish the opportunity to profess my own subjective stance, not to discount it, but rather to tease out ways in which my perspective might lead me down particular paths of data collection, or color my subsequent analysis of that data.

What are the implications of employing a phenomenological approach when studying the lived experiences of parents of children with multiple disabilities? While the case study approach dictated that the participant group would be quite small, a phenomenological approach would allow me to broaden the group size. If the phenomenon under study is the life experience of raising a child with severe cognitive and physical handicaps, the data could be enriched by including a large number of caregivers falling into this category. Both individual interviews and focus groups (semi-structured, with questions about advocacy, life in an "ableist" world, and positive coping strategies) would be appropriate methods. Internet tools—closed blogs, wikis, or discussion groups—would also be time-efficient ways to expand the data collection

process. A phenomenological approach, like the case study, would necessitate selective sampling. While multiple caregivers of children with severe cognitive and physical disabilities would need to be recruited for participation, each would be committing to just a few hours of time (unlike the intensive engagement required for the case study). Home visits and observations would be possible methodologies, but not critical to the process.

Many strengths begin to surface when weighing the merits of a phenomenological approach. Relatively short interview and focus group sessions are convenient for the already-harried parents of children with disabilities. The introduction of an optional on-line component for discussion and/or journaling also allows parents to pick convenient times, and adds a heightened measure of autonomy and privacy for those who find face-to-face meetings on this sensitive topic socially or emotionally difficult. The focus on a shared experience of a group of parents (versus the singular nature of the case study) allows for not only a rich give-and-take, which will benefit my eventual written work, but perhaps also overlies action research of a sort. Bringing mothers and fathers with similar experiences and challenges around the table could build bridges of support, leading to new and powerful connections in the local disabilities community. Finally, the chance to bracket and name my own experiences and biases is challenging yet intriguing, given my high level of personal and professional involvement with this population.

A phenomenological approach to the question at hand has few limitations, but they must be explored nonetheless. There is a potential challenge in finding enough caregivers (perhaps eight to twelve) who both meet the study criteria and are willing to participate in multiple interviews and focus groups. A phenomenological study also might be less likely to capture some of the richness and depth inherent in dealing with just one or two participants in a case study approach. By definition, the phenomenological tradition would seek to narrow the focus to the *experience* of raising the child with multiple disabilities, rather than portraying the full range of life events. The chance to do an entire family case study—perhaps involving spouse, siblings, and grandparents—would have to be abandoned for another time or another researcher.

Both the case study and the phenomenological study deserve consideration when planning an approach for examining the experiences of those who care for children with severe disabilities. A third approach, narrative research, is also ripe for exploration. Narrative research has been described as the gathering of data “through the collection of life stories & discussing the significance of those experiences for the individual & their relevance for the topic being studied” (Reitzug, 2010, p. 1). *Stories* are indeed fundamental to narrative research; whether the data takes the form of biography, oral history, personal/family artifacts, letters, conversations, or research interviews (Hatch, 2002), the centrality of *story* to the human condition is treated with honor. The individual resides at the center of the research, but must also be seen “as a social being whose experiences are mediated by and in turn mediate the social world in

which she lives” (Bloom, 2002, p. 311). Bloom (2002) also points out that the narrative approach is popular with feminist researchers, as it has a “liberatory” bent, a “location from which the researcher can generate social critique and advocacy” (p. 310). The narrative tradition is especially apropos when seeking to understand and perhaps provide a platform for “telling stories that raise awareness and promote resistance” (Hatch, 2002, p. 28) about a person or group of people whose voices have historically been silenced or devalued. As most caregivers are women, and as they are adjunct members of the disabilities community, many of my research participants live in two worlds that are historically underrepresented as to public voice.

The narrative approach privileges the participant’s retelling of his or her life history, with the researcher acting as moderator (while never “speaking for” the participant, or making overarching claims as to the participant’s intent). The narrative approach must strike a balance between foregrounding the writing/speech of the participant, and providing for the reader a cohesive and meaningful text that integrates story with interpretation. In other words, the researcher must “go beyond the transcript” (Glesne, 2011, p. 186), analyzing not just the words, but the “spaces between the words,”—the pauses, feelings, reactions and inflections—that are part and parcel of the storytelling process.

What are the implications for selecting suitable methods, should I decide to use a narrative approach in my dissertation? Face-to-face, one-on-one interviews would be the preferred data-gathering device. Careful selection of the participant or participants

would also be critical to the success of the endeavor. Without participants who are willing to lay out their life stories, the data could be relatively “thin.” Like the case study method, a narrative study would explore one (or just a few) study participants, with prolonged engagement to develop rapport and increase comfort levels. Careful transcriptions would be needed, going beyond text alone to include descriptions of non-verbal data (pauses, smiles, tears, and gestures) to more fully capture the entire storytelling process. Planning for participants’ physical and emotional comfort (locating interviews in the home, for example) would likely lead to higher quality data.

Rather than utilizing extensive coding and sorting of data to tease out essences (a likely technique in a phenomenological study), a narrative study would maintain the integrity of the participants’ words. Larger blocks of participant-generated text would stand alone, so that caregivers’ stories could be told in a somewhat uninterrupted fashion. Interpretations would not seek to generalize any one parent’s experiences to the lives of others, but would simply attempt to make meaning from a lone perspective, on its own merits. Instead of presenting data thematically, narratives would first be offered up more or less chronologically, so as to preserve the integrity of the stories. Life events or “epiphanies” (Creswell, 2007, p. 226) would hold a preeminent place in the presentation of data. As mentioned earlier, narrative studies can often be conduits for social justice; the study might be enriched by bringing in parents infrequently heard due to race, ethnicity or socioeconomic status. By virtue of focusing my study on

caregivers (usually women) and on disability, I have already attained this social justice focus to some degree.

What are some roadblocks to a successful narrative study? Clearly, not all caregivers of children with severe disabilities are willing to rehash life stories that might prove to be private or painful to relive. Becker (2004), in an article about her own participation in a research project as an undergraduate, reminds us that such roadblocks as power relationships, political concerns, and fear can color and temper the responses of those telling the story. As in the case study, selection of willing, highly verbal participants would be critical to obtaining rich data. Parents who are non-native speakers of English would require an accomplished translator, or else nuances of the native language could be “lost in translation,” so to speak. Some parents of disabled children are intellectually disabled themselves, which could make it difficult for them (if chosen as participants) to tell their stories unaided. As in the case study, the demands of deep engagement with just a few participants put additional time and scheduling strains on the researcher. Should a participant leave the study, as is his or her prerogative, precious time and effort would be lost as a new participant is found and the process is begun again. (This is less of a worry when dealing with the more numerous volunteers involved in a phenomenological study.)

My “situational subjective I’s” (Peshkin, 1988, p. 18)—the varied positionalities I bring to my work - could evoke challenges, should I choose to carry out a narrative study. My status of real or perceived power as a school administrator could color the

way in which participants choose to represent themselves to me. Whether attempting to paint their stories in a better light for my benefit, or to guard their true feelings and attitudes from judgment, it is difficult to discount the impact of my role. Standing outside of the circle that is only “owned” by those who care for a child with severe disabilities puts me at a disadvantage as well. In my previous pilot study (as well as in medical roundtables) it was clear that there were “places that only parents could go;” the rest of us were not privy to these private conversations.

What are the attributes of a narrative study that might be attractive to me? The narrative approach calls for a researcher who is comfortable with a high degree of ambiguity and a “loose” or innovative structure. Further, the researcher must be able to write in a narrative style, stepping out of the researcher’s mode to become another “voice” in the storytelling process. I am drawn to the creative demands of this type of work; I relish the writing process and tend to “think out of the box” rather than in lock-step mode. I have done enough writing over my fifty-five years to feel ready to remove the “training wheels” and try an approach that will not only allow me to contribute to the body of educational research, but also to inspire and motivate readers from other disciplines (medicine, counseling, social work), along with readers from the non-academic world. While not a card-carrying member of the group I am studying, I am a mother myself, and have intimate personal crossroads with disability. I believe that I can develop the rapport needed to elicit meaningful narrative stories from those caring for children with severe disabilities.

Having completed a brief examination of three qualitative methods of inquiry, the final task remains: which of the three—case study, phenomenological study, or narrative—would most richly serve my research questions? When Kamata (2008), a writer and editor, discovered that her baby was born with cerebral palsy and hearing impairment, she did not go first to research journals or medical textbooks. She looked for “deep and sustaining stories” (p. ix). As she insightfully says, “The best novels, short stories, and memoirs can pull us into the lives of their characters and provide a deeper understanding of others” (p. ix). Kamata’s words echo my thoughts on the benefits of employing a narrative approach when exploring the lives of mothers who parent children with multiple disabilities. It is perhaps no accident that my paper began with quotes from the writings of Brown (2009) and Berube (1996)—both of them sharing personal reflections on their sons’ impact on their lives. A narrative work, well-crafted and mindfully presented, has the power to transport the reader into the mind and heart of the writer. The narrative approach has the additional benefit of prolonged engagement over time with a parent (or parents). While this may be time-consuming and inconvenient for me as a researcher (given the demands of my “day job” in school administration), I believe that in the end it can provide the best hope for overcoming the challenges of broaching a difficult and emotional topic with parents. Mothers who are shuffled “in and out” for a single interview session likely will not choose to bring the same depth of commitment and honesty as will those who are engaged in multiple interviews over time.

“Like a novel, narratives have time, place, plot and scene,” and are centered on “a predicament, conflict, or struggle relevant to the study” (Reitzug, 2010, p. 1). Most of us can barely imagine the struggles involved with raising a child with severe disabilities. A narrative has the potential to open up this life experience to the researcher and reader. While other qualitative methods might dance around the edges, or “parts” of the whole, the narrative approach elevates the parents’ intact stories. The thoughtful researcher can cast a spotlight on pertinent events, “restorying” (Reitzug, 2010, p. 1) them to illuminate them for the readers, while keeping the theme of respect for the narrator’s voice paramount. A narrative study, in its best form, can lead us to listen to each other’s stories. The “collective dialogue” (1996, p. 244) that Berube yearns after, the “rare and exotic corner of existence” (2009, p. 10) that is Brown’s story—can be brought forward from the shadows through the narrative approach.

Call for Participants

A call for participants was issued in a metropolitan city/county region (with approximately 350,000 residents)⁶ in the southeastern United States. The request for volunteers was disseminated through two agencies:

- *A Non-Profit Center for Children with Disabilities and their Families*

This two-campus center is a public/private partnership (city/county consolidated public school system and local United Way chapter), serving children from birth

⁶ The county is 68% White, 27% Black, and 12% Hispanic. The median household income, 2006-2010, is \$46,749. 15.3% of households are at or below poverty level (also 2006-2010 figures). <http://quickfacts.census.gov/qfd/states/37/37067.html>

through age eleven with physical and cognitive disabilities and developmental delays. The combined enrollment at the centers is roughly 250 students (including 40 typically-developing “reverse inclusion” students).

- *A Local Affiliate of the Family Support Network*

The mission of this non-profit is “to enhance the lives of children with special needs by working with their families and the professionals who serve them, and to facilitate the development of family-centered services.”⁷ This particular branch of the Family Support Network (FSN) has an email database of over 450 families of children with exceptionalities; they serve families of children birth through age twenty-one. (Since FSN is funded through the disabilities center and is in the same city, there is some overlap between the populations at the centers’ schools and the FSN database.)

The executive director of the center and the coordinator of the local FSN agreed to disseminate the research flyers. Both signed letters of support (see Appendix A), received electronic copies of the UNC-G IRB training module “Protecting Research Participants” and signed statements indicating that they had reviewed the materials (see Appendix B). The Call for Participants (see Appendix C) was sent to caregivers’ homes by hard copy at the two school sites. The FSN coordinator distributed the flyers electronically to her full professional email database. As there are a substantial number of Latino families in this county with children who meet the study criteria, these parents

⁷ More information on the mission, vision and activities of this group may be found on their website: <http://www.fsngreaterforsyth.com/>

were included in the call for participants; all materials pertaining to the selection of study participants were shared in Spanish with families whose claim it as their primary language (see Appendices C, E, and G).

Participant Selection Criteria

My aim was to select seven to ten parents/caregivers willing to participate in individual interviews, home visit interviews, and a blog expressly for caregivers of children with disabilities. Without naming specific exceptional education “labels” such as MU (Multiple Disabilities) or IDS (Intellectually Disabled, Severe) in the call for participants, an attempt was made to cull parents and caregivers whose children had severe cognitive and physical disabilities. To be considered for the study, volunteers were required to have primary caregiving responsibilities for a child age birth through twenty-one who was classified under the Individuals with Disabilities Education Act (IDEA)⁸ as needing services through the Infant/Toddler program (age birth through two), or certified as eligible for special education services under federal guidelines (age 3 through 21). In addition, caregivers were asked to respond to the flyer if they saw themselves as hopeful, resilient, and as advocates for their children in a variety of community settings. Since parents were self-identifying as having these qualities (resiliency, hopefulness, and advocacy), there was no attempt to evaluate participants’ capacities for these three indicators prior to the interview process.

⁸ The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B. <http://idea.ed.gov/>.

I selected participants without regard to race, gender, ethnicity, sexual orientation or socioeconomic status, with the hope of amassing diverse caregiver perspectives for the study. I secured the services of a translator/interpreter (an employee of the non-profit school agency) to assist me, should any Hispanic parents/caregivers volunteer and subsequently participate in the study. While I am a Spanish speaker of moderate abilities, I felt that fine distinctions of conversation could be missed if I relied solely on my own non-native speaking abilities. If the child with a disability was being raised or cared for in a two-parent home, or had two primary caregivers (a mother and grandmother, for example), the option was offered for both caregivers to participate in the study.

Three weeks after distribution, there were a total of twenty-four email and voicemail responses to the flyers. At that time, I screened each of these respondents through either a follow-up phone call or an email exchange. If the nature of the child's disability proved unclear from their initial voicemail or email responses, I posed questions to better determine the child's functional level.

Protection of Human Subjects

Talking to others about a topic as sensitive and private as caregiving can be a therapeutic and salutary experience. Opportunities for personal growth and even community-building (in the blogging world) arise when caregivers find common touchstones and share strategies for success. Yet at the same time, the act of calling forth stories and memories of caring for a loved one can be charged with emotion,

eliciting feelings that are uncomfortable or even painful. Participants are also rightfully concerned that their stories be presented in an anonymous manner, so that their identity and dignity (and that of their family members) are protected and honored. Consequently, a number of safeguards were included in the study design. Hard-copy data (printed copies of transcriptions) were stored in a locked cabinet in my home. Electronic copies of interview transcripts were stored in a pass-protected, personal computer, also at my residence. Back-up copies of this data were kept on an external drive (memory stick) safeguarded in my workplace in a locked file drawer.

My Spanish language translator completed the required UNC-G IRB training module and signed a confidentiality statement (see Appendix D) before joining me for the interview of the Spanish-speaking caregiver. The audio file for that interview (and that interview only) was given to her on an external drive, which was returned to me upon completion of the translation and transcription. No copies of this interview were saved on her home computer.

Identities were protected in the data-gathering phase and in the published study. Interview appointments were noted on my personal calendar with initials of volunteers rather than specific names. Participants were given the opportunity to select their own pseudonyms; all but two preferred that I create them myself. Any family member, friend, doctor, or other individual mentioned in the interviews was also given a pseudonym. All references to school names, street names, and identifiable locations (shopping malls, parks, hospitals, etc.) were purged from the published study.

Pseudonyms were sometimes invented for identifiable locations to reduce chopiness in the narrative.

Last, the study participants were informed that they had the right to withdraw from the study at any time, without penalty; none did so. If any of the participants had chosen to withdraw, they would have been allowed to request that their data be destroyed, unless it was in a de-identifiable state (i.e., transcribed with pseudonyms). The caregivers were also assured that they would be kept informed should any information arise during the execution of the study which might affect their willingness to continue their participation.

Overview of Participants

Ten participants were selected based on the information they shared about their children in the initial contacts, or in the follow-up emails or phone conversations. Many of the twenty-four respondents who initially expressed interest in participating had children with only moderate or mild disabilities. A number of caregivers reported that their children had ADD or ADHD⁹; others had children with Down syndrome.¹⁰ Another reported that his son had Asperger's syndrome.¹¹ These (non-selected) caregivers had

⁹ The "official" clinical diagnosis is Attention Deficit Hyperactivity Disorder, or AD/HD. Common core features include distractibility, impulsivity and hyperactivity. In order to meet diagnostic criteria, these behaviors must be excessive, long-term, and pervasive. (http://www.add.org/?page=ADHD_Fact_Sheet)

¹⁰ Down syndrome is a genetic condition in which a person has 47 chromosomes instead of the usual 46. The extra chromosome causes problems with the way the body and brain develop. Down syndrome symptoms can range from mild to severe. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001992/>

¹¹ Originally described in 1944, the syndrome has more recently been classified as an autistic spectrum disorder. A qualitative impairment in social interaction, impaired communication skills, and a preference

children who were verbal to some degree, mobile, in general good health, and able to feed and toilet themselves. The ten caregivers who were eventually selected had responsibility for children with the most severe cognitive and physical disabilities. None of the ten children were able to communicate verbally; only one of the ten was independently mobile. Most of them were fed exclusively or in part through G-tube¹², and all were incontinent. Most had experienced untold numbers of hospitalizations, emergency room visits, and surgeries.

All of the selected participants were caring for children with cognitive impairments that were serious in nature. Disabilities were wide-ranging, including complications of prematurity, genetic disorders, and Shaken Baby syndrome. Some parents were made aware of their children's disability before birth, and some disabilities did not present until a year or longer after birth. The children ranged from age two to twenty. Developmental delays ranged from moderate (a three year old child with an approximate delay of one year) to severe and profound (the twenty-year-old, who functioned at a six- to twelve-month level). The eight children who were in a school age program (ages five through 20) attended alternative elementary, middle and high

for routine and consistency are common characteristics. <http://www.aspergersyndrome.org/Articles/What-is-Asperger-Syndrome-.aspx>

¹² A G-tube, short for gastrostomy feeding tube, is the placement of a feeding tube through the skin and the stomach wall, directly into the stomach. This is often called for in cases of babies with birth defects of the mouth, esophagus, or stomach, patients who cannot swallow correctly, who cannot take enough food by mouth to stay healthy, or who often breathe in food when eating <http://www.nlm.nih.gov/medlineplus/ency/article/002937.htm>

schools for children with exceptionalities, and were in the functional curriculum and Curriculum Extensions rather than the Common Core.¹³ The two children under the age of five were students in the infant/toddler and Exceptional Children's (EC) preschool programs of the public/private partnership mentioned above. All of the children received occupational, physical, and speech therapies in their school settings, in addition to special education classroom instruction. Some also received additional therapies in the home, as well as hearing impaired (HI) and visually impaired (VI) services.

Study participants hailed from a broad cross-section of economic and ethnic groups. Some caregivers depended upon food stamps and had no more than high school educations; others held MBAs and sent their typically-developing children to private boarding schools. Participants were White, Black, and Hispanic; one couple was interracial. Insurance coverage varied from generous employer-backed plans, to Medicaid, to none at all. Of the ten initial participants, nine were biological parents to the children under their care. One caregiver was a registered foster parent outside of county lines, whose foster child was able to attend the local school program through a reciprocal agreement between the United Way agencies of both counties. This caregiver and her husband were seeking to adopt the child in their care at the time of the interviews. By the time this study was completed, they had celebrated the finalization of

¹³ Like 44 other states and three territories, this southeastern state has adopted "The Common Core State Standards." Children performing on a functional level in this particular state are taught on the "Extensions of the Common Core." <http://www.corestandards.org/>

his adoption. Two spouses of participants asked to join the study after the initial interviews, and were invited to take part with their wives in the second (home) visit.

Data Collection: Interviews

The central data collection method for this qualitative research study was individual interviews. The ten selected participants agreed to initial interviews scheduled to last approximately one hour; all lasted from 45 to 75 minutes. These initial interviews were conducted in a conference room at one of the two cooperating school sites. Parents were given the option of a morning or afternoon time slot, as best suited their schedules. The conference room was windowless, and privacy signage was posted to assure that there would be no interruptions during the interview process. Gift cards (Wal-Mart or Target) in the amount of \$20 were given to the participants at the end of the interview in appreciation for their time. Spouses did not participate in these initial interviews. (Both participants who asked if their spouse might join the study did so *after* the first interview session was completed.)

At these initial interviews, caregivers read and signed the IRB-approved consent form (see Appendix E), and were given a copy for their records. They also completed a Participant Information Sheet (see Appendix F) which called for brief demographic and contact information. The form also allowed study participants to indicate their willingness to participate in a second round interview in their home, as well as their interest in joining the research study blog. Participants were also given the opportunity to create their own (and family members') pseudonyms if desired.

The interviews began with casual conversation to build rapport and put the participants at ease. A semi-structured outline was used (see Appendix G). I hewed to this general plan, while also allowing participants' responses to shape my questions and guide the conversation. Nine of the ten participants completed this initial, center-based interview. The Hispanic mother who wished to participate did not have transportation readily available, so arrangements were made to visit her at home with the translator, skipping the initial school-based interview. The Spanish language consent form (see Appendix E) was read aloud to this participant and her spouse by the translator, and the participants' signatures were secured. A Spanish copy of the form was given to this couple for their records.

I had initially planned to continue the study by conducting second (and possibly third) interviews in the home with just three to five of the participants, based upon the degree to which hope, resiliency and agency were present for each participant. After the first round of interviews, it was clear that it would be close to impossible to exclude any of these caregivers from continued study. *All* of the study participants shared narratives deserving of a retell; excluding more than a couple of them proved easier said than done. There were just too many interesting stories to be told to limit further study to half or less of the initial group. All ten first round interviewees were willing to continue with interviews in their homes, but I felt that two of the ten were quite similar in profile to others already included (White, middle class, married). And, as a secondary consideration, I was ambivalent as to whether my readers could mentally juggle *ten*

different story lines, no matter how interesting. In the end, I chose to complete the home interview process with eight of the ten original participants. Of those eight, two asked if their spouses might be included in the home interview, putting the aggregate total of participants at twelve, and the final total for second (home) interviewees at ten, from eight households.

After the completion of the first round of school-based interviews, I began to schedule the second (home) interviews with eight of the original participants. The home visits were designed to add depth to the collected data by allowing for the inclusion of observational, incidental information that would not be accessible in the “sterile” conference room setting. Additionally, home visits opened up opportunities for interactions with siblings, spouses, and other caregivers (such as home-based nursing staff). These second interviews were scheduled for an hour, and concluded within that time frame. Gift cards in the amount of \$20 were once again provided as a token of thanks. More than one caregiver initially refused the card at the second interview, but when I suggested that they should purchase something for their children, they all agreed to keep it.

At either the start or end of the hour, many parents took great pride in showing off their children’s bedrooms, explaining bedtime, bathing and feeding routines, and sharing family photos and mementos. Observational field notes were compiled during and immediately after each of the second interviews. Questions for the second interviews were tailored specifically to each participant’s earlier responses. For

example, if a participant did not touch on the role of religion or spirituality as a source of support in the first interview, I might include a question in that vein for the second round (see Appendix H). The home visits took me quite literally to the four corners of the county, into areas of both wrenching poverty and great wealth. It is impossible to overstate the elucidating effect of conducting these interviews on the caregivers' home turf.

Data Collection: Blog

As an ancillary data collection mode, I created a pass-protected blog and offered access to all participants. This was an optional, additional means for caregivers to share their experiences and reflections vis-à-vis caring for a child with a disability. There was no gift card or other compensation offered for participation in the blog portion of the study. The website was designed using Blogspot, a Google tool. Of my ten participants, eight agreed to submit their email addresses so that they could receive an electronic "invitation" to the blog. One of the two parents choosing not to participate admitted that while she had an email address, she was "technology-challenged" and unlikely to participate. The second non-blogger was the Hispanic caregiver, who did not have an email address or Internet access in the home. Blog participants were given the option of having their posts accessible to all other participants, or restricting visibility to me alone, as the blog administrator. Every caregiver chose to have his or her blog entries visible to all other study participants. Pseudonyms were not used on the blog, as Google puts the

user name on each post or comment as an identifier (generally a first name).

Participants were made aware of this.

The eight interested study participants received email invitations to the blog, with a “live” link that provided access to the website. As site administrator, I was able to post entries on the blog, and study participants could comment on my posts (see Appendix I). Blog posts and comments were captured and copied into a file on my personal laptop, time-stamped and cross-filed with the pseudonyms of the interviewees. Blog confidentiality was critical, given that the Internet can be a highly public space. I configured the blog so that I could monitor submissions and filter them before they went “live,” keeping any participants who might change their minds and request full privacy off of the viewable site. Additionally, these restrictive blog settings allowed only invitees to access the site; as a result, the blog could be seen only by the researcher, the UNC-G dissertation committee chair (co-researcher), and the invited participants.

Caregivers were duly warned in the consent form that absolute privacy protection could not be guaranteed when using the blog, since they would be accessing it in their own homes rather than in a controlled environment. The consent form included a written reminder to close the blog browser window when leaving the site, to guard privacy. When cutting and pasting blog comments from the website to my personal computer for possible inclusion in the study, no identifying information was included. The blog was closed three months after the last interview was held.

Participants were notified by email of the date that the blog would be expunged from the internet.

After a month with very little blog activity (two comments) on the part of the study participants, I issued a second invitation to the site; I also upgraded the participants' site privileges. The caregivers were moved from "readers" (who could only comment on my posts) to "authors" (who could create their own blog entries). This additional privilege triggered a slight uptick in blog traffic, allowing caregivers greater ownership and authorship of the site versus merely responding to my postings. Blog participants received occasional additional emails from me, thanking them for their contributions, and encouraging them to revisit the blog as time allowed.

Organization and Analysis of Data

Interviews were audio taped using both a battery-powered hand-held digital tape recorder, and a Samsung Galaxy tablet with a recording application. The interviews were then transcribed, and these individual documents were saved onto my personal laptop computer. The original recordings were converted to wave (sound) files and transferred to my laptop as well. Once finished with the research, these files were removed from the computer, saved onto an external drive, and placed in a locked file cabinet.

While the process of personally transcribing what would eventually be almost seventeen contact hours was time-consuming and physically taxing, I felt that as the researcher, it was apropos to "own" this groundwork rather than delegate it to

someone not personally invested in the participants and their stories. The one exception was the interview with the Hispanic couple; my translator transcribed this interview for the same reason that she facilitated the interview: to capture the subtle shadings of spoken Spanish that might have been beyond my skill level.

Once the interviews were transcribed, I used the rather old-fashioned technique of highlighting all passages of interest for inclusion in either the caregivers' general background narratives (Chapter V), or the more specific topics covered in Chapters VI, VII, and VIII. The color-coded highlighting aided in distinguishing between the topics buried in the hard copies. With the availability of sophisticated coding software, this procedure might seem outmoded, but as a learner who spent her first 43 years in the previous century, I unabashedly embraced Luddism when coding data.

Above all, I was concerned with allowing each participant's words to stand on their own merits without need for validation or hyper-analysis on my part. Each of the eight participants (or participant couples) had an incomparable story to tell. My first intention was to allow these eight distinctly individual narratives to stand alone, while keeping my commentary to a minimum. Chapter V is devoted to this goal: painting pictures for my readers, so that they may develop a deeper awareness of the nature of caregiving. Analysis in this chapter is limited to clarification and elaboration, interwoven with descriptive passages to bring the reader more fully "into the room" with the participants. To that end, the setting for each of these eight initial parent narratives is the home of the participant, rather than the conference room (although pertinent text

from both interviews was used to tell the stories). I hold that these introductory narrative summaries were a requisite for working with the data, building background knowledge for the reader while capturing the fundamental nature of these caregivers' lived experiences.

Next, commonalities across the participants' interview data led me to fuse emerging topics (beyond the caregivers' initial stories) into sources of support, specific challenges and transformations, and opportunities for growth and action. While common trends and outliers were noted, it was neither my aim to codify individuals into boxes nor to find ecumenical maxims. But conversational threads unmistakably coalesced as I listened and re-listened to the tapes and read through the transcribed texts. I teased out these central themes (and the sub-themes within them), supporting each with quotes from the caregivers' interviews.

By color-coding within each of the seventeen interviews, I was able to mine the data for evidences of these particular consistencies which presented themselves in the course of the research project. Throughout the process of data organization and analysis, the original research questions from Chapter I were always present as a framework for looking at the data; these questions are addressed organically within Chapters VI, VII and VIII, and more specifically in the conclusion. Yet the process of conducting qualitative, narrative research quite naturally took me down unexpected paths, and brought to light new questions as it answered others.

Trustworthiness

Acknowledging an affinity for the disabled community was necessary but not sufficient disclosure prior to proceeding with my research. The qualitative researcher uses different but no less rigorous safeguards from those employed in the quantitative realm to ensure that a study is reliable and valid. Glesne (2011) notes that such measures as triangulation (analyzing data from multiple frameworks), prolonged engagement with the data, assorted methods of data collection, and recognition of one's own cultural subjectivities can help to ensure trustworthiness. What are the ethical dilemmas that appeared in the course of my work? What aspects of my positionality perhaps hindered the trustworthiness of my study, or clouded a thorough analysis of the data? Lichtman (2010) tells us that it is impossible to discount "the role of the researcher as a filter through which data are collected, organized, and interpreted" (p. 116). Lichtman recognizes that rather than try to filter out subjectivity, the researcher must analyze his or her own biased nature.

My membership in the dominant White culture could have been problematic, as it is a position of power and privilege that was not shared by some of my participants. The middle class socio-economic status that I enjoy also grants benefits unavailable to a good number of my interviewees. My educational background could have created discomfort for my participants, if they were not afforded the same advantages. The status I hold as a parent did, conversely, likely garner some solidarity with participants, yet my own children and step-children are healthy. While my personal history (visited in

Chapter I) includes valuable interfaces with the world of disabilities, I have never faced the daily hurdles encountered by these parents. I am, plainly stated, not a member of their club.

A final ethical issue to be explored is what Glesne (2011) calls the dilemma of “backyard research” (p. 49). Glesne acknowledges attractive positives that flow from conducting a study in the workplace: ease of access and rapport, time and money considerations, application to daily work. But my status as the principal of a school for children with disabilities is a two-edged sword, especially for the participants that have students currently or even previously enrolled at my site. Toward the good, the parents whose children attend (or previously attended) my school were aware that I have a strong and ongoing professional concern for their needs, and a vested interest in their children’s well-being. They might have (correctly) inferred that my study was not just an attempt to fulfill degree requirements, but was also a sincere effort to improve my own professional practice. Conversely, my job title placed me squarely in a position of authority. Parents were aware that I am involved in the hiring, evaluation, and retention of staff. Conceivably, they could have posited that their responses would potentially color my perceptions of them as parents, or negatively impact staff members. As Glesne (2011) warns, backyard research “needs to be entered with heightened consciousness of potential difficulties” (p. 43). I therefore had to strike a balance between the potential for positives gained by conducting the study in and around my own work setting with the risks of muddying the results. By drawing participants as much as

possible from other local schools serving students with disabilities rather than my own, and focusing when possible on former rather than current students, I alleviated some of the risk inherent in staying “close to home” for my research.

Of the ten caregivers participating in the initial interviews, four had children currently attending my school. I did not invite one of those four to take part in the home interview, putting my final numbers at three from my school, two from another elementary school for children with special needs, one from middle school, and two from high school. As my site is the only location in this city for infant/toddlers with disabilities, and because the other school serving preschool and elementary children with disabilities has few medically fragile students, this skewed my participant affiliations toward my own building. I admit that had the study been an examination of the quality of public school education for children with special needs, or the role of the parent in the IEP process (or another school-related topic), the risks of tainted data would have been elevated. But the questions asked in this study placed the discourse mainly in the realm of the home and the medical community. Schools were mentioned on a few occasions, but were no more than tangential to the study.

CHAPTER V
CAREGIVERS TELL THEIR STORIES

Introduction

Goodall (2000) reminds us that writers must “create—out of the raw materials of lived experience, imagination, and reading and talking with others—some pattern in that storyline that is symbolically rich and significant for an intended audience” (p. 40). This was my challenge as I talked with study participants, listened and re-listened to more than sixteen hours of interview tapes, transcribed over 80,000 words, and then began to distill the data into cogent portraits of these caregivers. The individuals who were gracious enough to invite me into their milieu deserved as much attention and skill as I could bring to the task of forming what Goodall calls “raw materials” into a “rich and significant” rendering of the caregiving experience.

Goodall goes on to speak of the writer’s responsibility to the reader:

The pattern you help the reader to discover must contain some basic human grammar, out of which readers can find the blood link to their own experiences, their own reading and talking, their own constructions of how persons and things become meaningful through everyday actions. This is more than simple identification with the character or plot; it suggests a closer identification with the way in which the story that is told *could well be their own* [italics in original]. (p. 41)

I have endeavored to present these eight caregiving stories so as to illuminate the essentials of each journey. Whether the reader is a medical professional, an educator, a therapist, another caregiver, or someone interested in building an increased understanding of what it means to care for a child with disabilities, my intent was to forge, with the reader, the “blood link” of which Goodall speaks. We can never truly walk in one another’s shoes, but we can have a go at slipping them on to discover, if just for a bit, how they might feel.

These eight accounts serve as introductory narratives, crafted to set the stage for more specifically-themed explorations in Chapters VI and VII—a chance to meet the caregivers, if you will. These parents and foster parents are immersed in the acronym-heavy lingua franca of disability and medicine; for that reason I have footnoted liberally to provide parenthetical clarification for the reader. Descriptors of each participant’s emotional affect during the interviews, when pertinent, have been included in brackets. To mask identities, hospitals, cities, doctors’ names, and agencies have been converted to pseudonyms and bracketed as well, or redacted and replaced with generic terms. Ellipses have been used to connote excised text, or pauses in the interviewees’ speech. Table 1 provides a concise digest of the eight participants’ and participant couples’ basic information, as a reference for the reader.

Table 1

Study Participants' Demographics, Family Member, and Child Disability Information

Participant (Age)	Ethnicity, Education	Work and Marital Status	Caregiver for _____ (Age)	Disability of child (see key)	Other Family Members in the Home
Jackie (37)	White, High school + Technical certificate	Part time CNA2, Married	Troy (2) (Foster parent in process of adoption)	Shaken Baby Syndrome NV, NM, T, DD, VI, HI, S, I	Art (husband), Ashley (18), Doug (13), Amy (9), Carson (4)
Kristin (34)	White, College graduate	Full Time Private School Administrator, Married	Marc (3)	22Q Deletion Syndrome NV, T, DD, I	Larry (husband), Owen (Marc's twin) Ed (18 months)
Brenda (24)	White, High School Graduate	Part Time House Cleaner, Single	Carter (7)	Schizencephaly NV, NM, T, DD, VI, HI, S, I	None
Edith (23) and Jesus (25)	Latino (both), Grade School Education	Homemaker, Full Time Welder, Married	Veysa (6)	Cerebral Palsy NV, NM, T, DD, VI, HI, S, I	David (8), Lorenzo (2)
Janet (32) and Raul (32)	White (Janet) and Latino (Raul)	Full Time School Secretary (Janet), stay-at-home dad, Raul, Married	Anne Marie (7)	Cerebral Palsy NV, T, DD, S, I	None
Kate (41)	White, Associate's Nursing Degree	Part Time Licensed Practical Nurse, Married	Nellie (11)	Cryptogenic Epilepsy NV, NM, T, DD, VI, S, I	Robert (44), Grace (13), Julia (3)
Anna (48)	Black, MBA, Accounting	Homemaker, Married	Alex (15)	Cerebral Palsy NV, NM, T, DD, S, I	James (49), Jim (16), Dale (10)
John (63)	White, Juris Doctor	Public Defender, Divorced	Johnsie (20)	Rett syndrome NV, NM, T, DD, I	none

Note. NV = Non-verbal; NM = Non-mobile; T G = tube fed; DD = Developmental Delays; VI = Visually Impaired; HI = Hearing Impaired; S = Seizures; I = Incontinent

These eight caregivers (and caregiving couples) had profound lessons to share; it was intimidating to translate their wisdom to paper. How to turn a staggering 80,000 words into a “blood link” or “grammar” between the world of caregiving and the world of the reader? I was drawn to Lamott’s (1994) treasure of a book on the act of writing as I faced the voluminous task; her words were a guidepost and a balm:

Thirty years ago my older brother, who was ten years old at the time, was trying to get a report on birds written that he’d had three months to write. [It] was due the next day. We were out at our family cabin in Bolinas, and he was at the kitchen table close to tears, surrounded by binder paper and pencils and unopened books on birds, immobilized by the hugeness of the task ahead. Then my father sat down beside him, put his arm around my brother’s shoulder, and said, “Bird by bird, buddy. Just take it bird by bird.” (p. 19)

And so, then, bird by bird . . .

Jackie’s Story: Troy

Jackie is a 37 year old, generously-freckled redhead, with an earthy laugh and a wide smile. She and her husband, Art, both White, live in an aging double-wide trailer, perched on a generous-sized corner lot, just over the county line. A few miles beyond the Wal-Mart and the last gas station, their rural home contains a rowdy “yours, mine and ours” brood of five children. Chain link fencing surrounds the sun-baked front yard, littered with forgotten toys and a broken trampoline. As I drive past, scanning in vain for a street sign or house number, two men leaning against a pick-up truck eye me warily. Four or five children circle slowly on bikes in the ninety-degree heat. A teenage girl lounges languorously in a folding chair on the front stoop’s broken pavement, watching

with mild curiosity as I make two slow false passes by their home. Eventually I call Jackie from my cell phone to confirm the address, and she waves me in.

Jackie and her husband are foster parents to Troy. They have high hopes that adoption papers will be finalized soon, making him officially their son. Troy is a two-year-old toddler with Shaken Baby Syndrome,¹⁴ a medical term encompassing a discursive range of debilitating injuries that occur when a baby is intentionally shaken.

Jackie begins the story:

We picked Troy up on May 26, 2010 . . . We're licensed as foster parents through a private agency. Our social worker is Karen, and what happens is [we get children] either too medically fragile or too difficult to place with the parents they currently have. And so they called Karen, and we went up to the hospital and took a look at Troy. And the nurse said, "Do you want to hold him?" And I'm like, "Well, yeah, I want to hold him!" [Jackie laughs.] Anyway, he was very fragile. His breathing was very labored. He had a stridor.¹⁵ I don't know if you know what that is. It's a very loud breathing. And you can physically see his, uh, the airway around the collarbone sink in; you can really see the airway pull down. And it's very loud and noticeable.

As we sit in the dim, uncomfortably-warm living room discussing Jackie's first encounter with Troy, he is stretched out beside us on an over-sized, padded ottoman by the sofa. A beautiful boy, pale, with large eyes that look towards the ceiling, Troy lies on his back.

¹⁴ Also called Abusive Head Trauma, or SBS/AHT, this disability's major markers are subdural hematomas and retinal hemorrhages. <http://www.dontshake.org/sbs.php?topNavID=3&subNavID=23>

¹⁵ Stridor is an abnormal, high-pitched, musical breathing sound caused by a blockage in the throat or voice box (larynx). It is usually heard when taking in a breath. <http://www.nlm.nih.gov/medlineplus/ency/article/003074.htm>

His legs are braced with plastic orthotics,¹⁶ and he sports similar wrist supports. His audible breathing—the stridor—provides a rhythmic undercurrent to Jackie’s words:

He was injured in April, probably around the twenty-third or twenty-fourth. . . . When a baby is shaken, not only is the brain damaged and bleeding, but the eyes bleed as well. And the inside of both his eyes were full of blood and, um, scar tissue. And that was going to cause the blindness. . . . They did not expect him to live. They told us, straight out, “When you take this child home, he probably will live about a week. He may not even make it all the way home.”

So, we took a few days to prepare the other kids, and to prepare ourselves. And we said, “We really just need to bring this little boy home, and . . . he’s probably going to die at our house, but he needs some people to love him, and, and help him through that time. But on the twenty-sixth [of May] we went and picked him up. We were told he was blind. We were told he was deaf. We were told he would never do anything but . . . just breathe, until he, uh, died.

The implications of her words begin to register. Jackie brought home a stranger’s child, impossibly broken and fragile, to help him through the *dying process*. Troy’s own father allegedly did this to him. (While he has never been prosecuted, he is in prison on other charges.) I realize I am holding my breath with astonishment. Most caregivers have disability thrust upon them; Jackie *chose* this abused baby. Before I can process the enormity of this, she breaks into a devilish grin: “On the way home, a man on a Harley Davidson passed us, and the child about climbed out of his car seat, so I was pretty sure he wasn’t *deaf!*” She lets out a full-throated laugh, recalling this serendipitous discovery. But then her tenor shifts, her voice lowering to a whisper. She speaks deliberately:

¹⁶ An orthopedic appliance or apparatus used to support, align, prevent, or correct deformities or to improve the function of movable parts of the body. <http://physicaltherapy.about.com/od/abbreviationsandterms/g/orthotics.htm>

He started crying then, and didn't stop for about three to four months. That was due to the agitation. Children with these brain injuries have a high level of agitation, and it's difficult to manage at times. The first six months we had Troy, he had thirty-seven doctor appointments. And that's not counting therapy. We had multiple therapies coming to the house. Hospice was coming in. . . . He had three hospitalizations during that time. . . . He would cry and cry, and his head and his feet would touch the crib, and he would form an arch. And he would just scream and scream.

And at that point, he had been fitted with a helmet for his head. He had been fitted with hand splints to help the tone in his hands, AFOs, which are ankle-foot orthotics. You know, I mean, he was plastic from head to toe. . . . All of those things attached to this poor little child, and he's still forming an arch over the bed. He's tube-fed—at that time, he could take nothing by mouth, and he was getting twenty-four hour feedings. So, you know, he was very complex, and um, took a lot of care, and was very complicated.

Jackie's tone is matter-of-fact, almost clinical. She is not complaining; she is not seeking credit or approbation. Her background as a CNA2¹⁷ qualifies her to provide this level of care, and she seems rightfully self-satisfied at how well they all weathered those first trying months of Troy's homecoming. But Jackie is not a woman who dwells on the past; she deals in the moment at hand. She wants to bring me up to present-day, sharing the details of Troy's successes.

But anyway, that was the gist of his first six months, just trying to get him settled, and now he's two! Yeah, he's doing more than they said he would do. He's holding his head up, trying to . . . working on trying to sit up, to get that strength. Uh, fine motor skills, he probably doesn't really . . . well, I'll say they're emerging. Just getting him to be able to hold himself up is our big goal right now. Learning to eat a little bit. He can eat a Stage Two baby food consistency. Lots of

¹⁷ CNA2s are Certified Nursing Assistants trained to a deeper and more specialized level. CNA2 Acute Care training is focused on the knowledge and skills needed to work in hospitals and other acute care settings. <http://cascademedicalschool.com/classes/cna2-acute/>

therapy still! [laughing] We're starting two new therapies this summer. We're trying the horse therapy, and swim therapy.

To fully decipher Jackie's caregiving story, we must circle back to five years earlier, before Jackie and Art were married. Her pathway to becoming Troy's foster mother (and Art's wife) was set into motion by a horrific event. Art was a family friend from her teens and twenties. They had run into each other from time to time over the years, and at one such encounter, Art handed her a card with his phone numbers, in case she ever needed anything. In 2007, at age 13, Jackie's daughter Ashley was sexually assaulted. Jackie picks up the story thread:

It was a couple of weeks into the crisis with Ashley, that, um, I found the card again. And I said, "I need a friend." And, um, at that point in my life, there were not a lot of people that I had a lot of trust in. . . . So I called him up, and I came over. . . . This was around the time that Ashley was giving birth to Carson, and I had to have *no* job, because I was having to take care of them. And I was running out of money. And he kept saying, telling me, "You can come and stay here. You can come and stay here."

And um, I was afraid of what people would think of me. I was really afraid of what people would think of me. Because my daughter had been sexually assaulted, and here I was moving in with a man. And it took me six months to make that decision. . . . But I really prayed and worried over—and those are two contradictions; I guess I shouldn't be worried if I'm praying! [Jackie smiles.] You know, I really worried about the implications of that, and what would come of that.

And he went to great pains to split the house up. I mean, he cut the living room in half, and made me a bedroom. And you could only get to Ashley's room if you went past me, just to make me feel comfortable. But when I made that phone call, and I'm, like, "Art, I'm out of money," he goes, "You know what to do—load up the stuff, and come on." And at that point, we were still just friends. But somewhere along the way we decided that it was a good match, and . . . He

goes, “You know, I really like you. I’d like for you to stay a while. How ‘bout forever?”

Jackie tosses her head of thick red locks back and erupts in a glorious belly laugh. The assault on her daughter, and hitting rock bottom emotionally and financially, led her to Art. And the assault, ironically, also started her down the road that would lead to Troy.

After that time, I had to go back to work. And I had to find work that had a schedule that would accommodate all my family chaos. [She laughs.] And so, I went to home health care. ‘Cause I could kinda say, you know, “I can work these days, or I can’t work these days.” And, um, they put me with all the pediatrics cases. And there was a little girl there who had been, um, she was born at 23 weeks, and was born with only half of her cerebellum . . .¹⁸ But anyway we decided that we wanted to adopt this little girl.

I took her home, for about a two week respite. . . . And I had to find a way to use the skills I had learned, to give back also. That’s how we got started. . . . To give back to the community that had given to us, was part of that. There were so many people, who through our church, and in the community, that came forward when my daughter was hurt, and said, “How can I help?”

Jackie and Art did not go through with the adoption of that first baby, but they were hooked. The social workers at the hospital began to hear about this outgoing, upbeat woman with an affinity for the sickest, most grueling cases.

Not all foster children are this medically fragile. The word is slowly creeping out that, um, that I’m out there. And I had a phone call that somebody was in a meeting at [local hospital], and they had this child they were staffing. “Has Jackie been called yet for this child??? Why hasn’t Jackie been called yet for this child???” [laughing]

¹⁸ The cerebellum is the area of the hindbrain that controls motor movement coordination, balance, equilibrium and muscle tone.

The five children under her roof tell the story of her circuitous path. Ashley, now eighteen, is biological mother to four-year-old Carson, but Jackie and Art are his foster parents. 13-year-old Doug is from Jackie's first marriage, and Amy, nine, is Art's child. And of course Troy, the baby of the family, is about to become a full-fledged member. And when his adoption is finalized, it will create an opening for a second foster child. (Jackie is licensed for two at a time.) She says she will launch a search for another sick baby, another "tough case." "There are so many children in foster care right now, that need homes," she reminds me.

So, we try to push that message when we can. . . . Yes, it's a struggle. Of course it's a blended family, and that's always a struggle. . . . And it's an ongoing process, and nobody's perfect, and nobody handles every situation like they would like to. But we're all growing, and Troy's growing with us!

John's Story: Johnsie

If there *is* any such person as a "typical" caregiver for a child with disabilities (but of course in reality there is not), John does not represent that hypothetical norm. He is the lead attorney for the local public defender's office, rubbing elbows with society's worst miscreants—murderers, rapists—on a daily basis. A high-profile leader in the legal community, he is known for being both a ruthless alpha dog and an irreverent cut-up in court. At 63, his resume includes Vietnam War vet, hippie, and self-professed womanizer (more on that in a moment), and he exudes the devilish charm of an affable

southern “frat boy.” But his most cherished role by far is that of single dad and caregiver to “Johnsie,” his 20-year-old daughter and namesake.

John, a White male, lives in a middle class suburban neighborhood of small ranch houses and bungalows. His own modest split-level home sits amidst a pleasant tangle of shade trees, ivy, and untended shrubbery. He greets me at the door, looking as charmingly ruffled as his yard: shirttail out, an overgrown mop of white hair uncombed. We mount the half-flight of stairs to the wood-paneled living room, where Johnsie is reclining on the couch, her spindly legs covered with a blanket. Tara, her Black nurse’s aide, sits beside her, a hand resting on her ankle. The preschool cartoon character “Dora the Explorer” cavorts across the screen of the large flat-panel television.

Johnsie is a tiny young woman who would more easily pass for twelve than twenty. Her brown hair is short, fine, and wavy; her sweet but absent gaze is fixed on Dora. Her hands are drawn up tightly to her chest, motionless. “Isn’t she pretty?” John asks. And I respond sincerely that yes, she is. The father places a hand on his daughter’s head before we turn back down the stairs and settle onto a couch in a sparsely furnished basement “rec” room, overflowing with toys.

The story of Johnsie opens with an illicit tryst between John and Annette, a professional colleague. (“Little bit of a scandal at the time,” John says, chuckling gleefully, without a trace of contrition.) He continues with the sequence of events in those first years:

Johnsie was born in '92, uh, apparently normal. I say that because we learned later her disorder, which is called Rett's [*sic*] Syndrome¹⁹—not Tourette's, but Rett's—is a regression disorder, doesn't show itself until age two. Johnsie was born to me and Annette. When Johnsie was born, we weren't married at the time. Well, *I* wasn't. Well . . . Annette and I had *eventually* gotten married—after she got *divorced!* [He laughs slyly.] And we were both practicing law here in town, and we thought we had a completely normal child, although small at birth.

Uh, we didn't have any worries until about eighteen months. Some things didn't seem right. Nothing we could point to. Specifically, she wasn't walking, she wasn't crawling, were the main two things. She was talking—babbling. Saying a few things. Her name, she would say over and over. "Johnsie-Wonsie, Johnsie-Wonsie." Which is interesting, because she's not verbal now. So it's one of the things she lost, is the ability to talk. Um, at about eighteen, nineteen months, we decided to do something about it, check it out. . . . So we went to, I think we went to the TEACCH²⁰ place in [nearby town], and they checked her out pretty well. And they said, "Well, the good news is, it's not autism. The bad news is, we don't know *what* it is, but it might be something very bad."

And I think they mentioned Rett Syndrome, but as if . . . as if to say that it *couldn't* be that, 'cause that's *really* bad. So my wife got her in quickly to see Dr. K at [developmental evaluation center]. And back then they had the all-day deal, with all the people coming in to see her. It was like we'd get there at eight, and we came back at four o'clock to hear the bad news. He made a clinical diagnosis, and he nailed it, by the way. . . . And he diagnosed her with Rett Syndrome, something we'd never heard of. At the time, probably twenty-five girls in the United States had it. No boys, it's fatal in boys.

¹⁹ **Rett syndrome** is a unique developmental disorder that is first recognized in infancy. It is caused by mutations on the X chromosome on a gene called MECP2. Rett syndrome causes problems in brain function that are responsible for cognitive, sensory, emotional, motor and autonomic function. These can include learning, speech, sensory sensations, mood, movement, breathing, cardiac function, and even chewing, swallowing, and digestion. Symptoms appear after an early period of apparently normal or near normal development until six to eighteen months of life, when there is a slowing down or stagnation of skills.

²⁰ A University-based system of community regional centers that offers a set of core services along with unique demonstration programs meeting the clinical, training, and research needs of individuals with autism, their families, and professionals. <http://teacch.com/about-us-1>

Up to this point John has talked precisely, in professional mode, as if he is explaining legal procedure to a client. Now as he recalls the seismic devastation of the diagnosis and the particulars of Johnsie's limitations, his speech slows and he dabs at his eyes from time to time.

I was very disappointed in Dr. K. He . . . he gave us the option of institutionalizing Johnsie, and that . . . I can't . . . I don't think he would do that now. I think that was what he felt he had to do back then, but I don't think he believed in it. I was horrified, and so was my wife. And uh, after we went . . . on the way home, by the way, my . . . my wife, very matter-of-factly, and probably seriously, suggested group suicide. It was that bad a day.

She lost all the skills she'd previously acquired, such as talking, and using her hands. At one time she could feed herself, but that was over by the time she was three or four or five . . . she could no longer use her hands, no longer talk. Really never has walked. . . You have to help her; she can't walk by herself, except for a few steps. She's developed kyphosis,²¹ scoliosis,²² uh, apraxia²³ is one of the words. She can't do a voluntary motor movement. She's tested at profound mental retardation, but she can't, she can't be tested because she can't use her hands, she can't speak. It's really hard for her to demonstrate what she knows.

Annette and John stayed married until Johnsie was six years old, but divorced in 1998.

Numerous studies cite raising a child with disabilities as a contributing factor in divorce, but John sees it otherwise, at least in his case:

²¹ Kyphosis is a curving of the spine that causes a forward bowing or rounding of the back, which leads to a hunchback or slouching posture. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002220/>

²² Scoliosis is a sideways curvature of the spine. Scoliosis can be caused by conditions such as cerebral palsy and muscular dystrophy. <http://www.mayoclinic.com/health/scoliosis/DS00194/>

²³ Apraxia, also known as verbal apraxia or dyspraxia, is a speech disorder in which a person has trouble saying what he or she wants to say correctly and consistently. <http://www.nidcd.nih.gov/health/voice/pages/apraxia.aspx>

Johnsie kept us together. And I am a little bit proud of myself about this. Because I've seen the way that . . . that other fathers just couldn't handle it. Johnsie kept me in my marriage for a long time. I wasn't happy after . . . shortly after we got married. I mean, we got married because we had Johnsie. Johnsie was born . . . [laughing] nine months after we met! So, uh, she did keep us together, and certainly has been the bond between my ex and me, now, for *years*, because I'm sure, because of Johnsie, we are still friends, still in constant touch.

John kept Johnsie for three or four nights per week after the divorce, but in December of 2000, Annette remarried, and relocated to another city three hours away.

She lived there just a little over ten years, and I would see her once a month, twice a month, on the weekends, that sort of thing. It was a little hard, back and forth, 'cause it's kind of a trip. . . . And when I would have her, it was intense, but it was short. . . . Um, my ex and I have always gotten along well about this. She's . . . she's a good mom. Now, about a year or so ago, back in March of 2011, Annette and I . . . I became Johnsie's sole guardian because of Annette's health problems, and she's been living here with me for a little bit over a year. So, she and I live together. I have two other children, smaller. They live with their mom, here in town, and everybody's good buddies. Yeah, I'm very lucky. And, I . . . it's amazing. In fact the lady I see now . . . the mother of my two small children is my ex-girlfriend. She's getting married soon. The lady I'm presently seeing is in *her* wedding! Probably a good reality show! [He smiles, then laughs.]

John seems to take this surfeit of exes and elementary-aged children while in his sixties in stride. It is clear now why his basement room is littered with balls, dolls, and riding toys. But his love of Johnsie seems to override the pandemonium that is his personal life. He is eager to make sure I know how much joy she brings, and how inimitably extraordinary she is.

She's . . . she's, um . . . anybody who's ever met her remembers her. Because she's very pretty. All the Rett girls have a real . . . a beauty. It's like, maybe the

Rett gene—before we knew what it was—maybe the Rett gene is beside the *prettiness* gene. ‘Cause it seems like, there are a lot of pretty Rett girls. She looks like my baby sister, who was a fashion model for twenty-seven years, a beautiful woman. And she looks just like her.

John goes on, enumerating Johnsie’s positive traits and the comfortable rhythms of their life together:

Her mom’s doing better now, and her mom sees her a lot of weekends, and Johnsie has a generally happy life. She loves to be read to, she loves to look at movies, and she loves to go swimming, and she likes to hang out with folks. She’s very vocal! She’s not verbal, but she’s very vocal. And she can let her wishes be known. She attends very well. She, uh, routinely, the movies she watches, if it’s a story she likes, she’ll attend for an hour and a half, two hours, however long you want to go with it. And, um, of course the theory is, there’s a lot of trapped intelligence in these Rett girls. That’s a theory we parents hope is true.

John insists on taking me upstairs to see Johnsie’s room before I prepare to leave. It is nothing fancy: a worn dresser, a twin bed. But it is pink, and girlie, and frilly—a room for a young woman who will always be childlike in an abundance of ways. Diapers are stacked beside the nightstand; plastic tubing snakes over the headboard. John takes pains to explain to me how her feeding pump is set up each evening to deliver her nutrients, and how he listens carefully for any indications of discomfort:

It’s constant vigilance, at night, to have to listen. She still sleeps with a monitor in her room, so I can hear her. Because she’s tube-fed at night. She can’t eat, oh, that’s another thing. You have to feed her by tube. So I sleep with one ear open, listening for the machine, for the alarm to go off, that sort of thing. Or her to make an odd noise, or something.

But John is quick to indicate that he believes he has it pretty easy. He muses that Johnsie's disability—which to the lay person or even a medical professional would seem to be well into the parameters of severe—is not that big a deal in the scheme of what other parents face.

She's delightful to be around. She's not . . . one of the good things about her disability is . . . no behavior problems. I mean, God! I hear these stories about parents with these kids, some of the runners, the autistic kids. And they're worried all the time that they're going to get in trouble, and get in a . . . perilous situation. I've never had to worry about that. Johnsie's not going to do that.

She's . . . she sits there and she's happy usually doing something. If she's unhappy, we look for the problem, if it has to do with some sort of pain thing, which is rare. So I don't have a lot of the problems that some folk . . . I think that would be harder than the stuff I have to deal with. Of course, it's just a matter of perspective. Certainly mine's not a walk in the park. I have people all the time saying they don't know, "I don't know how you can do that. That's got to be . . ." Well, I don't know how I can do it either, but it's . . . you just do it. It's not . . . I'm sure other things could be worse.

John has an enviable income, and is pursuing a vocation about which he is passionate.

He has a civil, even amicable relationship with his ex-wife, based on their shared love for their daughter. And he reminds me, with a wink, "I have a lady I go out with, who's thirty years younger than me . . . and that keeps you young!" He's already surpassed the age at which his father and grandfather died, which gives him pause. "I want to live a long time," he says. All in all, he believes his life is pretty great. "It seems impossible," he admits, "But it's not. It's not even hard. . . . I'm her daddy; I just want her to be happy. . . . I'm in charge of making sure she has a decent life."

John reserves his final editorializing for the parents who romanticize disability. His patience wears thin with people who blather about how their children are “special angels” or “chosen” for this life:

I’ve never understood this; this thing has always gotten to me: the number of parents, it’s always been women, but then again most of the parents I’ve ever talked to have been women, ‘cause the guys do . . . something, I don’t know. I remember, there was one woman especially, she had a grown son with autism, and we got into discussion one time, and she said that if all of a sudden an angel appeared, and said, “I can cure your son,” she would say, “No, I want him just the way he is now, that’s the son I grew up loving.”

And . . . whew . . . all I could think of was, you know, “That is so selfish and *stupid!*” I understand this whole notion of, uh, they have as much worth the way they are, but don’t you think that . . . if given . . . if they had the choice, don’t you think they’d pick being normal, and pick not having some horrible disorder? If somebody . . . if an angel showed up, or some scientist showed up, and said, “I can fix your daughter,” I’d say, “Yeah! Let’s do it *now!* Do it *right now!*”

This philosophical riddle (whether disability is something to be corrected or celebrated) has no facile answer. But the fact that John would put forth his truthful assessment—he loves his daughter, but would jump at the chance to allow her to experience life without disability—is refreshingly blunt. And John is nothing if not direct; he is devoid of artifice or airs. His position on the issue softens as he considers how Johnsie’s disability has changed him:

Look, Johnsie made me a far better person. . . . I wasn’t that bad of a person before . . . [smiling] And I’d just have soon stayed a *less-good* person, and her be normal. I was a firecracker in different ways. I just wanted to drink liquor and chase women! And then, you know, I was good at that . . . *very good*. I kinda *miss* that! [laughing]

But, uh, you know, when Johnsie came along, I channeled it somewhere else. . . . I have plenty of help, I have a girlfriend who is very supportive. My life's fine. I probably drink too much . . . [laughing] But I probably did that before Johnsie came to live with me!

Johnsie chooses that particular moment to emit what sounds, to my untrained ear, like mournful keening. John looks calmly overhead, to the room where Johnsie is watching "Dora" with Tara. He grins up at the ceiling and then at me. "That's probably a good sound. She's probably liking what she sees on TV." We rise and head up the stairwell from the basement. We shake hands warmly, and I turn to leave. Heading down the front walk as dusk falls, I take one glance back at John's home. He has already covered the half-flight of stairs from his entryway to the living room. I can see him through the picture window, sitting on the arm of the sofa, stroking Johnsie's hair, watching Dora's adventures.

Janet and Raul's Story: Anne Marie

The drive to Janet and Raul's home on the north side of town takes me past half-empty shopping centers and other shuttered shops, victims of the economic downturn. Pockets of active commerce remain: a movie theatre, a car-parts store, a second-hand bookstore, a bakery and a bodega.²⁴ The couple's apartment complex is a bright spot of new construction in an area dotted with older structures. The two-story vinyl-sided buildings with brick trim are devoid of clutter, and a well-kept, gated pool and clubhouse area is empty of patrons on this oppressively hot evening. As I park and

²⁴ A Latino store with groceries and sundries. This particular southern city has a burgeoning Hispanic population.

follow the sidewalk toward Janet and Raul's ground-floor unit, a small child pulls to her knees at a low windowsill, gazing at me through the glass panes as I walked past. From Janet's earlier phone description of her daughter Anne Marie, I am confident that I have found their place.

I was faintly familiar with Janet before this initial face-to-face meeting. She is the financial secretary at a nearby public school for preschoolers and school age students with special needs. (In my role at a similar school, I've called from time to time to speak with various staff members there.) I had formed a picture of Janet in my mind's eye, based on the audible "smile" in her phone persona; I find I am not off the mark. She throws the door open eagerly before I even finish a perfunctory knock, and I am met by a thirty-two year old Black woman with a megawatt smile and a happy profusion of short dreadlocks. My previous aural impressions align perfectly with this first visual; Janet is indeed a sunny bundle of positive energy.

She leads me into their comfortable, carpeted apartment. The kitchen, dining area, and living room, while small, comprise one airy space, all in tones of beige and cream. Stacked packing boxes line walls here and there; after a few months in their place, Janet and Raul are still getting settled. Janet insists that my first order of business is to meet Anne Marie, who is playing contentedly on a foam mat of colorful interlocking puzzle pieces. She looks up as we enter her room, her long, curly black hair gathered into a tight ponytail. Anne Marie sports hair bows and dainty crystal earrings; she is a beautiful and happy child. Her matchstick-thin arms and legs protrude from her ruffled

lavender shirt and tiny black leggings. She crawls on all fours slowly to her mother, who picks her up and rests her on her hip. Anne Marie, at seven years of age, is no bigger or heavier than a toddler.

Janet and her husband Raul had asked to be interviewed as a couple, and I am glad to oblige. We return to the living area, and as we sit down at the dining room table, Raul emerges from the master bedroom. He is slight of build, no taller than Janet, with a pale complexion that belies his Hispanic heritage. He joins us at the table, and Janet, the more loquacious of the two, launches into the story of Anne Marie's early months:

I was a very sickly mother, at the time I was pregnant, I couldn't get out of bed a lot . . . I didn't get to really eat very much 'cause I couldn't keep anything down. So I had a very rough pregnancy. Um, when I did have her, no one had any signs or knew that anything was wrong with her. She looked like a typical child . . .

When I was sick I had a lot of opportunity to read, so I read a lotta stuff on the stages that she would be in, and what she would be doing. And I noticed at three months, I'm like, "She's not touching her toys. She's not moving things. What's going on? She's not doing what she's supposed to." And my husband's like, "Nah, she's just a little behind." I said, "No, there's something wrong." So, [we] went to the doctor, and they felt concerned for us, so we went to a neurologist in [nearby city], and they, he diagnosed her with mild cerebral palsy.

For the first time since I've entered the apartment, Janet's brilliant smile fades. She looks to Raul, but he nods for her to continue. She pauses for a moment before going on:

At that time, we didn't know she was going to have epilepsy. . . . Um, let's say two months after that visit, at ten months, Anne Marie had her first seizure—

grand mal seizure.²⁵ I really thought my child was gone. I know a lot of people probably laugh at this, but I kind of remember it as a “Color Purple” thing. I’m running out in the yard, and I’m holding my child and I’m screaming to the top of my lungs!

Janet imitates her own actions on that terrifying day, holding her arms skyward as if she is lifting her sick baby high overhead; her kohl-dark eyes opened wide in mock-panic. She breaks into paroxysms of contagious laughter, and I join in. Raul, the quieter, more reticent partner, smiles gently at his wife. Janet takes a breath and returns to a more serious tone:

They had to take her all the way to [larger city]. . . . She was actually so bad with her seizures that they had to sedate her, put her under, with a tube for her to breathe, ‘cause they couldn’t get ‘um under control. We were probably in the hospital about a week, with those, ‘til they could find something to actually stop the seizures. ‘Cause she was continuing to have them, even though she was sedated.

Once we got them under control, then we had to say, “Oh, she has CP *and* epilepsy.” Funny thing I found out? You have a cerebral palsy child? Fifty-fifty chance they’ll have epilepsy. We got the flip of the coin.

Brought her home. Whatever the doctors have said about her—that she’s not gonna walk, or she’s not gonna crawl, or she’s not gonna sit up—she has proved them wrong! [Janet laughs again.] Yes, I think one doctor we went to kind of came to the conclusion once she set up on her own, and she started to pick up things on her own, once she started to manipulate objects, hand-to-hand, she just said, “You know what? Just let *me* know what she does! We’re just going to leave it alone, not do the guessing game anymore!” Um, so even though she’s had her difficulties, she’s a very strong, willing child. And she is just *determined* to do what people think that her body won’t be able to do!

²⁵ A grand mal seizure—also known as a tonic-clonic seizure—features a loss of consciousness and violent muscle contractions. It's the type of seizure most people picture when they think about seizures in general. <http://www.mayoclinic.com/health/grand-mal-seizure/DS00222>

Anne Marie, contrary to Janet's optimistic report, cannot yet walk, although physical therapy sessions focus on building the skills necessary for her to perhaps do so in the future. She is non-verbal, and remains incontinent. Medications are successfully keeping her seizures in check at the moment, but those initial seizures escalated the cerebral palsy from mild to severe. Raul and Janet must feed her, diaper her, and anticipate her needs based on her gestures and vocalizations. So, Janet tempers her positive frame of mind with a heavy dose of realism, and finds it frustrating that her family doesn't fully accept Anne Marie just as she is.

My family, they're having a really hard time understanding (excluding my mother) that my child is disabled. That it's a possibility that she may not walk. It's a very strong possibility that her delays are layered. They really have the idea that one day, she is gonna wake up talkin' and bein' just like everybody else. And I have a hard time explaining to them that that's not really how it works, that's *not* how it works.

They're thinkin' that it's kinda like a Jesus Christ *miracle*, rise from the tomb, and everything's gonna be alright. And it's not that. And they still have a problem with that. They *still* have a problem with that . . . I think the family members just needs [*sic*] to spend more time, but it seems like every time I do that, it just don't work out too well.

I mean, I have a hope that Anne Marie will get better, and she'll get less dependent. No, I *know* she won't be like me one day. You know, if so, that would probably be a miracle. [laughing] If they get really good with this *science* stuff, and cells . . . But I *do* have a hope that she will . . . find ways to live, you know, surpass, when I am gone. And I think that is a realistic goal, and a realistic reality for me . . .

Anne Marie has just recently started school. Janet and Raul were perfectly content caring for her at home, where Raul was her primary caregiver throughout the

day while Janet was at work. But compulsory attendance laws required them to begin her public schooling when she reached age seven.²⁶ To draw Raul into the conversation, I ask him whether this has been hard for him—giving up his role as full-time caregiver.

He responds:

She's my baby, but I don't . . . I mean, for me, what I want her to do, I want her to continue to grow. So, it doesn't bother me quite as much to see her, to see her become more independent. Because, I guess you're always going to have that thing inside you as a parent, like "Oh, my baby's growing up!" You know, you're always going to have *that* . . .

I've seen some parents treat their—see that their child can't communicate in a certain way, so they treat them like they are a thing. Like a lump. Like, it's an extension of the attitude of, "Well, you know what? I'm not going to take my child to this amusement park, or this place, until they get older, because they can't appreciate it." Or, "I'm not going to read to them until they are older; I'm not going to play like this, with them, until they're older."

Raul becomes more agitated as he talks ardently of granting children with disabilities access to all of the experiences and activities available to other young people. This topic seems to have struck a nerve with him, and he goes on:

Don't . . . don't treat them like they're in a coma. Treat them like they can hear, and understand, and comprehend everything that you can say. Treat them . . . if they can't go play with something help them, do it for them. Because if you don't give them any type of interaction, they're going to be miserable. And I've seen kids like that, where the parents don't give them anything, you know? They treat them like they're lumps. Like they're just lumps of flesh. And that is so sad.

²⁶ "In accordance with G.S. 115C-378, every parent, guardian, or custodian in [this state] having charge or control of a student between the ages of 7 and 16 years shall cause the student to attend school continuously for a period equal to the time which the public school to which the student is assigned is in session." <http://www.ncpublicschools.org/docs/fbs/accounting/manuals/sasa.pdf>

Then Raul relates an episode from five years earlier that apparently created an indelible impression:

One therapist at Anne Marie's old therapy clinic in [previous hometown], she said that they had a child like that. And the mother never played with him. And he didn't move. He never lifted a finger, he didn't look around. And she said she had him there for one session, and um, talked to him, asked him . . . And he looked over, and he reached over, and he touched the toy. [Raul pauses. His voice is choked with emotion.] And the mother started crying. Because she had never *tried*, I guess. Or she didn't try *enough*.

It bears mentioning that during my time with Janet and Raul at their dining room table, Anne Marie has made her way slowly on hands and knees from her room, down the hallway, and now busies herself crawling around the table, visiting with each of us, one by one. She now pulls to her knees on Raul's pant leg, and he lifts her to his lap, drawing her close and resting his cheek on the top of her head. It is a moment almost too intimate to watch—father and daughter exchanging a wordless moment of affection. Janet breaks the spell:

Hey! We made a video of Anne Marie! It's about a four-minute video, and it's things that we put together, that she's accomplished. We've been working on it, collecting it little by little. And when you put it all together, it's like, "You know what? She has went [*sic*] somewhere. She is going forward. She is moving; she is trying!"

Raul carries Anne Marie to the living room and sets her gingerly on the carpet. He unhooks the laptop from its perch on the kitchen counter, bringing it to the table, so

that I can see the home movie. As he sets up the computer and locates the video, he chimes in:

Yes, I tried to incorporate her, like, her firsts. So, like, when she's playing with the toys, in the beginning, that was the first time that we saw her touch a toy. She never reached out for things, and her hand went out. And those pictures of her laughing, those are the first two times she ever did that. Where she just started, she just opened her mouth, and I happened to catch it, both times.

Then Janet contributes:

Or just the finger-food eating, or with the cup in her hand. She's actually holding it by herself for the first time. So everything in there is a first thing.

Raul can't resist one more explanation:

One was where she looks up at the camera; it was the first time that she ever made eye contact with me, that day. Every time I said, "Hello, beautiful!" she would turn and look at me.

We gather ourselves in close to watch, leaning on elbows, heads drawn together. The music swells, and images of Anne Marie appear slowly and then dissolve. Anne Marie as a newborn baby in the hospital. Cradled in Janet's arms at home. Beaming up at the camera. Surrounded by Disney characters, on vacation. Probably 40 or 50 of these photographs, assembled by Janet and Raul into a loving ode to their only child. The video is *about* Anne Marie, but it tells just as much about the devotion and persistence of her parents.

As the music fades away, I compliment Raul and Janet on providing fitting closure to our meeting, and push back my chair to head out into the steamy night. Suddenly Raul cries out, “Holy crap!!!” and leaps from his chair. Anne Marie, left to her own devices while our attention was on the computer screen, has pulled herself up onto the arm of the sofa. But she’s not on her knees—her usual trick. She is precariously standing upright—ballerina-style, en pointe—looking shocked and quite proud of herself at the same time. “Oh my gosh! Go, Anne Marie!!” Janet yells. “Look at her!” Raul scoops her up as she wobbles and falls, and both parents are beaming at this “first.” Janet walks me to the door, and leaves me with this thought:

I think it’s just a hope that she gives us, that, “Yes, I’m here, Mommy and Daddy, and yes, I have this [a disability], but look! I’m trying to do something, I’m not giving up!” And I think that’s what has this hope in us, that she, through all this adversity, and you know, her not being able to communicate. . . . She just has so much happiness and glow about her, and it kinda passes on to us. And yeah, I think, yeah - that’s what gives us our hope and resilience, to just kinda push forward.

Kristin’s Story: Marc

I first heard snippets of Kristin’s story in the spring of 2012, on an outdoor stage in a city park. Kristin, her husband Larry, and their children had been chosen as the local March of Dimes “ambassador” family. (Thankfully, the “poster child” shibboleth was retired more than a decade ago.) She stood at the microphone, addressing hundreds of t-shirt and sneaker-clad supporters preparing to embark upon the annual fundraising walk to prevent early births and birth defects. While Larry wrangled their three busy

boys (all under the age of three), Kristin enthused the crowd with an abbreviated version of their journey, thus far, parenting a child with exceptionalities. From that cursory encounter, I knew that I wanted to learn more of this young woman's caregiving story.

Kristin graduated from a prestigious state university and works full-time as the development director for an exclusive K-12 private school; husband Larry is a successful banker with an MBA. At just 34 years of age, Kristin and Larry, both White, have achieved a sizeable degree of financial and professional success. Their home lies in a fashionable, older section of the city, a neighborhood that has undergone gentrification in the last quarter-century. The mission-style 1920's bungalow sits on a hillside; an expansive planked front porch carries the tell-tale signposts of a family deeply ensconced in toddlerhood: riding toys, a miniature plastic picnic table, and baby gates.

On the afternoon of our rendezvous, Larry is scheduled to pick up Owen, three, and Ed, 18 months, from day care at 5:00. Kristin collected Marc, Owen's twin, from his school ahead of schedule, so that we can enjoy a (relatively) quiet hour at home with just one toddler. Kristin opens the front door and I step into a front room worthy of a magazine spread—tasteful, eclectic, and classy. The home has been lovingly restored to early 20th century perfection. Kristin, pencil thin and stylish, with a glossy mane of brown hair, is warm and welcoming. We chat concerning the particulars of the house as she leads me to an adjacent sunroom that has been transformed into a playroom for the boys. The walls are lined with low shelves stocked with a cornucopia of books, trucks,

musical toys, and building blocks. Marc, age three, sits on the sisal area rug, joyfully banging trucks together. Kristin and I sit cross-legged on the floor with Marc, and she launches into an account of the twins' birth:

I think our story begins even well before Marc came into the picture. Because we struggled with infertility for a really long time. And so, like a lot of parents, we had all of this anxiety about just *getting* pregnant. And it took years and years and years—and I can't even imagine how much money—to actually *get* pregnant to begin with. And then, we were so excited when we found out we were pregnant with twin boys. And everything was moving along so beautifully, and we were . . . over the moon.

And then we went in for our nineteen-week anatomy scan. And, like most people, we went in just thinking, "We're going to find out whether they're boys or girls!" That's what you find out at an anatomy scan, is what "flavor" baby you're going to have. And, it never occurred to us, that we would find out that something was wrong, because that . . . it's just not what *happens*. You go in, and you find out if you're having boys or girls, and then you start planning a nursery. And, you know, the scan of Owen, everything went according to plan, they looked at it, and [said], "It's a boy," and then they started doing the scan of Marc.

And even though everybody was very professional, and doing exactly what they were supposed to . . . we could tell something . . . wasn't right. It was taking, I mean, two, three times longer. And the ultrasound technician left, and came back in. . . . So at that point in time, they identified . . . some sort of a congenital heart defect. They said, "We're not exactly sure what it is, but some sort of congenital heart defect." So they sent us in to go see a, you know, a pediatric cardiologist, so they could start looking more closely at his heart. And it took a couple of those appointments before they actually sort of diagnosed the Tetralogy of Fallot.²⁷ And then they said, "It may just be a heart defect. *Could* be just a heart defect. But . . . heart defects commonly go along with a whole host

²⁷ Tetralogy of Fallot is a congenital heart defect causing low oxygen levels in the blood, leading to cyanosis (a bluish-purple color to the skin). The classic form includes four defects of the heart and its major blood vessels. Surgery is done when the infant is very young; sometimes more than one surgery is needed. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002534/>

of different genetic conditions. Both of the trisomies,²⁸ uh, Down Syndrome (see Footnote 10), de George's Syndrome,²⁹ a whole host of different things. We're not seeing any of the markers for Downs; we're not seeing those things, but who knows? You're not a good candidate for an amnio, because you're carrying twins."

So Kristin and Larry, unlike most parents of children with disabilities, were aware months before the boys' due date that one of them would be facing critical health issues. Kristin, aggressively pro-active in her professional role of fundraising, kicked into take-charge mode:

So all of a sudden, just the whole tenor of the pregnancy changed. And it really didn't at that point change for me, in that, I thought something was wrong, other than his heart. I was still able to sort of compartmentalize it and think, "Ok, we've got a heart problem, and that's what's going on." And I immediately went into, "Ok, we'll meet with the surgeons, and we'll figure out what our birth plan is, and we'll start shifting gears, and we know once he's born, we're gonna have to have a heart surgery, and what does that mean?"

And then, you know, the big concern was, because I was pregnant with twins, it was all of that. "We've got to keep this baby cooking as long as we possibly can, because we know he's going to need a really major heart surgery, we want his heart to be . . . because on the inside his heart doesn't have to do anything, but once he comes out, that's when his heart actually gets called to task."

²⁸ Almost any chromosome can be seen in trisomic form, but very few trisomies are compatible with life. Some chromosomes - 13, 18, X and Y- are seen in liveborn children, while trisomies of chromosomes 15, 16, and 22 are often seen in miscarriages. http://downsyndrome.about.com/od/whatcausesdownsyndrome/a/othtrisomies_ro.htm

²⁹ DiGeorge syndrome (22q11.2 deletion syndrome) results in the poor development of several body systems, including heart defects, poor immune system function, a cleft palate, and complications related to low levels of calcium in the blood and behavioral disorders. <http://www.mayoclinic.com/health/digeorge-syndrome/DS00998>

Kristin, at that point in the pregnancy, was able to manage thoughts of a baby who would need heart surgery, but she put the other possibilities hinted at by doctors on her mental back burner. Imagining a “reparable” disability was infinitely more palatable than the thought of a lifelong, debilitating syndrome. But the babies were on their own schedule, and Kristin had to deal with the realities of Marc’s health issues much sooner than expected.

So we wanted to keep him in, and then once things kind of spiraled out of control with my pregnancy, that was when everybody started getting . . . really nervous. So, we ended up delivering at thirty-one weeks.³⁰ Owen, his twin brother, was three pounds eleven ounces, and Marc was two pounds, nine ounces. Marc was immediately transferred to [local children’s hospital]. Owen went, you know, a couple of days later, because he just needed to “grub and grow” and there was nothing really going on [medically] with him.

Now that Marc had arrived, Kristin and Larry began to discover the magnitude of his challenges. As the doctors had surmised, the heart defect was only a marker for much more serious problems:

He had, what I really called, sort of, “The Trifecta of Suck.” [Kristin laughs.] Which was, he was a preemie, he had a congenital heart defect, and . . . because once they see the congenital heart defect, they immediately bring in genetics . . . we determined that he did, in fact, have the 22-Q deletion.³¹ So all of a sudden, it’s

³⁰ Babies born prematurely are at a higher risk of health issues than babies born at full term. Disorders related to short gestation and low birth weight are one of the top three leading causes of infant mortality in the United States. Anywhere between 37 weeks and 41 weeks is considered full term. <http://www.misacor-usa.org/index.php/full-term-pregnancy-how-many-weeks>

³¹ The 22q11.2 deletion syndrome can affect almost every system in the body, causing a wide range of health problems: heart defects, palate differences, feeding and gastrointestinal difficulties, immune system deficits, growth delay, kidney problems, hearing loss, low calcium and other endocrine issues,

not just, “I’ve got this teeny tiny baby.” I’ve got this teeny tiny baby who is incredibly medically compromised—I mean, he was intubated³² for seventeen weeks; he had his first heart surgery . . . at four months, when he weighed less than four pounds. You know, he had all sorts of—you know, he had all the premie stuff, he had the heart stuff, he had . . . just other medical issues that were going on.

Owen stayed in the NICU³³ for just six weeks, thriving and rapidly gaining weight. Marc, however, remained there for more than seven months. When Kristin and Larry were finally able to bring him home, it was a harrowing experience.

It was bringing this . . . this unbelievably medically fragile child . . . into the home. I mean, he was on oxygen twenty-four hours of the day, he was on an apnea monitor,³⁴ he was on pulse-ox.³⁵ He was blue . . . for . . . until he got his second heart surgery, around his first birthday . . . And during that surgery, his left side of his diaphragm was paralyzed. So, all of a sudden, we didn’t just have a *heart* kid. We also had a heart kid and a *pulmonary* kid on top of that. . . . And we would get those three a.m. phone calls that said, “We don’t know if he’s going to make it until tomorrow morning. You need to come in, *now*.”

As I look at the small boy playing contentedly on the rug between us, it is hard to imagine how very sick he was for his first two years. Marc’s life-threatening medical

cognitive, developmental and speech delays, and behavioral, emotional, and psychiatric differences.
<http://www.22q.org/index.php/what-is-22q/overview>

³² The most common use of this term in the ICU refers to placing a breathing tube into a patient’s airway (endotracheal intubation). Endotracheal intubation is necessary when patients cannot cough and clear secretions or breathe on their own. <http://www.icu-usa.com/tour/procedures/intubation.htm>

³³ Neonatal Intensive Care Unit

³⁴ A home apnea monitor is a portable machine used to monitor a baby’s heart beat and breathing after coming home from the hospital. When the baby has a heart rate or breathing rate that is below the limits set on the monitor, an alarm goes off. <http://www.nlm.nih.gov/medlineplus/ency/article/007237.htm>

³⁵ A pulse oximeter is a device, usually attached to the earlobe or fingertip that measures the oxygen saturation of arterial blood by transmitting a beam of light through the tissue to a receiver. <http://medical-dictionary.thefreedictionary.com/pulse+oximeter>

concerns have largely been resolved. Kristin reports, “My life has certainly gotten, our life has certainly gotten easier, from the early days. And he’s doing way better than he was, now.” Right now she is focused on an upcoming family trip, pointing out pleasant disparities between present day and Marc’s first two years:

We didn’t go anywhere, we didn’t go on vacations, because we had this kid who was on oxygen, and, by the time we tried to figure out how to get oxygen delivered somewhere, and could we, you know? We’d always gone to Ocracoke for Easter, forever and ever. And, really, you can’t take a kid on oxygen to an island you can only get to by ferry.

We’re getting ready to go to the beach next week. And I’m leaving on Wednesday, and I’m taking Owen and Ed. And Larry’s leaving on Friday and bringing Marc down. Because Marc, he’s got to take him to the dentist, and he’s got horseback riding, so he’s coming down a little bit later. And he’s like, “If you would have ever told me, “Which one of the children would you prefer to be left with, for two days?” He said, “I never would have known!”

And when I think about a year ago, we made this same trip. And we had our oxygen concentrator, and we had our portable tanks, and we had all that kind of stuff . . . And now, I think things are so much better and so much easier . . . He’s a little more portable, and we’ve gotten more comfortable with what he requires . . . So he doesn’t have the same sort of cumbersome medical needs that he once did.

But other issues remain; Marc still is not able to eat by mouth, and therefore receives all nutrition through a gastrostomy tube. (“I can do a G-tube feeding at the playground, or in the back of my car, or whatever,” Kristin says.) He has not yet begun to speak, despite intensive speech and oral/motor therapies. 22-Q deletion can encompass a broad range of functioning, depending on the child, so doctors cannot portend Marc’s personal trajectory. Kristin describes the syndrome’s givens, and its unknowns:

You know, 22-Q in and of itself is a very broad spectrum. I mean, you have . . . I went to a conference at one point, and a mother was talking about transitioning her child with 22-Q into college! And then, you hear another mother speak, and she's talking about transitioning her child with 22-Q into a group home. And it's that very . . . broad spectrum. You know, nobody knows what any of their kids are going to do, but certainly there are a lot more question marks with Marc.

It's the second most common chromosomal disorder, second only to Down syndrome. But the kids are not stigmatized physically, quite like Downs kids are. There definitely are some common characteristics among 22-Q kids, and if you ever hear a geneticist talk about it, they'll be able . . . you know, they can look at Marc, and they can say, "Well, his fingers taper slightly, and his nose is slightly bulbous, and his ears are slightly like this . . ." I mean, they can pick up on a lot of those things. And some kids with 22-Q look a bit more atypical, and some of them, like Marc, I think look very much like every other kid that you see walking down the street . . .

And developmentally, who knows where we're going to be? And there are all sorts of things, like 22-Q has really high instances of mental illness associated with it. Instances of schizophrenia and bipolar disorder and things like that, are significantly greater in the 22-Q population than in the general population . . .

Those are the things that worry me way more . . . those kinds of *bigger* things. And if you spend all your life kind of thinking about those things, you know it's really hard to . . . [Kristin's voice trails away, and she takes a moment to gather her thoughts.] It would be really hard to get through every day if you're trying to figure out, "*What's the next shoe that's going to drop?*"

Kristin has decided how much time and energy she can allot to worry, and has made a conscious decision to live in the here and now, rather than project forward to a future that is uncertain. As the mother of three toddlers, she says she has let go of the notion that she must do everything, and do it right. She tries to appreciate Marc for who he is *today*, not who he may or may not become.

It's really easy to get caught up in all of the therapies, and all of the doctors' appointments. And always try to . . . look ahead to what's next, whether it's the next doctor's appointment, or the next surgery, or the next developmental milestone, and when you're going to hit it, and when you're going to do it. And I think that it's easy to spend so much time [She pauses for a moment.] focused on all of *that*, that you don't get a chance to just enjoy being with your kid, for who he *is* . . .

You know, at some point, cutting yourself a little bit of slack and saying, "You know what? I want to do what's right by my kid, but if he wasn't in his stander for forty-five minutes today, is it really the end of the world in the big scheme of things? I mean *is* that, is that *really*?" Obviously you want to be on top of all of that kind of stuff, but is it *really* that important *every* second of *every day*? You know, and it's not.

Kristin is aware that she did not reach this level of competence and confidence in her caregiving skills in a vacuum. She bestows credit on both her personal circumstances and the network of supportive people in her life.

I have said all along, I cannot imagine, I cannot imagine doing this at eighteen, versus thirty-five . . . I can't imagine doing it as a single mother; I can't imagine doing it without a very supportive family network. I can't imagine doing it without a supportive workplace . . . And I have a spouse that's active, and willing to pick up the kids, and, you know, we have college degrees, and we're somewhat savvy in the world . . . All of that's a big part of what we can kind of bring to the table. I mean, you pull any one of those . . . you pull any one of those pieces out . . .

She is forthcoming with the fact that she sought professional counseling while going through the stresses of infertility, and continues to see a psychologist on a regular basis. The excellent insurance coverage provided by Larry's employer keeps major financial worries at bay. And while expenses for three toddlers are steep ("Our biggest cost, quite

frankly, is not so much for medicine, it's child care!"), their dual incomes in well-compensated professions are sufficient to allow for a comfortable lifestyle.

As we are about to finish our conversation, Larry comes through the front door, stopping by after work before heading off to pick up Ed and Owen. He sweeps Marc up in his arms, and they "talk": Larry with words ("How are you, buddy?!"), Marc with a happy jumble of syllables that unmistakably indicates his joy at seeing his dad. Kristin is happy to hand off responsibility for the busy boy for a few moments. She sums up her viewpoint about their unexpected journey as we close out our visit:

It's what we know; it's what's been put on our plate. And so we just, we just kind of figure it out, and we do the best we can, and we muddle our way through it. And we do our best, you know, to find things that are good for him, and good for us, and good for our other kids. And we'll make it.

I think that I've definitely grown as a person, and am a much, a much better person, I would like to think, than I was three years ago, or three and a half years ago, or whatever . . . Nobody wants, or signs on . . . nobody wishes this on their kids . . .

There was a very open mindset in our family, that, you know, people come in all sorts of different shapes and sizes, and they all bring different things to the table. Some people have different challenges, and some people have different strengths. . . I feel like I had my mother sort of sitting there saying, "You know, this sucks, but it's not the end of the world. I mean here's all the great things, and these are the different ways that we can look at it, and the best way you can get through this is to arm yourself, and to be a good advocate, and to be well-informed."

It becomes clear to me, by the end of the hour, why it was Kristin up there on the March of Dimes stage, her voice quavering only slightly as she told the story of

Marc, inspiring scores of other caregivers and stalwarts to walk on that April morning for her son and children like him. She was on that stage heeding her mother's voice, goading her to pick herself up, play the cards she had been dealt, and then reach back and bring others with her, down a path of acceptance and joy.

Brenda's Story: Carter

Brenda's apartment building sits along a busy commercial thoroughfare, sandwiched between a day care center and a pet grooming business. When describing the location to me, she mentions how lucky she was to find a safe place with such a reasonable rent, and as I turn into the driveway, my skepticism dissipates. A pair of brick and cedar-shake structures face one another, with a generously-sized grassy courtyard between them. Neat rows of mature crape myrtle bushes are blooming a riotous hot pink, and the grass is freshly trimmed and edged. While the units are cramped, and some admittedly have broken grills and furniture cast-offs rusting on their porches, it is a surprising oasis of green tucked just off the "main drag."

Brenda lives here in a ground-floor unit with her son Carter, who is seven. She found herself pregnant at age 15, and delivered Carter during her junior year of high school. Another parent in this study spoke earlier of having just what she needed in her "tool kit." To the outsider's view, Brenda's tool kit appears austere; she is single, with no education beyond high school and a poorly-paying part-time job - a daunting situation for *any* parent, but with her son's disability, decidedly more intractable. Carter has

schizencephaly,³⁶ an extremely rare developmental birth defect characterized by abnormal slits, or clefts, in the cerebral hemispheres of the brain. He is non-mobile, non-verbal, tube-fed, and must rely on others for all of his personal care needs on a quotidian basis. I was intrigued by the opportunity to spend time with Brenda, who self-identified as “resilient, hopeful, and an advocate for her child,” despite her multiple challenges.

Brenda’s door is answered by a White male who appears to be in his teens or early twenties. Two other young men, similar in age and appearance, are seated in the living room. The space is claustrophobically small with the five of us clustered there. Soon after Brenda introduces the three guys—boyfriend Kyle, his younger brother, and a high school buddy—they shuffle off to the rear of the apartment, carefully avoiding eye contact with me. (I remind myself that I likely fall somewhere between their mothers and grandmothers, age-wise.) Brenda and I settle in on the threadbare couch. She notices that I am looking for her son Carter, and remarks that he is still at his grandparents’ house after a weekend visit. “They begged to keep him an extra day,” she says, “and I said, ‘Sure!’”

Brenda—barely five feet tall, with a milky-white complexion—wears her strawberry blonde hair in a loose ponytail. Her short-shorts and oversized men’s t-shirt make her appear even younger than her 24 years. Chagrined, she apologizes for the

³⁶ Children with clefts in both hemispheres, such as Carter, may also have “an abnormally small head, mental retardation, partial or complete paralysis, or poor muscle tone. Most will experience seizures.” <http://www.ninds.nih.gov/disorders/schizencephaly/schizencephaly.htm>

heavily cluttered apartment. As discreetly as possible, I ease dirty cups and melted candles aside to make room for my tape recorder on the coffee table.

You see how my house is . . . I got equipment everywhere. And stuff! I had to help my mom work today, so I was like, “Kyle, try to clean up the house while I’m gone!” He done as best he could.

When I query Brenda about “the story of Carter,” her cheeks flush a mottled pink, and her eyes immediately fill with tears. I wonder if she *is* resilient and hopeful (as my call for participants requested), or just a young girl desperately in need of the twenty-dollar gift card that this meeting will earn her. She sweeps the back of her hand across her eyes and forges ahead:

Well, I had him when, um, I was very young, when I was sixteen. I actually didn’t have any prenatal care until I was eight months pregnant. I was a junior when I had Carter. I had just gotten in my junior year. So yeah, um, it wasn’t easy. . . . I was already pretty good at school, didn’t really have any problems with grades. I was the ‘good kid’ until . . . [chuckling] I got pregnant, I guess. And I wasn’t, you know, considered the bad kid then, just. . .um, but you know, I stayed on top of my schoolin’, and tried to take care of Carter the best I could.

Yeah, they had a teacher come out to the house, and give me my classwork, and if I didn’t understand something, she’d explain it to me. And it’s funny because, whenever I came back to school, I was still making better grades than most of the people in my class!

Brenda laughs, and I detect a note of pride in her voice. She circles back to the fact that she did not visit an obstetrician/gynecologist until the final weeks of her pregnancy. It is hard to imagine the fear and shame of being fifteen, and carrying such a heavy secret in

solitude. But Brenda's decision to keep her pregnancy covert created an ironic twist, for which she is grateful:

Until I was about eight months pregnant, I didn't tell almost anybody. Which actually turned out to be a good thing, because my doctors had told me that if they would of found out that Carter was the way he was, that they would have tried to get me to . . . have an abortion, because of the quality of life and everything. [Brenda begins to weep silently.] I . . . I'm glad I wasn't put in that situation. So . . . I'm kinda happy! With hiding everything! I'm so glad I wasn't put in that situation; I'm so happy that I didn't have to decide that, that young. And even though Carter is . . . the *way* he is, I'm *happy* with him, the way he is. 'Cause he is so happy, and does so much more than anybody ever thought he would be able to do. So that just proves that doctors don't know . . . you know . . . very much.

Carter's disability, then, was likely not related to Brenda's decision to conceal her pregnancy, or her lack of prenatal care. Research on schizencephaly is still inconclusive, but points strongly to a random genetic abnormality or mutation. Yet there may also be cases tied to fetal infection, hemorrhage, toxins, or medications ingested by the mother. Whether this frightened 15 year old contributed to her child's disability or not is immaterial at this point; she is glad, today, that she had no inkling of his limitations (which would have been revealed in a fetal ultrasound), so that she was not faced with pressure to terminate the pregnancy.

Brenda had a C-section³⁷ birth, and returned to high school two months later.

Doctors did not initially detect any warning signals that Carter had a disability.

³⁷ Cesarean delivery—also known as a C-section—is a surgical procedure used to deliver a baby through an incision in the mother's abdomen and a second incision in the mother's uterus.

We didn't find out that he was handicapped until he was six months old. And, um, it was just 'cause, um, he wasn't, you know, doin' things that normal six months old kids was doin'. And, um, [choking back tears] well, we took him for a normal checkup, his pediatrician, and she noticed that things wasn't going as they should be, and, and um . . . so we had tests done and everything, and they came back to me tellin' me that he had this, um, really rare brain malformation, called schizencephaly. And, um, his pediatrician didn't even know what it was. She had to look it up, and then she told . . . she really told my mom, 'cause I was, you know, sixteen, and really didn't know much . . . about *anything*. So I was *freakin' out*. [Brenda giggles and smiles through her tears.]

But, um, after that he started . . . well, we started noticin' that he started havin' seizures shortly after, so, you know, we went back to the neurologist about that, and from there we just, you know, went to a bunch of different doctors. He has so many different doctors.

Brenda and Joe, Carter's biological father, attempted to keep their relationship going after Carter's birth, but were ultimately unsuccessful.

We tried to stay together. We stayed together for about two years after Carter was born, and we didn't get along . . . He's had his own problems. He's been *homeless*. He's been having problems getting and keeping jobs, and stuff like that. And he tried to act like he's concerned with Carter, but I mean I kinda question how much he is, because of how little he's involved in his life. And it's not like I try to keep him *away* from him. If he said he wanted to come see him, I'd be like, "Well, if you can make arrangements, you can come." Every once in a while he'll make a child support payment! [laughing] But, it's not that often.

So Brenda has lived on her own since age 17, managing the overabundance of doctors' appointments and therapy sessions that are part and parcel of raising a child with as many special needs as Carter. When I ask her how she copes with this very demanding job, while also cleaning houses for her mother's company part-time to make ends meet, she is matter-of-fact:

Well, I grew up with two brothers, so I had to be tough. They were always beating up on me and stuff, so I just kinda rolled with the punches. Hmm, yeah, I think that made me tough. My parents split up when I was kinda young, so I was a little more independent than, I guess, some people are. Yeah, I learned to cook for myself and stuff, because both of them [her parents] had to . . . work to make a living and everything . . .

And I know that some things are a little harder, like going to the grocery store and stuff, things like that, you know, may not be as hard for people with regular kids? But at the same time I look at it as, Carter ain't runnin' around, getting' into stuff, or back-talkin' to me, or stuff like that! [laughing] So, I mean, it's a give and take between the good . . . and the little bit worse!

Despite her truncated education, her youth, and her hardscrabble upbringing, Brenda communicates a sense of maturity and responsibility. At age seven, Carter still requires the same degree of care that he did as a newborn; this is a level of dedication (and sleep deprivation) that most parents must muster for only the first few months of their infants' lives:

Um, he usually sleeps pretty good. He might wake up wantin' to be rolled over, 'cause he can't roll over himself, and he still wants to be repositioned. But usually I can just go in there, and roll him over, and he'll go back to sleep. And if he don't sleep all night, he might wake up once or twice . . . He's good at sayin' "Momma" now. So, uh, now in the middle of the night, instead of just crying, he'll go, "*Momma! Momma! Momma!*" in a cryin' way, but you can hear him say it!

Brenda has organized all of Carter's evaluations and appointments into a tabbed three-ring binder. She proudly explains her system for staying on track with his care:

He's on, I think . . . four or five medicines, that I gotta give him, two to three times a day. And everybody's like, "oh my gosh, how do you remember how to

do all this, and everything?” And, I’m like, “you do it every day, you get used to it. I mean, it’s no big deal to me.”

He has a . . . a vagal [*sic*] nerve stimulator . . .³⁸ He has lots of equipment at home. It’s not just schizencephaly, he has several different diagnosis [*sic*]. He has, um, spastic quadriplegic cerebral palsy,³⁹ he has a seizure disorder, he has, um, obviously the eating disorder, with the tube . . . He has septo-optic dysplasia,⁴⁰ um, the nerves going to his eyes, wherever they go to, are small and pale.

I have a packet that I actually typed up, that everyone tells me is so great! [laughing, proud] It has all his doctors and what they specialize in, and where they’re at. And it also has all the surgeries Carter’s had, ‘cause he’s had . . . a good bit of surgeries. He’s had to have ear tubes several times, he had to have a shunt put in for hydrocephalus.⁴¹ He’s had, um, a Nissen stomach wrap⁴² for vomiting . . . he’s actually had to have that surgery twice, ‘cause one time it came undone. He’s had his adenoids out, one time, when they did the ear tubes, so that was at the same time. He has been put in the seizure monitoring unit, so that they could try to figure out his medicines and stuff. Something as simple as a teeth-cleaning, he has to be put to sleep for, so, that’s like a [*sic*] OR⁴³ visit.

³⁸ Similar to a pacemaker, a vagus nerve stimulator (VNS) is a small device implanted under the skin near the collarbone programmed to produce weak electrical signals at regular intervals to help prevent the electrical bursts that cause seizures. <http://www.webmd.com/epilepsy/vagus-nerve-stimulator-for-epilepsy>

³⁹ Spastic quadriplegia is the most severe form of cerebral palsy in which all four limbs and the trunk are affected. Children with this disorder usually have mental retardation, problems with muscles that control the mouth and tongue, and difficulty in speaking. http://www.cerebralpalsysource.com/Types_of_CP/quadruplegia_cp/index.html

⁴⁰ Septo-optic dysplasia (SOD) is a rare disorder characterized by abnormal development of the optic disk, and pituitary deficiencies. Symptoms may include blindness in one or both eyes. http://www.ninds.nih.gov/disorders/septo_optic_dysplasia/septo_optic_dysplasia.htm

⁴¹ Hydrocephalus is a buildup of fluid inside the skull that leads to brain swelling. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002538/>

⁴² The Nissen fundoplication surgery procedure is an option that alleviates chronic reflux where the patient’s condition cannot be controlled by medication or other means. <http://www.direct-healthcare.com/eu/nissen.htm>

⁴³ Operating Room

Brenda is keenly aware (and rightfully pleased) that her capabilities are quite remarkable for someone without a background in the health care fields. She relishes relating this story about her encyclopedic mastery of medical lingo. (Her little sister Pam, mentioned here, is in fact a year *younger* than her own child.)

It's always funny, because my mom will be talking about, like, the ear, nose, and throat doctor that she's going to take my sister to, and I'm like, "Oh, the *Otolaryngologist!*" And she's like, "you can *say* that word??" And I'm like, "He's been going there a long time!"

Brenda lets loose with a musical laugh. The scope of what this young woman manages on her own would bring most educated, financially-secure, partnered parents to their knees. She ticks off complicated diagnoses and procedures with the aplomb of an expert, and coordinates operative procedures, appointments and therapies like an air traffic controller. Even with all of this on her plate, Brenda is excited about heading back to school in a few weeks:

I actually just signed up for a medical unit secretary course . . . that's from July to December, so it's not a degree, but it's a certificate. Yeah, so I'm looking forward to doing that . . . And having a nice little job sitting there! At a *desk!* [laughing] . . . Yeah, I've always been in and out of hospitals. I had to have open heart surgery when I was four. I was born with two holes in my heart. So, between Carter and me . . . [laughing again] hospitals don't bother me.

She mentions almost as an afterthought that last year she had to have back surgery, as a result of lifting Carter in and out of her compact car, while also disassembling and assembling his heavy wheelchair for each trip in the small sedan.

Yeah, I've got to pick him up out of the car and put him in the chair, and I've got to take the wheelchair apart to put it in the trunk. And, um, my mom told me that within the next year she wanted to try to help me get a van, you know. I think she's gonna take my car. . . and then she's gonna try to help me get a van . . . I feel bad, because I don't take Carter to the grocery store and places, 'cause it's just so hard to get him out of his wheelchair, and take his wheelchair apart, and put it together, but I know, like, if we get a van, I'll take him everywhere with me! [laughing]

Brenda looks down the road hopefully, towards a better job, and a handicapped-accessible vehicle so that she and her son can run errands together. She even dreams of marriage and perhaps more children one day.

I would like to have, uh, at least one or two more kids. Whenever the time comes, I'd like to be married, and financially stable a little bit more. Now that I kinda know what you gotta look at! [laughing] But Carter gets so jealous! Me and Kyle was sitting here on the couch the other night, and Carter was sittin' in his wheelchair. And I just kinda layed back on Kyle, and he put his arms around me. Carter stuck out his bottom lip, and gave that puppy dog face, and started crying! [She chuckles.] And I'm like, "Carter, you are going to have to get *over* it! Mommy is not just yours, and, you know one day, I might have *another* kid!" . . . He is very attached to me. He loves his momma!

My initial assessment of Brenda as fragile and foundering based on how easily her tears flowed, or how bare her "toolbox" seemed to be (by my middle-class standards) was embarrassingly shallow. She is fully aware of what she faces, and not just accepts, but *embraces* her caregiving role. A loving and attentive mother, proud of her son and proud of herself, she takes the youth and inexperience that most casual observers would label as impediments, and renames them as assets. As she says, "I mean, him bein' handicapped is *all I know*. He's the only kid I've ever had, so, you know,

it's *normal* to me." Asked what is most special about Carter, she doesn't hesitate. "He's happy. He's very happy." In the long run, is that not what all loving parents wish for their children?

Anna's Story: Alex

My neighborhood of townhomes is quite small, so, in search of variety, my brisk walks at daybreak often take me to a nearby community. These stately brick colonials bring to mind English country estates, nestled as they are on leafy cul-de-sacs with their carefully manicured lawns, and well-tended flowers spilling from window boxes. Late-model SUVs and sleek sedans wait in the driveways. The automated sprinkler systems tick and hiss in the cool morning air as I walk past these impressive houses, iterative of stability and success.

As I enter an address into Mapquest to plan my route for a visit to Anna's house, I am startled to find that I have been passing her home every morning on my six a.m. treks. Pulling to a stop, I admire the massive silver Denali in her circular drive. I realize that this particular house sits on a lakefront lot, the back yard sloping away to a forested glen with an expanse of shimmering water visible through the branches. As I ring the doorbell, I take in the stained glass windows, with their ivy motif, surrounding the front entrance. Anna, James and their three boys seem to "have it all." But to define them by my hasty cataloging of their material trappings would be disingenuous; there is much more to their story.

Anna, a 48-year-old Black woman who could easily pass for mid-30s, answers the door, cool and sleek in a salmon-colored tennis top and shorts. I look past her to the high ceilings, arched windows, and polished oak floors. In the background I hear the banter of basketball game commentators, and we follow the sound to its source: a wood-paneled den, where oldest son Jim, 16, stretches his lanky frame on the sofa, and Alex, 15, sits beside him in his wheelchair, arms resting on a Plexiglas tray. (Youngest brother Dale, nine, is out with playmates.) As mothers are wont to do, Anna prompts the boys to greet me, and they politely oblige. Jim rises from the sofa with a shy “hello,” and Alex makes a guttural sound and rocks in his chair. The teens quickly turn their attention back to the lure of ESPN, while Anna and I walk back to the front of the house, settling into chairs at one corner of an elegant dining room table. Anna needs little prompting to begin her story:

Let’s see, it was nineteen years ago that my husband and I moved to [southern state]. He was a graduate student at [prestigious university], so he came to work at [major corporation]. And our oldest son was born in ’95. We’re planners. We’re both accountants. We both—like to have things organized. So it was a joy when our son came. No complications, first child, I was doing well; everything was great, happy family.

This first child of course is Jim, the tall, athletic teen lounging in the den. Then Anna relates the story of Alex, her second son. She hardly pauses for breath as she recounts his first two years of life.

We were surprised that we were getting ready to have another child *quite* so soon, planners that we are! [laughing] So they were going to be nineteen months apart. And then, out of the clear blue sky, my water broke! And I was at work, drove myself to the doctor's office, the hospital was right next door, and they said, "Well, you'll need to be on bed rest until the baby's born." Well, at that point we were a little over . . . twenty-five weeks into the pregnancy, so I was sixteen weeks early at the point when the water broke. And by the time Alex was born, about a week after being there, five days later . . . he was born fifteen weeks premature.

And for the planners that we are, that was a bit of a surprise! That was the beginning of [pause] a very, very difficult time. They told us, as they do with all premature babies, that most premature babies come home by their due date. And his due date was April the 28th, and this was January the 13th. So here we are with this baby, and it's like, OK, he's no bigger—he's one pound nine ounces—no bigger than James's hand.

Anna holds her palm out to me, cupped and upturned, as we both envision a baby tiny enough to nestle there. She goes on to detail a litany of endless complications, sadly commonplace with babies born at such an early gestational stage:

In February, the doctors called me and said, "Oh my gosh, he's not going to make it through the night." It's a thing that all families deal with when you have a baby that's born that small; you have all the drama, and trauma. . . . We get to April, and they said, "Well, he needs a shunt."⁴⁴ He's there, but he has an infection, so they can't do the surgery. And then, the infection gets worse. And so the first of May, the doctors at [local hospital] call me. And they say, "You might not make it here in time, but he's not going to make it." He had developed meningitis . . . So we're flying there, rushing really fast, and we go, and he was very, very sick.

Anna goes on to describe another five months of daily trips to the hospital to see Alex, working part-time, pumping breast milk, then driving 90 minutes each way to deliver

⁴⁴ Shunting is surgery to relieve increased pressure inside the skull due to excess cerebrospinal fluid (CSF) on the brain (hydrocephalus) <http://www.nlm.nih.gov/medlineplus/ency/article/003019.htm>

the milk so that it could be given to Alex through a G-tube. Finally in August the shunt was implanted, and at the end of October, Alex left the hospital for the first time since his birth, nine months old and still weighing less than nine pounds. But the home stay was short-lived. Three days later, Alex was rehospitalized.

It was Halloween night, and we ended up having to rush him to [local hospital]. . . . Well, they couldn't figure out what was going on. And then I went to visit him one day. I'm kind of condensing it all down. And he had what I will say was the equivalent of a heart attack right in front of me. So they had to push me to the side, pull in the crash cart . . . [pause] So you're watching your child literally die, right in front of you, and you realize, [whispered] "Oh, my gosh." And it got to the point, and I have to be honest about this, and I say this to other people, and I know it sounds so bad, but he just kept getting sicker and sicker. I finally said, *"God, just take him. Take him."*

It breaks all taboos for a mother to profess that she is ready for her child to die. Anna's admission to petitioning God to "take" Alex sends a frisson of surprise through me, and I suspect it would shock any parent. But then, against all odds, both Alex and Anna somehow turned a corner.

Well, they did figure out what was going on with him. He had pulmonary hypertension.⁴⁵ And then, again, at that point, they had him in the PICU.⁴⁶ And again, we got a call that said, "He's not going to make it." And then at that point I said, "Well, you know, the Lord's got a different plan, because I've heard that before! I appreciate you telling me this, and I realize that you have to say this, but . . . eh! We're just gonna kind of see what happens."

⁴⁵ Pulmonary hypertension is abnormally high blood pressure in the arteries of the lungs. It makes the right side of the heart work harder than normal. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001171/>

⁴⁶ PICU stands for Pediatric Intensive Care Unit. The PICU is the section of the hospital that provides sick children with the highest level of medical care. <http://kidshealth.org/parent/system/ill/picu.html>

And I think that's when it changed, for me. When I heard it the *third* time. Because I said, "You know, I asked God to take him, and he won't, and Alex just keeps fighting. So if he's going to fight, then I'll fight with him!" . . . For whatever reason, he started to fight a little bit more. Just enough to survive.

There was one last curve ball thrown, and it was a big one. But this time Anna had already developed a tenacious and steely resolve. While at a routine appointment with Alex's pulmonologist, the doctor detected an ossified mass in Alex's abdomen. Anna at first waved off his professional concerns.

He was feeling around, I said, "Oh, you know, that's probably . . . he's just backed up." And he said, "No, go get some tests." So we did. And so when we come back in, and I'm all perky and everything, and he's sitting there at the conference table, with his head down. And he's a very confident man. But he looked distraught. [long pause] And he said, "I don't know how to tell you that lightning strikes in the same place." He did not want to have to be the one to tell me, on top of everything else that had gone on, *that he now had cancer*.

The doctor's lightning-strike metaphor could not have been more appropriate. It was a cruel twist of fate that Alex somehow survived the incalculable issues of his premature arrival, only to now face a life-threatening cancer diagnosis. But Anna had developed a fighter's resolve, and she met this unexpected added challenge without flinching.

Nurses who did not know her well approached the oncologist in charge of Alex's care to voice concerns about this mother who seemed to take the horrific news in stride. Anna quotes the nurses, furrowing her brow and imitating their worried looks:

"Does she understand what's going on? Because she doesn't act . . . like a normal parent. She's just going through the motions, and getting stuff done. 'I've got to

take care of this, and you all take care of this, and I'll be here for your report.' Just like it's a job."

Anna explains that her business-like demeanor sprang from what was by now her encyclopedic knowledge of hospitals and surgeries. She knew how to "do" medical crises, and at this point had full confidence that she (and Alex) could survive any challenge, even kidney cancer. She explains her serene countenance more fully:

Now I had to recognize that we were a different oncology family. Because of the fact that Alex had never run around and played, and he had never done . . . he had *always* been in the hospital. So quite frankly, he was an easy patient to take care of. Because he had his oxygen. At that point we had a G-tube (see Footnote 12), so he could be fed, and he could be cared for. He didn't need to get up and run around and have exercise, because he had *never* been able to do that . . . We were used to the hospital environment, and knew when they did rounds . . . So we have a cancer, we go through six rounds of chemo.

The chemotherapy and subsequent operation are successful; Alex has beaten the cancer. Soon he is back home, and this time is in fact home to stay. Over time, Alex grows stronger and healthier, and Anna discovers ways to keep her young family from becoming house-bound by Alex's needs.

So we got the portable stuff for the G-tube, and we got liquid oxygen, so we had the cute little oxygen tank, not the green giant, that you have to walk around with all the time. But you had, like, this thing that looked like R-2 D-2, you put the little, um, tank on it, fill up for each day, and you know you could go for about 12 hours. And then you'd come back. And so, we were able to get a portable oxygen tank that had, not 100 pounds of oxygen, but maybe just 50! We could put them in the back of the van, we could travel!

. . . And then by the time Alex was four, we were off of oxygen. And we were taken off all these meds when he got the cancer anyway. . . And everything was great. And then we learned how to bolus feed⁴⁷ him so we didn't have to have this pump that we were attached to. And I was like (shouting, arms in the air) "Oh my God, this is *fabulous!*"

Six years after Alex is born, Anna and James add a third son, Dale, to their brood. The shiny SUV in the driveway that I had mistaken for a luxury item has a quarter-million miles on it, Anna reports with pride. She and James have crisscrossed the country with their boys in tow, in their "truck" (as she calls it), visiting Disney World, family in Maryland, and NCAA sporting tournaments.

We have decided that we want to see all the United States, take the boys to see all the United States, and we're going to figure out how to do it, based on where there are major league baseball teams. We can tell you which stadiums are very, you know, wheelchair-friendly, and which ones aren't. I'm not a Patriots fan, but they were so wonderful to Alex. It was such a gift. And great seats!

So if the boys ever felt like, "Oh, I can't do this, because I have a brother with special needs, I'm just like, "No there's *nothing* that you haven't been able to do. We have figured it out. Life has happened. But still, we work through all that, because the idea is . . . is that Alex is part of our family, and each person is a wonderful part of our family. We try not to allow the challenges to overwhelm us.

Jim briefly interrupts our conversation to tell his mom that he is driving up to the nearby shopping center to mail a package. As he pulls the front door closed and heads to the car, Anna leans forward to share a revelation about her oldest son. He was expelled

⁴⁷ Bolus feedings are delivered four to eight times per day. Bolus feedings allow freedom of movement for the patient, so the child is not tethered to a feeding bag, as would be the case in a tube (pump) feeding. <http://depts.washington.edu/growing/Nourish/Tubetech.htm>

earlier in the spring from the elite private boarding school he had been attending. Word of the offense traveled fast in the tight-knit community.

Everybody's like, "Oh my gosh, this is the end of the world!" And I said, "No, it hurts really, really bad." Because we were able to see, in Jim's situation, that he didn't know how to bounce back when everything got hard. . . . Everything had always been easy for him. So he and Alex were polar opposites. Jim could do everything easily—academically, athletically—everything was easy! And for Alex, he can't do *anything* on his own. And when he [Jim] got to this place, everything, suddenly—nothing worked. And he couldn't figure out how to make it work. And so, he did something and was expelled. And he was hurt by it. We were all hurt by it.

Anna goes on to describe how Jim has matured in the process of "losing it all" and then working to rebuild a social and academic life at the public high school, holding his head high in the face of whispers and rumor.

Jim has come back into an environment now, where there's some people that talk about him. But everything's flowing in a way that it needs to be for him. We are in a family that could have that happen to us. We've been through stuff before. But now, in the process, we can teach our children that when something bad happens, you have to figure out how to go on. And you can tell your sixteen year old, now that you've done something really really dumb, you will be able to extend your grace and mercy to other people who do things that are *really really* dumb!

Anna sits back in her chair, folds her arms and smiles. So brotherly roles are turned topsy-turvy; the non-verbal, non-mobile brother has lessons of will and perseverance to teach his older, able-bodied sibling. A family faces yet one more challenge, this one with

the son who has known nothing but health and success. Anna finds an apt sports metaphor to describe her frenetic life thus far as a caregiver and mother:

Some people have lives . . . like a game of golf. You have time to set up your shot. You can walk to the next hole. Our lives are like a game of basketball. There's always something coming at you. You never know what's going to happen on any given day . . .

Alex, this year, received his notebook from the oncology department, to say that he was cancer-free. And they would have given it to us sooner, if I would have just brought him back, but I refused to take him back! [laughing] "No," I said, "Everything's good, and every time I bring him in, you all tell me bad news, so I'll just stay away!" . . . But with all that, it's been a very interesting adventure. One that I can honestly say, in my organized, accounting world, I would have never have planned . . .

But, it's all gonna be OK, somehow, some way, because . . . I recognize it could be a whole lot worse. And where the people around us may think, "Oh, my gosh! Oh, honey, let me help you get through that," this is how we're gonna do it: we're gonna love on each other. I have to trust God every day to give me the strength to lift up this child, and go places, and do things. We'll figure it out.

Kate's Story: Nellie

It is indeed a shame that my readers cannot hear Kate's voice as she tells her story. A transplanted Australian, Kate, 41, has a distinctive Aussie accent and a sparkling wit. She and husband Robert, 44, are the parents of three girls: Grace, 13, Nellie, 11, and little Julia, three. Nellie, the middle child, is in the sixth grade. She was diagnosed with cryptogenic epilepsy,⁴⁸ and has global developmental delays. Nellie cannot walk, talk, or

⁴⁸ Cryptogenic epilepsy (from the Greek word "kryptos," meaning "hidden") is epilepsy with no obvious cause. <http://www.aboutkidshealth.ca/En/ResourceCentres/Epilepsy/UnderstandingEpilepsyDiagnosis/Classification/Pages/Cryptogenic-Epilepsy.aspx>

feed herself, and relies on others for all of her personal care needs. Her sisters dote on her; she is a happy child with expressive green eyes.

Of all my interviewees, Kate is the caregiver most familiar to me, as Nellie spent nearly a decade attending my school before moving up to the middle grades a year ago. Kate and I met in my office, with three-year-old Julia playing at our feet—coloring books, stickers and snacks spread out on the floor for entertainment. This would be our only opportunity to talk, as Nellie’s health crises and doctors’ appointments (her specialists are in a medical center in another region of the state) required us to cancel our second interview time after time.

Kate’s story began like many other caregivers’, with a recount of Nellie’s birth, and the dawning of a foreboding realization that something was not quite as expected with her second newborn:

We didn’t want to find out the sex, and it was going to be a surprise, but then as Grace got bigger, you know, she wanted to know, “What’s the baby’s name?” And we always had her sex in an envelope, just in case we wanted to know. And two weeks before she was born, we opened it up, and she was a girl. And she was always Nellie. Nellie, from the moment that we knew, until we had her.

And just an emergency delivery . . . they thought that the cord was prolapsed; it was a very big emergency; she came in with a lot of drama. And we didn’t get to see her, neither one of us got to see her come into the world, and, um, we got to see her about eight hours later. And I remember looking at her and remembering, “She’s just a miracle.” You know? “Just a miracle.”

And they said, well, that was a traumatic delivery, but the nurses who I knew of there said to me, “Wow, you are truly lucky to have her. Because you almost lost her.” And her face was cut, coming out, cheek to cheek. And I remember saying, “Why did that happen?” And he [the doctor] said, “It was an emergency, and I

had to get her out.” And I asked him, “Was there any damage? And he said, “No.” And I said, “Did she suffer any lack of oxygen?” And he said, “Well, no, only as much as holding your breath. As long as you could hold your breath . . .”

They sent us home . . . And then, probably the first week of life, I noticed something was just a little different. Because I’m a nurse, a registered nurse . . . But I couldn’t get her to nurse properly. That’s a real basic function, suckling, to suckle. And I couldn’t even get her to take a bottle nipple. I couldn’t get her to take much at all. And I remember, just thinking, “Oh, something’s not quite right.” But you tell yourself, “Oh, you’re just overly worrying, hormones and stuff.”

And then, probably the second week into life, I would be nursing her, and she’d stop, and kind of stiffen . . . throw her arm out to the side. [Kate demonstrates the posture.] And I remember thinking, “That’s such a peculiar position for a baby . . . to do.” And I just started feeling a little uneasy. And we went to the two-week check—first weigh-in—and I said, “You know she does this funny thing where she stiffens her head and her arm.” And he said, “Oh, Kate, she’s perfectly healthy.” And I said, “OK, I’m overly worrying.” And I went home.

It’s painful to imagine that a parent would describe the classic symptoms of a seizure to a medical professional, only to be brushed off. Mothers, especially second-time mothers like Kate, seem to have a sixth sense about their babies’ health and development; Kate, as a nurse, was doubly wise. Yet she was casually dismissed as a worrier and sent home with her baby, a Cassandra-like figure with the gift of prophecy, unheeded by those with the power to act. Unbelievably, this cycle was repeated yet again.

And I went home, and there were just more of those instances, where she’d kind of tilt her head, and arch, and her arm would go back. And again we went back for another visit. And I said, “She’s still doing this peculiar thing. Do you think she could have suffered any damage at birth?” And he said, “No, no. Her Apgar

scores⁴⁹ were low—three and four—but they popped back up, and I think she is fine.”

And then I noticed, as a baby is developing, they’ll start to look at you. They start to find you and, “Oh, there’s Mum! I recognize you!” And she wasn’t doing that . . . Well, she’d do it a bit, but there’d be times when she’d have a . . . just really absent kind of look. Still I kinda kept telling myself, “Everything’s fine.”

Nellie’s failure to nurse, her absent gaze, and her seizure activity were indeed harbingers of serious problems. Yet through a combination of the doctor’s *laissez faire* attitude and Kate’s understandable desire to discount her own instincts, Nellie continued to go undiagnosed until the day her seizures escalated to another plane.

I was listening to the monitor, and washing dishes, and I remember hearing this kind of “Gurrhhgghh . . .” gurgling noise. And I thought, “Geez, that’s a peculiar noise!” And I kept washing dishes, and I kinda heard it again. Went in, and she was in a full grand mal seizure (see Footnote 25). Um, and I remember not even panicking at the time, and thinking, “Oh, she’s having a febrile⁵⁰ seizure. Kids do that, when they get fevers. She must have a little illness or something.” And I stood at the crib and watched her. And she was just flailing, starting to foam. And Robert came in, and he said, “Do something!” And I said, “It’ll stop.” And he goes, “No it’s *not* stopping, *do* something to make it stop!”

In an instant, Kate came to the profound realization that for the last three months, she had in fact been in serious denial about Nellie’s problems.

⁴⁹ Apgar is a quick test performed at 1 and 5 minutes after birth. The rating is based on a total score of 1 to 10, with 10 suggesting the healthiest infant. <http://health.nytimes.com/health/guides/test/apgar/overview.html>

⁵⁰ Febrile seizures are convulsions brought on by a fever in infants or small children. Children prone to febrile seizures are not considered to have epilepsy, since epilepsy is characterized by recurrent seizures that are not triggered by fever. http://www.ninds.nih.gov/disorders/febrile_seizures/detail_febrile_seizures.htm

And then it hit me, all the things I'd been worrying about seeing. Something was really wrong. And it hit me in that very moment . . . there was something really wrong with my baby. And I knew it wasn't a small thing. Called the ambulance, and it came. It was an hour-long seizure, straight seizure. They couldn't stop it. Got to the hospital; she came out of it. I remember thinking, "She's got a brain tumor. Something's really wrong." And just as I was trying to explain to the doctor what was happening, she . . . full grand mal seizure. Turned gray, and I felt we were about to lose her. They were giving her everything they could possibly give her. After about fifty-five minutes she came out of it.

A third grand mal seizure occurred within the hour; Kate and Robert began to absorb the fact that their daughter was a very sick child. Nellie was transferred to ICU⁵¹ for monitoring.

I remember looking at her, little tiny body, and she had all the tubes and everything coming out, and at that instant I remember thinking, "Wow. I've lost . . . a big part of her. Something's . . . changed." And I don't know if it was . . . that I realized there was something wrong, or if I realized that the idea that she was a healthy baby was lost. Do you know what I'm saying? That she would never be the same. That you'd never look at her the same.

Kate and Robert took Nellie home with a tentative diagnosis of epilepsy and RSV,⁵² and administered the heavy doses of phenobarbital prescribed to keep her seizures in check. But her seizures continued, increasing to a mind-boggling 60 per day at one point.

⁵¹ Intensive Care Unit

⁵² Infection with respiratory syncytial virus (RSV), which manifests primarily as bronchiolitis or viral pneumonia, is the leading cause of lower respiratory tract infections in infants and young children. <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002531/>

I remember every time I was looking at her, she was having a seizure. And I remember thinking, “There’s rarely a time I’m looking at her throughout the day, that she’s not having a seizure, or not recovering from one . . . It was like her brain would have a seizure, no matter what we did. And they [the medications], um basically sent her toxic, the medications in her little body. And she went back in the hospital. So this was kind of our life, ‘til she was about . . . a year old. You know, they realized that we needed to start to do physical therapy. She wasn’t meeting her goals, you know, her milestones. Wasn’t sitting up, and stuff . . .

. . . They told me that, uh, it was the drugs. Several times we’d go into Dr. W, the neurologist, and he’d say, “Oh, I think she’s got this terrible genetic disorder, that we’re going to test for.” And, “They can only live a year.” And, “I can see cataracts in the back of her eyes.” And every time, there was some *terrible* scenario that they thought it was. And then we’d find out, it wasn’t . . . But we still never had an answer.

Nellie’s doctors continued to be confounded as to a clear diagnosis; they eventually settled on cryptogenic epilepsy which is, as its etymology implies, a seizure disorder of unknown origin. By the time Nellie was two, Kate and Robert decided to enroll her in a specialized day program where she could receive all of her therapies under one roof. There was a moment of reckoning, when they walked into a school devoted to serving children with disabilities, and realized that this was Nellie’s future, and theirs.

You don’t anticipate putting your child . . . somewhere like that. You know, that’s not your . . . “I hope I have a special needs child, and get to put him in a . . .” [Her voice trails off.] And walking into a school, with wheelchairs and everything, it kind of, it was like, “Oh my gosh, this is going to be my life!”

But then you’d see some beautiful child, walking along with a little walker, and they almost look more beautiful and more adorable than a normal child, just walking along. You know? . . . So it was like, “I can do this. We can do this.” And she was—though not typical like other children—she had so many, really special

things about her, that other people would never get to experience with their children . . . Each year, you know, even though she'd have her setbacks, and go into [the] hospital, um, everything she accomplished was a *huge joy* for us.

There were more hurdles to be cleared. Nellie suffered a series of strokes in subsequent years, the first at age six and a half, and another at age eight. ("When we brought her home after that second stroke, she couldn't even blink her eyes. We'd have to tape her eyes shut at night. But she made it through.") She takes soft foods by mouth ("She has an oatmeal-consistency-type food"), but all medicines and liquids are administered by gastrostomy tube. A vagus nerve stimulator (see Footnote 38) implanted in her chest augments the seizure medications; while she is not seizure-free, there are no longer any 60-seizure days to weather.

Nights were the hardest for Kate. She was fearful of sleeping through one of Nellie's seizures and possibly losing her. But she told me that she seemed to have the gift of prescience when it came to Nellie's care:

It's been very profound at times. I've been woken up in my sleep, heard nothing, but in a way heard her, walked in , and she's been like this—asleep, eyes closed—and has looked up at me, and has gone into a massive seizure that she would have died from if I hadn't have been there. And Robert would be like, "How did you know?" And I'll be like, "I heard her calling me."

I mean those things? Who experiences that? You cannot tell me that people with typical children have experienced . . . I mean, well maybe they have, but that's not a common thing. And it's not my mind. It is truly something that is there. And it is a part of her; it's who she is . . .

Last year, Kate, Robert and the girls took their yearly excursion to the beach. Nellie has a large-wheeled beach chair, so that they can take her out onto the sand. Kate shared a story about meeting a man on one of their walks who, like Nellie, was in a wheelchair. Whereas most people would have averted their eyes and avoided contact, gregarious Kate ended up joining this total stranger on his back deck to have a conversation about disability as they gazed at the ocean together.

[I] went over and met this gentleman. He basically could only speak; he had very severe MS.⁵³ You have no idea the insights this man had, the thought process. He . . . he's just a completely normal human being that people would have passed up, and never taken the chance to meet. And he said to me, "You've got a lot of questions for me, don't you?" And I said, "Yeah, I do. How do you know?"

And he said, "I could just tell. Go ahead. Ask me." And I said, "I just want to know how you deal with people looking at you, and staring at you." "Honestly?" He said. "People's first impression of me is that if I can't talk, I don't have a brain. When people come up to me . . . Go ahead, give it a try. Say, 'Hi, how are you?' And I said, "Hi, how are you? What's your name?" So he said, "So I'll start by going, [slowly and robotically] 'My . . . name . . . is . . . Al . . . an . . .' Like that."

So he said, "So *then* what would you say to me?" And I said, "Well, I suppose I'd say, you know, 'How do you like the beach?', or, 'Are you enjoying your trip?'" [Alan says], "So then I'll go [speaking rapidly and fluently], 'It's really great, I love it, it's fantastic, and I come here all the time!' And you see people's faces go . . ." [Kate mimics Alan's shocked expression, and laughs heartily.]

He had such a sense of humor! And again, people would be missing out on that, not realizing who he was, because they can't see. So, um, I just really wish I could write a book, or do something to let people know, to take that opportunity to meet these special people, these special children. These special children grow into special adults.

⁵³ Multiple sclerosis is an autoimmune disease that affects the brain and spinal cord (central nervous system) http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0001747/#adam_000737.disease.symptoms

Nellie's "mum" Kate is a woman who has embraced the world of disabilities. Life with her daughter has expanded her vistas, not narrowed them. She reaches out to meet strangers, and clambers to explain her daughter's gifts and talents to anyone who will listen.

I don't think I've ever, really, ever thought, "Oh my God, how am I going to deal with this?" Or, "She's never going to be able to do anything." Never! You know, I've always strived much higher than that . . . I think I strive more, to show other people, "My God! You have no idea; she's so incredible!"

. . . And sure, there are sometimes that it does matter that she can't do this, this and this. Yeah, I miss that, and I mourn for that sometimes, but she really is a special individual, a special child . . .

The word "special" takes on optimistic ramifications in Kate's vernacular. It has nothing to do with wheelchairs, seizures and hospitals. Nellie is special because she has a smile that "could melt your heart" and an ability to teach others that people with disabilities are just . . . people.

Edith and Jesus's Story: Veysa

Edith, Jesus, and I have been acquainted for a number of years. Their daughter Veysa has attended my school since infancy; she is now six. Jesus is a welder, and Edith works at home caring for Veysa, nine-year-old brother David, and baby Lorenzo. Jesus, like a great many Hispanic men in the community, has picked up a smattering of English through his dealings in the workplace, while Edith, a homemaker, does not understand or speak any English. As I am the only Spanish-speaking person on my school staff, I

often translate for Edith and Jesus. Conscientious parents, they call frequently with questions: “Did Veysa have a good day?” “Do you need more diapers?” “Can you explain therapeutic horseback riding to us?” Each year on Valentine’s Day, Edith and Jesus drive to the school to deliver a bundle of silk roses, individually wrapped and labeled with the names of all of Veysa’s caregivers: teachers, assistants, nurses and therapists. There is always a rose for me as well.

I invited a native Spanish-speaker (also named Carol) to my interview with Edith and Jesus, as I did not want to miss any nuances of their narrative. Driving separately, Carol and I both made repeated passes up and down the main thoroughfare in search of Edith and Jesus’ street. Finally we realized that the sole road marker was hand-lettered on the side of a white mailbox. Edith and Lorenzo’s home was the only residence on a single-lane gravel path that wound through heavily forested land, opening out onto an expansive, sunny clearing. Their house, a beige double-wide trailer resting on a brick foundation, sat in the middle of an acre or more of land, dotted with hardwoods and fruit trees. White picket fencing lined the path to their front steps, and a manicured hedge of rose bushes, blooming with an excess of color, filled the front garden. Jesus has created a pleasing oasis of beauty and order for his family, invisible from the paved road.

Hearing the crunch of our tires on gravel, Jesus and Edith are outside and heading down the walk, smiling, before Carol and I are even out of our cars. Pleasantries are exchanged in Spanish, and Carol is introduced. I ask about Veysa, and Edith takes us

directly to her room. Colorful school art projects are pinned helter-skelter to every wall. Veysa lies on her back on the twin bed, clad in a soft pink and white track suit, her feeding tube and formula bag on a nearby IV⁵⁴ pole. She is positioned so that she can turn her head to peer out of the front window into the rose garden, or gaze up at the small television on her dresser. Edith murmurs endearments sotto voce (“mami,”⁵⁵ “linda”⁵⁶) and strokes Veysa’s leg as we say our hellos. Like the other children in my study, Veysa is dependent on her parents for all of her daily care needs.

We turn away from Veysa’s room and enter a sparsely-furnished living area with gleaming vinyl floors. Family pictures are pinned here and there to these walls as well, and I slowly realize, on this sweltering afternoon, that there is no air conditioning in the spotless trailer. Edith motions for me to sit to her right, while Jesus perches to her left, on the arm of the sofa. They seem to be leaning into one another, touching slightly. Chubby baby Lorenzo reclines with his bottle of juice in a car seat by our feet. David, with a bristly black buzz cut, is stretched out on his ample belly, intently racing cars across the floor. Translator Carol is nearby in the lone living room chair.

Edith and Jesus lean forward and begin to tell Veysa’s birth story. Mom and Dad speak in an effortless cadence, finishing each other’s thoughts. Edith goes first:

⁵⁴ Intravenous liquids

⁵⁵ Literally, “little mommy,” a term of endearment

⁵⁶ “Pretty girl”

She was born at the complete nine months. We realized in the hospital when she was born, we saw that the child would close her eyes, one little hand would tremble. And then we asked the doctors, and they told us that maybe it was colic, but no, it was not colic. And we took her home, and we started to notice that she continued to act the same way.

Jesus: Each time we noticed that the small attacks were stronger.

Edith: [nodding] Stronger. She would close her eyes, she would turn them to one side, her hands and feet would tremble. After that we took her to the pediatrician. We once again explained the same thing. Well, they would not believe us. Until one day me and my husband said, "What . . . with what? Something so they could see the child!" So then my husband had the idea. If we tape her, and . . .

Jesus: But we did not have a camera.

Edith: And we did not have a camera, until later my husband thought . . .

Jesus: And we went for the first time to apply for credit . . .

Edith: . . . to be able to get the camera, to tape the child. And my husband taped the child when the child closed her eyes, turned her gaze to one side, her little hand started to tremble, and her little feet. And then my husband, um, was taping when my daughter was making those movements. Then we again returned to the pediatrician, but not with that same one. We went with different doctors, and then they watched the video, and then they gave a paper, a note.

Jesus: A referral.

Edith: Yeah, like a pass to a hospital, for emergency. Then they told us to take the child to the hospital, and from there, they admitted her. They checked her, all the doctors were examining her. Then they told us that the child had the illness called sclerosis.⁵⁷ We did not understand what that was, and they started explaining little by little what that was. They gave us some sheets [of information]. That we should read those sheets.

⁵⁷ Tuberous Sclerosis Complex is a genetic disorder that results in a variety of symptoms, including brain lesions that can cause seizures. (90% of TSC patients have seizure activity.) <http://www.tuberous-sclerosis.com/patient/learn-about-tsc.jsp?site=PC001166&source=01030>

Jesus: When they gave us that news, it was something very hard for us. Well, first we did not understand what kind of illness this was. We thought it must be a terribly grave illness. Then, well . . . one is not . . . this is a defenseless child. Well, the truth is that we both cried. Well, then, it is an emotion that cannot be avoided.

Around the time that they were absorbing the devastating news of Veysa's disability, Edith and Jesus were also seeking answers about their older child. David, they were discovering, had his own developmental challenges, though not as severe as Veysa's:

Edith: Well, David has a story also. When he was three years old, we noticed that he did not want to speak. Also several people told me that he needed therapy. So we took him to a school and he spent a year in therapy in California.

Jesus: At first when people would tell us that the child needed therapy, I used to get annoyed and tell them that he could walk, run, and eat, and that the only thing was that he did not speak well, but when he grows he will speak. Little by little I realized that he was not speaking more, so that is when we took him to be evaluated.

Edith and Jesus [in unison]: In California.

Edith: Then he went to school and had therapy.

Jesus: As a result of the evaluation we found out that he has autism, so he needed therapy.

Edith and Jesus, with newly-diagnosed David and their very sick baby girl, decided, on the advice of their doctors, to move their small family from California to a southeastern state with a renowned children's hospital.

Edith: And then the doctors referred us here . . . that there were more treatments for her here, and better doctors. So we decided to move here so that she would improve and get better.

Jesus: We had to abandon everything that we had there.

Edith: And then here, thanks to God, we found many good people. Miss Jennifer [CDSA⁵⁸ worker] helped us a lot and from there, she recommended the school where she is now. Her doctors, the doctors are good people. They have given us much support for the child.

Things also were improving for David. Edith and Jesus were diligent about finding appropriate services for him in their recently-adopted home state, to continue the treatments begun in California:

Edith: When we got here we got a referral for schools for him. We looked for the school and found it. We got the papers from California that explained what he had. His evaluation, everything. Then here we were told the same thing. But thanks to God, the child started speaking when he was five years old. He used to be in [special education] classes, but this year he was moved into regular classes.

Jesus: He did not do well on his report card, but we realize that he has his disability, so for us it is not a big problem, because we know he has no control over that . . . He does not understand what is dangerous, or what is not safe. He does not understand the dangers of crossing a street. He is still like a younger child that does not yet understand.

Jesus has accepted that David indeed has a disability (mild autism), and holds appropriate expectations for his behavior and academic progress. In a culture that values machismo and independence, Jesus is surprising sensitive to David's shy

⁵⁸ Children's Developmental Services Agency

demeanor and halting speech. (When Carol and I first entered the home, he gently guided David toward us, and helped him to welcome us properly.)

Negotiating the triple challenge of financial worries, language barriers, and a move to a new state with no family close by, Jesus and Edith have managed to get their children the educational and medical services that they need. They describe an average day with their family:

Jesus: A typical day consists of getting up at 5:00 to connect her feeding tube. Yes, afterwards, go to eat breakfast. Well, if it is on a Sunday, I go get breakfast because the missus does not cook on Sunday! [smiling, looking at Edith] Then, maybe go to the church, if that is a day we can go. Everyone gets a bath and goes to church, and then we might go by a store after church, and we might go get something to eat in the afternoon. Here at home, if it is a nice day, we might all go outside.

Edith: Sometimes we might go to distract ourselves and play games at Chuck E. Cheese . . .

Jesus: . . . or the mall. Not to buy anything, but just to look around.

Edith: So she can look around and have fun. We walk her around. So she can enjoy herself.

Jesus: The idea is that she not be stuck in one place. Yes, we love her, and we try to . . . Right now we are in this house primarily for them, so they can have a better life . . . Since I am the only one working, it is difficult to maintain this place, but we focus on them, and especially her. So they have a good space. The sacrifice does not matter.

Jesus sweeps his arm in an expansive motion, toward baby Lorenzo in his car seat, to David sprawled on the floor, to Veysa's doorway. Looking after this large, beautiful property is undoubtedly labor-intensive for him, and rental costs must be

substantial in relation to his welder's income. But he is justifiably proud of the standard of living he is able to provide for his wife and three children. Before Carol and I rise to leave, I ask the couple for any last thoughts. Jesus, who by now has his hand on Edith's shoulder, says,

I have friends who tell me, "I could not take having a child like that. If I did, I think I would die. I could not stand to see them this way." Well, I think God continues to give us strength. One learns. Also, many people tell that God knows who to give a child like this. And I think, yes, there are people who might have a child like this and would abandon her. They could not handle that pain or emotion, and they would abandon her along the way . . .

[He pauses, then continues.] Keep moving forward. Do not despair. There is a reason why God put this in your path. And continue to work for the child and, well, everything will work out.

Jesus and Edith bid us good-bye as if we are family, with much hugging and back-patting. They thank me for bringing them a second friend named Carol. As we start down the stairs, once again complimenting Jesus' talent with roses, he turns back to Edith and whispers something. She dashes inside, emerging with a pair of kitchen scissors. Jesus begins pruning roses for Carol and me to take home to our families. I am reminded of the silk roses, bought and distributed at school by Edith and Jesus each February 14th. And I am reminded that time and time again, the caregivers of children with disabilities are themselves "gifts" to their children and their communities.

Conclusion

Berube (1996), like the eight individuals and couples with whom I spoke, is caregiver to his son Jamie. He bemoans the fact that “we seem incapable of empathizing with other humans in the abstract, and we need to have them represented to us before we can imagine what it might be like to share their feelings and dreams” (p. 255). Like Berube, I have made an attempt to represent the caregivers in my study “with all the fidelity that mere language can afford” (p. 264). In subsequent chapters, I will tease out both common denominators and outliers. But while I have, like Berube, attempted to work within the aesthetic of language to communicate caregiving portraits, I remind myself that I am no more than an amanuensis. It would be a conceit to imagine that I have crafted more than a gloss of these lived experiences in just a few paragraphs. Yet my hope is that the narratives in this chapter provide the sine qua non—the necessary groundwork—for a deeper exploration in Chapters VI and VII of both overarching trends and surprising deltas in the caregiving experiences of the eight participants.

CHAPTER VI

SOURCES OF SUPPORT: OBSERVATIONS AND REFLECTIONS ON “WHAT’S IN THE TOOLBOX”

Introduction

Everybody comes into this stuff with their own toolkit. And some toolkits are chock-full of all sorts of tools, whether they be financial or emotional, or whatever. And everybody’s doing the best with what they’ve got . . . Nobody’s prepared to have a kid with special needs . . . Everybody just does the best that they can with what they have available, the resources they have available.
(Kristin, mother of Marc, age 3)

Kristin, mother of a child who has 22-Q deletion (see Footnote 31) heart problems, and developmental delays, expresses a sentiment that is echoed by her confreres who care for children with disabilities. The chasm between the able-bodied world and the world of disabilities is vast and often tricky to navigate without a web of supportive services and individuals. Most of us have no more than fleeting knowledge of the daily flak faced by parents such as Kristin. Historically, a “psychopathology model” (Dykens, 2005, p. 36) was used to describe the parents and siblings of children with disabilities, assuming them to be maladjusted and traumatized by their “plight.” Yet a growing body of qualitative research tells us that parents of children with severe cognitive and/or physical disabilities are not only coping, but thriving, when appropriate supports are in place (Dykens, 2005; Grant, Ramcharan, & Flynn, 2007; Hastings &

Taunt, 2002; Knestrict & Kuchey, 2009). In reviewing a number of studies on the positive impact that a child with a disability can have on family life, Taunt and Hastings (2002) distilled a list of ten affirming outcomes:

(a) Pleasure/satisfaction in providing care for the child, (b) The child as a source of joy/happiness (c) The child provides a challenge or opportunity to learn and develop (d) Strengthened family and/or marriage (e) A new or increased sense of purpose in life (f) Development of new skills, abilities, or new career opportunities (g) Family members have experienced personal growth (more compassionate, less selfish, more tolerant, increased strength/confidence), (h) Expanded social and community networks (i) Increased spirituality (j) A changed perspective on life (e.g., clarified what is important in life, making the most of each day, living life at a slower pace). (p. 411)

Raising a child with a disability can be, without a doubt, a transformative and enriching experience. Yet indubitably families that include a child with special needs also face a myriad of challenges and stressors; basic needs (food, shelter, transportation), informational needs (medical, educational, governmental) and emotional/social needs (stress, isolation) at times combine to create a perfect storm that can threaten to capsize even the strongest of families (P. Wang & Michaels, 2010). It is incumbent upon those who have professional and personal intersections with these families to explore strategies for support that allow them, as Kristin says, to “have the right tools” to thrive.

In this chapter I discuss a number of both internal and external support systems that empowered the caregivers in my study not only to cope, but to flourish. I examine the ways in which these supports provided (and, sadly, sometimes *failed* to provide) parents with the tools that they needed to navigate in a world that was designed not for

them, but for the “ableist” masses, a world in which normalcy is revered and those who are different risk sublimation.

Formal Supports: Community Agencies

Medical Care

Brett (2002) states that “it is inevitable that due to the complexities characterized by profound impairment many professionals will be involved with the ‘world’ of the child” (p. 826). Parents, then, must rely on multiple external supports as they deal with the realities of raising a child with special needs. In most cases, a family’s first encounter with community supports for disability falls into the medical arena. The assistance and expertise offered by medical professionals has, over time, proved to be a two-edged sword. Historically, children with severe disabilities were viewed by doctors as deviants to be hidden away in residential facilities. Mary Pym recounts her experiences half a century ago with a physician who considered her child to be anathema to his practice:

She was born in 1955, around midnight. The doctor talked to me for a while—not about Martha. He just talked and left. The next morning he told me Martha was a Mongoloid. He said they tend to be happy children and sometimes they’re the pet of the neighborhood. But you can put her in an institution and forget about her and have another baby. I’ll never forget those words. I thought I can’t tell my girls I didn’t bring Martha home because something was wrong with her. I cried for three days, looked at myself and said, enough, let’s get on with life. (Schwartzenberg, 2005, p. 22)

This mother defied conventional medical wisdom, and brought her infant home. We might expect that these professional attitudes died out long ago, but Brown (2009), the father of a severely disabled son, endured a similar experience less than a decade ago: “The pediatrician couldn’t have cared less. He told me to take him home and love him. ‘You got what you got,’ he said. So I got rid of the doctor” (p. 153).

There is irony in the fact that the very advancements that allow smaller and sicker babies to be saved are also a factor in the “de-humanization” of the practice of medicine. It can be a Pyrrhic victory when the child survives, and parents are left to make sense of the aftermath. Vacca (2006), in a qualitative study of parents’ perceptions of health providers, shared this mother’s perspective: “All I got were clipboards full of notes and sad and stoic faces. I really felt the hospital staff robbed me of my right to celebrate the birth of my child, even though she was disabled” (p. 66). Another caregiver opined that her newborn “had by now become a medical puzzle whose broken pieces were each examined by a different specialist” (Marsh, 1994, p. 2). Doctors from a variety of disciplines may focus incredible efforts on saving a life, but the “heart” of the medical profession is at risk of being lost in the tangle of high-tech interventions.

Support personnel in the medical community are without a doubt often talented and even heroic; yet sadly the emotional intelligence of these same professionals gets poor grades. Thankfully, other parents noted in the literature have a different story to tell. They have found pockets of caring and compassion in the halls of medicine.

One evening after eight, our pediatrician stopped in to say hello after doing rounds visiting his patients . . . Unexpectedly, he came over and asked me if he could hold Jeremy and sit and rock him for a few minutes—and he did . . . It was the most striking act of kindness by a physician I have ever seen. (Marsh, 1994, pp. 35–36)

This and other positive reports offer hope that physicians can infuse an ethic of caring into their clinical repertoire. Current medical school curricula now include planned opportunities for clinical, school and even home interactions with children with disabilities. Roundtable discussions involving parents of children with special needs allow for frank doctor/parent interchanges; mothers and fathers retell stories of some doctors' insensitivities, and others' profound compassion. Pediatric residents are listening to and learning from parents and caregivers.

By nature of the fragile health conditions of their children, the eight caregiving families in my study were all well-acquainted with the world of medicine. Several of their children spent months in the hospital setting before moving home. Frequent emergency room visits and surgeries were the norm for this group, rather than the exception. Even after children's immediate health crises abated, all families continued with multiple specialists' visits, and a panoply of ongoing therapeutic interventions. Therefore all of them had palpable feelings about the support—or lack of it—that they found in the medical arena.

While participants often credited medical professionals with keeping their children alive, a common song ran through the caregivers' narratives: doctors

discounting their children's physical and cognitive potential. Time and again, parents felt that doctors held low expectations for their young patients with disabilities.

That's one of the things that drives me crazy about his doctors, is that they, they underestimated him so much. And they were surprised that he had such emotions, and such personality, 'cause he'd get mad, Carter'd get mad, if I walked out of the room; he'd start crying. And I guess they didn't think he'd be able to do that. [Brenda]

Brenda ran up against low expectations for Carter a second time, at a specialist's office:

Whenever we were sent to the eye doctor, and he was diagnosed with that [septo-optic dysplasia] (see Footnote 40), it was when he was on that medicine that I was telling you about. And he wasn't, you know, being responsive to anything. So the doctor was like, "Consider him legally blind." And I was like, "You're crazy, but, whatever. You can write down anything you want to, but I know that he sees me!" [laughing]

Janet and Raul expressed the same frustrations. Janet shared advice for the doctors who constantly seemed to disregard their own high hopes for Anne Marie:

I guess I would say, just like you don't know how the brain work [sic], you're not gonna know how these kids are gonna work. Their brains are developing on a level that we don't understand; I don't think we understand to this day. And you can't estimate, there's no way you can estimate what they're gonna do, or how they're gonna come out. There's just no way. And, I think it's just, take a step back, just stop guessing. And wait and say, "Let's see. We'll see . . . what happens."

Raul then tried to place himself in the doctors' shoes, searching for an acceptable explanation for professionals' tendency to devalue the potential of children with disabilities:

They would rather err on the side of caution, than to give you a false sense. 'Cause we'd be like, "Well, you said they could do this, and they can't do it." Yeah, and they can't say, "I was just being nice." They'd much rather, they'd much rather . . . I guess what I would tell them is to try to balance . . . not giving them false expectations, but . . . keep in mind that some people are more sensitive about their child. They might not be logical, like I might approach it. They could get upset.

Janet insists on the last word; she is as emotional and impassioned as Raul is cool and logical. "They make it so severe. They do! Like, 'She'll never move any limbs; she'll just be a veg . . .' I mean they make it so . . . severe!"

Not all medical professionals are as woefully lacking in bedside manner. Anna says that their pediatrician "was just very sensitive to our family." Jesus and Edith also reported that doctors and nurses were there for them as they struggled to come to terms with Veysa's diagnosis. Jackie had a vivid memory of a doctor who knew when she had "hit the wall" emotionally, and responded with the gift of time and compassion. After a week of emergency room visits, eight doctors' appointments, and an MRI,⁵⁹ Jackie broke down:

⁵⁹ Magnetic resonance imaging (MRI) is a test that uses a magnetic field and pulses of radio wave energy to make pictures of organs and structures inside the body. <http://www.webmd.com/a-to-z-guides/magnetic-resonance-imaging-mri>

The last appointment we had was with the ear, nose and throat doctor. And . . . I just kinda lost it, at that appointment. I'm the type of person . . . it, it takes a little bit to make me cry. If you've made me cry, I'm either mad, or I've hit my limit. And so I'm sitting in her office and I'm just sobbing like, you know, a basket case. And I'm going, "I'm sorry! I don't do this!" And instead of being upset with me, like, "You're wasting my time," or "I have other patients," she sat down in a chair and she said, "How can I help you? Let's talk about it." And, like, everything I had been through with Troy at that point just came falling out at her. And she sat there, and she listened to me . . .

While the "assembly-line" nature of health care may drive the frenetic pace of most doctors' schedules, home health care nurses, with their more intensive home visits, have better opportunities to develop lasting and layered relationships with their patients and their families. Anna's most positive interaction with medical professionals centered on a nurse assigned to help with Alex's care.

We were blessed to have this nurse [Bea] who helped us learn to treat Alex like a child, and not a patient. She was from Philadelphia, and they did things differently up in Philly! [laughing] Where they could do a lot of stuff, and she was just like, "Oh, no. You need to get this, and you need to get that, and you need that." And the equipment guy, from the company, you could tell, he was just like, "*Bea* is in this house!" Because she gets all these things for her families.

Medical supports were not unanimously lauded by my study participants. They found certain doctors to be blunt and dismissive, while others were the embodiment of compassionate care. Home health workers, not under the time pressures of physicians, could develop deeper relationships with caregivers and children.

Educational and Therapeutic Supports

Hand-in-glove with medical supports are the specialized educational supports available for children with disabilities. While medical supports may be set in motion at birth (or even in utero) and frequently continue throughout the child's lifetime, educational and therapeutic supports usually commence later. Under IDEA (see Footnote 8), children from age three through twenty-one with disabilities are eligible for special education (Part B) services. For children birth through age two, Part C authorizes special education services targeting family, rather than school-based outcomes. Historically, parents were instrumental in securing the right to a free and appropriate education for their children with special needs; this was not available with any certainty until the passage of Public Law 94-142 in 1975 (Friend, 2006). While federal law places stringent guidelines on the administration of these programs, Turnbull et al. (2006) are swift to remind us that "no law can create genuine partnerships. All the law can do is to provide rights, impose responsibilities, and create the structure within which parents, students, teachers, and administrators can relate to each other" (p. 141).

Despite the support that can flow from schools, for particular families the process of entering the world of schooling can be fraught with stressors. Leiter (2004) outlines antecedents for parents' lack of engagement with schools. First, school professionals (teachers, administrators) may not have the skills or training to work in a collaborative mode with families. In addition, "power struggles" can exist when professionals are not willing to acknowledge that parents have great depth of

knowledge about their children; hence school personnel can be reluctant to cede a degree of control to the parents. This parent's sentiments about the school/home partnership echo the experiences of her peers:

Sometimes I feel overwhelmed. How can I evaluate this program? How do I know this is the best? Then I remember that it's a team approach. I'm not in it alone. It's just my job to get the specialists I trust to talk to each other about it. I remind myself that they know programs, and I know Wilson. (Simons, 1987, p. 54)

There is also a wide variance in parents' ability to actively participate in the life of the school, due to "parental illness or disability, parental employment, or other family concerns" (Leiter, 2004, p. 12). Language difficulties can make school seem forbidding; some parents who are in the country illegally are averse to contact with schools and other agencies for fear of deportation. Mueller, Milian, and Lopez (2009), in a qualitative study involving interviews (conducted in Spanish) with Latina mothers, found that "when parents come from a minority culture, speak a different language, and are unfamiliar with the system, parents participation can be very difficult without a medium to empower them to do otherwise" (p. 114).

Adults whose own school experiences were traumatizing may resist collaboration with school personnel. Curtis (2005) maintains that scarce financial reserves can also lead to schools' inability to meet the needs of students and parents. The demands of IDEA compliance on teachers' time and energies can have an additional negative impact on the quality of parent/teacher interactions:

Special educators get scared of being sued by parents or audited by the state, so they spend an inordinate amount of time engaging in activities designed to avoid these outcomes . . . When teachers devote a large amount of their time to paperwork and other compliance activities, they spent less time preparing lessons and teaching creatively, developing positive relationships with students, and establishing good communication with parents. (p. 513)

While there are, to be sure, stumbling blocks to developing effective school supports, in some cases teachers and administrators *are* successfully partnering with parents in educational settings. The primary indicator for these productive collaborations is trust (Shelden, Angell, Stoner & Roseland, 2010; Turnbull et al., 2006). In a collective case study involving sixteen mothers of children with a variety of disabilities, participants cited “approachability . . . authentic caring . . . and a perception of warmth” as the personal attributes they valued in school administrators, and also the professional qualities of “accessibility and knowledge of disabilities” (Sheldon et al., 2010, p. 165). Turnbull et al. (2006) used the metaphor of an archway, with trust as the germinal supportive “keystone,” for building relationships with parents. Other critical components in parent/school relationships cited by the authors were “communication, professional competence, respect, commitment, equality [and] advocacy” (p. 141).

Perhaps nothing speaks more powerfully than a parent’s own narrative. Previous researchers have gathered success stories of effective home/school partnerships. When these relationships are functioning well, this is the happy outcome:

It was such a relief that I didn’t have to try to fake my emotions when I was around my son’s teacher. If I got choked up with tears, I knew that it was going

to be okay to do that. In most of my relationships with teachers in the past, I have always felt that they expect me to “keep a stiff upper lip” and always be objective when I hear bad news about my son. I can’t separate myself from my emotions, and I’m so glad that I finally found a teacher who is comfortable with me expressing my true feelings. (Turnbull et al., 2006, p. 149)

Mirroring the positive trends in the medical community, educators of children with exceptionalities are also seeking to build stronger and more equitable relationships with the children and families they serve. As Case (2001) declared,

Possibilities for more parent-friendly, partnership-type relationships are emerging . . . The role of the professional as an expert who controls service provision and decisions regarding the child is gradually being replaced, in favour of a movement towards the ‘Negotiation Model,’ which defines the parent-professional relationship as a two-way dialogue, underpinned by negotiation and active listening. (p. 846)

All eight of the caregiving families in my study chose to place their children with disabilities into full-day public school or non-profit special education programs. The youngest (Troy, age two) was in his first year of structured schooling; Johnsie, at 20, had been in formal instructional programs since the age of eighteen months, and would be aging out on her 22nd birthday. Some of the children in the study were placed, for short intervals, on “hospital/homebound” services, in which a public school educator traveled to their home or hospital room to deliver curriculum when they were too ill to attend school. As expected, the quality of school supports received a range of caregiver reviews, from glowing to subpar, with most participants being satisfied with or even ecstatic about current educational settings.

Kate, mother of Nellie, age eleven, contrasted her grossly divergent experiences at two different special needs facilities in the same city:

I just really didn't like that school. When I kind of showed up, from the start, they looked like, they just looked like, like they wanted the day to end. And I didn't want someone like that looking after my child. And they said, "Well, there's another school." So they said, "Why don't you go and have a look at that one?" And I wanted to prove to them that I wasn't wanting to have control, I just didn't like that situation.

And I walked in [second school] . . . The school was big and bright. Kathy [teacher] was so loving. "Come in!" I walked in the classroom, and it had a happy feel to it. So much love in it. And I said to her, straight out, "I'm having a hard time." And Kathy said, "Honey . . . you can come and be with us; come sit with us." First week or two, like most parents, I sat outside, waiting, you know. And then I started to realize . . . Nellie loved it. She looked forward to coming; she lit up when she saw Kathy. And it started giving me hope . . . And I can honestly say, with every year things just got better. She learned more, she did more.

John, like Kate, had dissonant experiences in facilities run by the same school system. While Kate described two "non-traditional" (specifically for children with special needs) schools in her critique, John's highs and lows came at regular education facilities that included a select few classes for children with disabilities. John was met with unbelievable calumny from a group of insensitive parents, indulged in a moment of Schadenfreude, and honed in on school administration as the decisive factor in both schools' degree of hospitality to his daughter.

She went to [first school] for a year. And not the most pleasant year, I'll tell you. Simply because the principal out there wasn't very welcoming, and that made all the difference in the world . . . Some of the parents actually thought they could catch it [Rett syndrome] from going to the water fountains and stuff like that.

And they didn't want their kids to be in the same class with her. And that . . . that irritated me a little bit. I had a problem with that . . . "What's going on? Can my kid catch this?" [laughing] "No, your kid can't catch this. It's a genetic mutation. But I wish they could!" You know, I felt like that. [laughing harder] "If they could, that would be alright!"

So we took her out, sent her to [second school], where, the difference was, the principal at [second school] *loved* having Johnsie. The little prissy-ass principal at [first school] didn't like her . . . [laughing] Oh, man! I wanted to . . . I blame the principal.

Brenda took the extreme measure, as a teen mom, of moving from the security of her mother's home to an adjoining county purely because this metropolitan school district had services that, in her opinion, could better meet Carter's needs:

My family actually lives in [home county], most of 'um. And I was livin' there, and the programs there . . . they told me that, you know, fifty per cent of their kids that was in 'um, the preschool program, was handicapped. But none of 'um was like Carter, and I felt like the teachers really didn't know . . . Their definition of handicapped is like, ADD (see footnote 9) and stuff like that! I mean, not what I'm thinking. And he was the most severe kid that they had there, and I think that they just really didn't know what to do with him, and how to play with him, and stuff.

And I was like, "No, I gotta move to [new county]! He's got to go to those schools!" And it has worked out really good, and the transition is like . . . he got better, his health got better . . . he's advanced a lot more.

Across the board, the participants in my study were proactive in their sometimes quixotic search for quality education. Regardless of economic status, they possessed a laser-focus on finding appropriate settings for their children. They seemed to have

internal radar when it came to detecting teachers or administrators who were not unreservedly passionate about students with special needs.

Government Agencies and Non-Profits

While the lion's share of families' daily interactions revolve around the medical and educational needs of their child with disabilities, there are other state agencies and groups offering a plethora of supports. The Community Alternatives Program for Children (CAP/C), administered through the [state] Division of Health and Human Services, "provides cost-effective home care for medically fragile children (through age 20) who would otherwise require long-term hospital care or nursing facility care."⁶⁰ The Community Alternatives Program for Mentally Retarded/Developmentally Disabled Individuals (CAP/MR-DD) Program, administered through the aegis of the same office, is "designed to give persons with mental retardation and developmental disabilities a cost-effective alternative to care in an intermediate care facility," allowing "individuals to return to and live in their community with as much independence as possible."⁶¹ Without question, these services can be life-changing for those who qualify, providing equipment, respite and nursing care, van conversions, and home care supplies. Many families, however, "fall through the cracks" due to protracted waiting lists, a labyrinth of arcane and obfuscatory qualifying regulations, or immigration status of the child.

⁶⁰ More information in CAP/C is available at <http://www.ncdhhs.gov/dma/services/capc.htm>

⁶¹ More information on CAP/MR-DD is available at <http://www.ncdhhs.gov/dma/services/capmrrdd.htm>

Along with the supports outlined above, direct government funding programs are another lifeline of assistance. The Supplementary Security Income (SSI) program is available to selected citizens, including “children under 18 who have significant disabilities,” as long as “he or she meets the ever-changing federal standards for poverty and thus does not have the means to meet his or her basic needs” and can demonstrate “a physical or mental condition that results in marked and severe functional limitations” (Turnball et al., 2006, p. 221). Medicaid funding is a second safety net for families facing the prospect of mammoth expenses related to disability. Typically Medicaid funds can provide such supports as case management, adapted equipment, respite care, home modifications, and a variety of therapies (Turnbull et al., 2006).

Non-profit organizations—Easter Seals, UCP (United Cerebral Palsy), The Arc, and MDA (Muscular Dystrophy Association), to name a few—fill many service gaps, providing connections to information, support groups, and advocacy initiatives. Shapiro (1993) warns that agencies such as these can at times use “the pity approach” and present those with disabilities as “appealing and huggable” (pp. 22–23). But this cloyingly twee charity model has begun to give way to a methodology fashioned after the civil rights movement, emphasizing issues such as accessibility and equal rights.

For the caregivers in my research study, the availability of government-funded programs often meant that they could seek work outside the home, access health care, or in some cases, procure “the basics” of diapers, formula and food. All caregivers, in light of the severity of their children’s disabilities, qualified for Medicaid, along with

CAP-MRDD or CAP-C services. Some did not utilize all services available to them, but most were plugged into at least some support programs and agencies. Jackie, as a foster parent, had perhaps the most comprehensive support network.

Well, while he's a foster child, everything is covered by the county that is needed . . . Once he's adopted, we get what is called an Adoption Assistance—a yearly adoption assistance. It's \$2,400. And it's to use until it's gone to cover things like therapy that's not covered, you know, equipment he might need that's not covered . . . And you know, he will have lifetime Medicaid. We are working on looking at CAP-C (see Footnote 60), because when he turns three, they will cover diapers, and they will cover bathroom modification, and wheelchair ramps. Things like that. Formula, he already gets covered; they ordered it through the doctor, and the medical company sends me a shipment once a month . . . You know, I hear a lot of people talk about adoption, and how expensive it is. Well, and that's because they're talking about brand new, *perfect* babies. And that doesn't exist, even if you pick out one! [laughing]

Jackie has her “perfect” baby. Troy is exactly the type of child that she wished to foster, and now wants to adopt. Luckily, the state provides ample financial remuneration so that parents with Jackie's healthcare skills (and heart for the work) can provide loving homes for those children euphemistically labeled as “complex” or “difficult to place.”

Brenda, who, like Jackie, is a low-income parent, relies heavily on government supports. Young and underemployed, she is grateful to have both financial and emotional backing. A CNA (see Footnote 17) comes into her home four days a week, allowing her to clean houses for her mother's company. A Case Manager⁶² checks in

⁶² Case Management is the service of a Nurse or Social Worker, to help caregivers oversee and coordinate the child's health care as well as social, educational, and other services related to the child's health care needs. <http://www.ncdhhs.gov/dma/capc/capcparenthandbook.pdf>

quarterly, bringing diapers and other incontinent supplies. Supplemental Social Security quite literally keeps a roof over Brenda and Carter's heads.

He . . . he gets SSI. He's been gettin' it since he was about eight months old. And we didn't have any problems getting' it, either. Like, most people have to get lawyers and stuff, and we got it . . . within two or three months. And he's been gettin' it ever since. And, um . . . we do get food stamps, stuff like that. We don't get housing, though, like the Housing Authority. I've tried to talk to them a couple of times about it, but, you know, the waiting list for HUD⁶³ is closed. You can't even get on the waiting list. So, I . . . I use his SSI check to pay the power bill and the rent, and just try to find somewhere that is as cheap as possible, but in a good area. You know, that's livable.

For Brenda, government assistance programs allowed her to feed and care for Carter while also earning a salary (albeit modest) to help cover his expenses.

Three caregivers in my research study—Anna, Kristin, and John—were comfortably in the ranks of middle or even upper middle class. Yet they, too, professed that government programs designed for children with disabilities were crucial to their families' emotional and financial well-being. Kristin sang Medicaid's praises:

For the first year, we were on Medicaid, because he was quote-unquote institutionalized because he spent so much of that first year in the hospital . . . We had private insurance, and things like that, but you know, Medicaid picked up everything that private insurance didn't . . . And even with, even when you have pretty good insurance, you know, we're still spending thousands and thousands and thousands of dollars a year in medical costs.

⁶³ The Office of Housing and Urban Development gives funds directly to apartment owners, who lower the rents they charge low-income tenants, including senior citizens and people with disabilities. <http://www.hud.gov/apps/section8/>

Anna and her husband James, like Kristin and her spouse, had excellent insurance coverage. Her story uncovered the shady machinations of a large insurance company:

His [Alex's] medical expenses were at least 1.1 million dollars. James's insurance company had a million dollar lifetime max. So we were kicking in to the next insurance, almost. And then that's when they dropped us . . . They realized that they were about to have to pay . . . When my insurance realized they were going to have to start paying these astronomical bills, they found a loophole, and they dropped us.

At Anna and James's lowest point, they began to research bankruptcy as an option. ("It was at the point of throwing bills up in the air, and paying the ones that landed closest to our feet.") But assistance became available, thankfully, through SSI, because Alex was under two pounds at birth, and also through the Medicaid waiver (which does not take family income into account—only the severity of the child's disability). Anna's family got the coverage they needed, plus nursing hours at home to help with Alex's care.

At times my research participants found support from non-profits and disability-specific organizations. As John dealt with the devastating news of Rett syndrome, a rare diagnosis in the early 90's, he sought out information from the newly-formed group for this "orphan" syndrome. The day after John's diagnosis, when, shockingly, he and his ex-wife Janet discussed group suicide with some seriousness, they reached out for help:

The next morning, she [Janet] called this number in Ohio. A lady named Karen Howell. Called her at home, that's the only number she had. A lady answered the phone. [John stops and takes a deep breath, and continues in a voice choked with emotion.] Janet said, I think she squeaked into the phone, "Is my life over?"

...

So, uh, Karen said, “No,” and commenced to tell her how good her life was going to be *because* of this. It turns out, she was an amazing woman; her daughter was the first Retts girl, diagnosed in America, in 1984 . . . So, uh, Karen talked Janet down off the ledge. And uh, so I got to know her. And I joined this group called the International Rett Syndrome Association . . . It’s a huge deal now; it’s all around the world.

John went on to become an active and vociferous member of this group, lending his legal know-how and gift for orating to their national meetings for the next two decades.

Like John, Kristin sought out a non-profit as she began to look for sources of support.

She gravitated to the March of Dimes, saying, “because we had had a preemie, because we had had a child born with a congenital birth defect, and all of those things . . .

obviously their mission, and what they’re working towards, meant a lot to us as a

family.” Kristin, like John, drew potency from her friendships and associations with her

chosen non-profit. The group benefitted as well; her family’s ambassador status and

participation in fundraising events was a win-win for parent and non-profit.

To recap, families of children with disabilities must run a virtual gauntlet of medical specialists and exceptional educators/administrators as they attempt to procure the best possible outcomes for their children. These professionals can at times provide caring and compassionate support; they can also be a source of frustration and heartache when services are not paired with a benevolent spirit. Other external supports may be pursued through local, state and federal agencies and non-profit support groups devoted to particular disabilities or syndromes. Yet research has evinced that for many parents of children with disabilities, the most efficacious support tools are

not complicated, expensive, or far-flung; powerful sustenance can emanate from family, friends, and one's own personal and spiritual philosophies on disability.

Informal Supports: Family and Friends

A Caregiving Partner

Relationships in any family have the potential to provide both the balm of emotional Sang-froid and the burden of stress. Turnbull et al. (2006) include marital, parental, sibling and extended family relationships in their analysis of familial supports when the family includes a child with a disability. Family members, (in the Turnbull et al. model, p. 29), are capable of providing (to varying degrees) affection and self-esteem, as well as support with financial needs, daily care, socialization, recreation, education, and spiritual growth. The marital bond is the primary relationship for many parents, but research results are decidedly mixed as to how this relationship is impacted by a disabled son or daughter. "Are marriages on the whole hurt, unaffected, or improved by the presence of the child with a disability? As cryptic an answer as it may seem, research gives a yes answer to each of those questions" (Turnbull et al., p. 30). Fewell and Vadasy (1986) capture this dichotomy well:

Spouses share in the emotions, the physical care, the nurturance, and the concerns about the future. They can listen to one another, cry, laugh, and play together. The mutual support that parents provide each other is important, since there is evidence that the presence of a handicapped child affects marriages one way or another. (p. 7)

In general, sturdy marriages seem to be bolstered by the experience of raising a child with special needs, and those marriages already foundering are doubly stressed.

There seems to be coherence in the literature that the task of caring for children with disabilities falls primarily to the mother (Boyd, 2002; Costantino, 2010; Hubert, 2010; Kaplan, 2010). One mother expressed her frustrations thus:

I was doing four therapies a day, 30 minutes each, plus washing, cooking, cleaning and taking care of two other kids. I was going crazy. Finally I said to my husband, "Look, I can't do this myself. You have to help." (Simons, 1987, p. 25)

It should not be assumed that all mothers are in a marital or other committed relationship; without doubt plenty of parents are raising their children with special needs without another parent in the home. In fact, when P. N. Cohen and Petrescu-Prahova (2006) examined 2000 Census data on 2.3 million children (130,000 of whom had mental and/or physical disabilities), they discovered that while 62% of non-disabled children were in a two-parent home, only 46% of children with disabilities had two parents in the home providing care. (And it is noteworthy that only 5% of children with disabilities were living with a single father.) Single parenthood can increase caregiver burden; a study of single mothers caring for sons and daughters with disabilities, age three to eighteen, was carried out by Gottlieb (1997), with the researcher hypothesizing that these women would experience lower overall wellness (parenting stress, physical health, depression, and psychological health). As expected, "mothers who were primary providers but who did not have the support of a partner experienced greater depression

and lower psychological well-being, as compared to their partnered counterparts” (p. 10).

While mothers are often found “in the trenches” in the role of primary caregiver, more researchers are turning their attention to the role of fathers. Turbiville and Marquis (2001) postulated that interactions with community supports are focused on mothers by virtue of convenience, availability, and service providers’ higher “comfort level” with women (since these service providers themselves are often female). Higgins (1995) shares one father’s take on why his involvement is not optimal:

It seems to me we guys are less likely to share our feelings, do it rather badly when we do, and are more likely to be blasted . . . I am told that many fathers become overwhelmed and bail out of marriages when handicapped children enter the picture. Those of us who are working to stick it out need as much nurturing . . . as our spouses. (p. 5)

There are a number of excellent first-person memoirs by fathers of children with disabilities (Berube, 1996; Brown, 2009; Naseef, 2001). Naseef (2001), speaking from personal experience as the father of a son with autism, shares his estimation of how fathers fit into the pulse of family life:

We men are supposed to be the ‘strong, silent’ gender and most, if not all, of our previous experiences with intense passions are alone, unspoken, and unshared. What a relief it is, I have found from my own experiences, to tell your story and to feel empathy from other men. So often we just wanted to be heard and appreciated as friends. (p. 123)

The lesson to be gleaned from Naseef's story (and the accounts of other fathers) is that men are searching for their own ways of nurturing their child and family, and that they in turn need sustenance. Turnbull et al. (2006) also remind us that "there can be a number of key men in the lives of children who do not have a formal father figure" (p. 36). Neighbors, uncles, male partners of mothers, male teachers and others can augment the support system regardless of whether they carry the title of "Dad."

In my research study, the configurations of caregiving partnerships were diverse; the study encompassed five married couples raising their own children, a married couple raising a foster child (and their hybrid brood from previous marriages), a single mother, and a divorced father. As mentioned earlier, all of the respondents had originally volunteered as single participants. After the first round of interviews, two of the mothers expressed an interest in having their spouses participate in the home interviews; this request was honored. Still, as other research suggests, the primary caregiving role fell most often to the mothers in my study, often because the father held the higher paying job while the mother worked part-time, or stayed in the home. In two cases (John and Raul), the dads were more immersed in the daily personal care of the child than the mothers—John, by virtue of his sole custody, and Raul, as the stay-at-home spouse.

In the six families that *had* married caregivers, no prodding was necessary to elicit praise for the value of spousal support; moms and dads were generally eager to

extol their partners' caregiving assistance. Jackie was effusive with her kudos for

husband Art:

He does a lot of things that, that make taking care of Troy possible. There are so many things he does for me that I could not do for Troy, if he didn't do the things he does. He has . . . in Troy's room, he has built an *entire care station* where all of his stuff is within reach. And I'll show you before you leave, but it's diapers and wipes, and nebulizer,⁶⁴ and suction machine.⁶⁵ Everything is within my reach, if I need it, if something goes bad with Troy. And he built that out of what was the closet . . . There's a lot of things. He does a lot of the leg-work, and a lot of the heavy work. If he thinks it can make life easier on Troy, or on me, he does it. I think his love speaks volumes, in that way.

While Jackie appreciated Art's handyman skills, Kristin spoke of Larry's willingness to pick up the slack with hands-on parenting when she had reached the end of her emotional "rope," not only with Marc, but with her two other toddler-aged boys:

I was a little short, and Marc climbed up on the coffee table one more time, and I was like, "I've said 'Keep your feet on the floor' eighty-seven times!" I was like, "Today was not my best mothering day." And Larry was like, "I'll bet you've been a fine mother today." So, I feel like it's, you know, I have the luxury of being able to say, "Today has not been my best mothering day. When you get home, I need thirty minutes. I need you to take them for just thirty minutes, so I can catch my breath, and go to the grocery store by myself, or *pee* by myself." Or do whatever. Those exciting things! [laughing]

⁶⁴ Nebulizers are electric- or battery-powered machines that turn liquid asthma medicine into a fine mist that's inhaled into the lungs. http://kidshealth.org/parent/medical/asthma/nebulizer_inhaler.html#

⁶⁵ This usually refers to a portable suction apparatus used in wards and theatres for aspirating fluids and vomit from the mouth and airways, and from operation sites by sucking the material through a catheter into a bottle. http://home.btconnect.com/MalcolmBrown/entries/SUCTION_MACHINE.html

Jesus and Edith were an unmistakable team as well, finishing each other's thoughts during their interview. Jesus cited marital cohesiveness as the single most important factor, in his eyes, for successfully raising a child with disabilities:

Stay united as a couple. Keep a strong bond. For example, I think a mother by herself would struggle with a child like this. Or a father, it is difficult. So a couple united makes it a little easier. They can share everything . . . and although you may be exhausted, you can compensate with a laugh together, a smile . . . Be there for each other.

He even admitted that parenting not one but two children with disabilities may have held the fabric of their marriage together during rough patches:

I think she is the one who keeps us united. At times, we have problems, but then we think about them [motioning towards David and Veysa] so as a couple we try harder, and we try to work things out and have more conversations. Yes, they keep the family united.

Brenda was a single parent, and Carter's birth father was largely absent in the life of his son. But Brenda's current boyfriend was unperturbed by the prospect of dating a young woman with such prodigious responsibilities. (Brenda said, "I told him, I was like, 'I have a kid, and he's handicapped.' And he was fine with it. And . . . he's been here to help me. From the first time he met Carter, to now.") Like Larry and Art, Kyle provided both emotional and physical support for Brenda:

Kyle does help me out a lot with Carter, like, just even with the smallest stuff, like running up the road, so that I don't have to put Carter's wheelchair in my car, and put Carter in my car; Kyle will watch him for me. Um, just simple stuff

like that, Kyle helps me out a lot with. Carrying Carter, Kyle's my muscle. It's funny, 'cause one little story about Kyle and Carter. It's funny 'cause I walk out of the room and hear Kyle talking to Carter . . . and then I'll come back into the room and Kyle will kinda stop! [laughing] I think he's a little embarrassed, but it's cute.

Brenda was pleased to have a boyfriend who not only was undaunted by the responsibilities that tether her, but was likewise unfazed by (and actually relishes) the prospect of carrying on intimate "conversations" with her non-verbal child.

Anna recounted the story of how husband James went to bat for her at the hospital, when doctors suggested that their newborn son might need a tracheotomy⁶⁶ and a ventilator,⁶⁷ and she could not handle the idea of any more wires and machines. ("I'm sorry, but I can't program my VCR; you'll have to come up with something else!")

So, my husband came in that evening, because he would always come in after work. And they pulled him to the side and said, "Your wife doesn't understand." And I'd already talked to him. He [the doctor] said, "He's gonna need a tracheotomy . . . because he's just at a place where he needs more support." And he [James] said, "You don't understand. I sleep with her. And if *she* says she can't do it, and *she's* going to be the one taking care of him the most . . . and if *she* says 'You're going to have to find something else,' then *that's* what you're going to have to do." So then they had these *two* crazy parents that they had to deal with! [She crosses her arms and nods, with a satisfied grin.]

⁶⁶ A tracheotomy is a surgical procedure in which a cut or opening is made in the windpipe (trachea). The surgeon inserts a tube into the opening to bypass an obstruction, allow air to get to the lungs, or remove secretions. <http://medical-dictionary.thefreedictionary.com/tracheotomy>

⁶⁷ A machine that supports breathing. A ventilator may be used during treatment for a serious lung disease or other condition that affects normal breathing. <http://www.nhlbi.nih.gov/health/health-topics/topics/vent/>

James drew a line in the sand on his wife's behalf, and it paid off; a new doctor on staff was willing to try a novel procedure with Alex. It was successful, and the tracheotomy was averted.

All of these caregivers gained comfort and peace of mind from their mate. While there was an amalgam of relationship configurations (intact first marriages, second marriages, and live-in arrangements), the constant seemed to be a willingness to divvy up the "heavy lifting"—literally and figuratively—that comes with raising a child with disabilities.

Siblings

It would require an entire paper to do justice to the topic of the relationship between non-disabled siblings and their brothers or sisters with disabilities. The sibling bond is in all likelihood "the longest and most enduring relationship of the family, perhaps spanning thirty years longer than that of the parent-child relationship" (Rawson, 2009, p. 225). Researchers, predictably, have found a diverse set of outcomes for these young people facing life in the shadow of a sibling who may demand an unequal measure of parents' time and energy. Dykens (2005) presents an excellent summary of the bifurcated role:

Siblings may experience both positive and negative responses simultaneously, switching back and forth in their responses over the course of time. One can easily imagine cases in which a sibling uses her relationship with a brother or sister with disabilities to cultivate strengths in the areas of humanity, kindness, love, and social justice. Such strengths may not necessarily protect this same

sibling from also having negative feelings, perhaps being angry at their sibling or embarrassed by his or her appearance or behavior. (p. 362)

It would follow, then, that siblings could at times be supportive in day-to-day family life, and yet could also present parents with an additional set of challenges. Rawson conducted semi-structured interviews with sixty 15-25-year-old siblings of students with complex needs. She reported that siblings fulfill such roles as attending school meetings, aiding with care planning, and providing emotional support to parents. Yet these brothers and sisters also carried apprehensions about their heavy responsibilities, and what the future might hold. As one interviewee stated, “The only thing that bothers me is like there’s only me and [sibling] so when it is just left down to me . . . I’ve got to make all these decisions on my own, and that’s a bit daunting” (Rawson, 2009, p. 229).

Most (though not all) of my research participants had other children under their care. Anne Marie was Janet and Raul’s only child, as was Carter, for Brenda. Johnsie was John’s only offspring in the home, although he did have two young children living with their mother, his former girlfriend. Anna, Kristin, and Kate, like Edith and Jesus, all had three children in the home. And of course Jackie, with biological, step, and foster children, led the group with five dependents under her roof. All of the caregivers who had more than one child volunteered stories, sans prompting, of how able-bodied siblings interacted with their son or daughter with disabilities. Kristin may have summed it up best: “Marc will . . . Marc will indelibly mark my other children, I think in really

good ways.” Most commented that benefits flowed bilaterally; able-bodied siblings were helpful, to be sure, but they reaped untold rewards from their experiences growing up with brothers and sisters who had special needs. (Anna’s story of how Alex’s matchless resilience provided a lesson for his able-bodied brother when he was expelled from boarding school was case in point.)

John, with 20-year-old Johnsie and young children from a later relationship, proudly pulled out his cell phone to share pictures of his seven-year-old daughter reading to the half-sister nearly three times her age. The younger children visit him often, and sibling relationships are a work in progress.

Yeah, they come over. She [Johnsie] thinks they’re hilarious! They’re young. I mean, I’m an old guy [62], but I have a four-year-old son and a seven-year-old daughter, and she finds them very entertaining, and they’re warming up to her. It took them a while. They just . . . in the last year, the last two years, for the seven year old, realized that there’s something really wrong and different about her. And they’ve asked me a lot of questions. So now, especially the little seven-year-old, she thinks she’s an expert on Rett Syndrome now! [laughing]

But it took the little boy . . . he was four before he would sit beside her. When she’d make the noises, it would scare him. And she was so different, they were a little afraid of her.

And they’ve . . . they’ve . . . now they know exactly, they come in and know they have to look in her eyes and say hello, not just from a distance, they can’t say it behind her back . . . they have to sit beside her, and my little seven year old will read to her. That’s Johnsie’s favorite deal.

You know it’s an odd thing. They may be the answer to my problem of what happens to Johnsie when I die. But I can’t . . . that is such a life-changing thing, I’m not going to put any pressure on them to do that. They’ve just got to . . . one or both of them have got to . . . I mean, maybe one day they’ll come to me and say, “Don’t worry, Daddy, we’ll take care of her.”

Paralleling findings by other researchers, John saw Johnsie's siblings as his best hope for eventual caregivers. Yet he recognized that this would be a weighty mantle, one to be taken on willingly, not through his coercion.

Jackie's two children, step-child, and other foster child were seamlessly integrated into Troy's care plan from his arrival at their home. In the way that other children might make a bed or pick up toys, these children were adroit at performing caregiving tasks.

Everybody at the house pretty much knows Troy's schedule, needs. Ashley can do his meds. Ashley can do his care . . . Even the kids, they know how to work his equipment, they know . . . "Troy's feeding pump (see Footnote 47) is alarming. Can somebody hit the 'shut' button?" Oh, and they go and do it . . .

I think they have empathy for others, now, that maybe they would not have learned. My son, Doug, he's very, very much quick to say, "Oh, let me go open the door for this person." He's very in tune, most of the time, to, "Mom, let me help you get that cart," you know, because Troy's cart is heavy.

Kate, with two daughters in addition to eleven-year-old Nellie, related a story illustrating how her daughter's embarrassment and discomfort at having sibling with special needs was ameliorated by a caring adult's intervention:

Grace [13], my oldest, started playing volleyball. And we were really excited, because she was taking on this new sport, and we would go and watch her. But, you know, as Grace's gotten a little bit older, it's gotten a little bit different, having a sister with special needs, 'cause, you know, she picks up on it that people are looking, and that's an impressionable age, and that sort of thing.

But we went to this game, and it was the first game ever. And the coach recognized me and she saw Nellie and she said, "Well hello, what's your name?"

and started talking to her straight-away. And I said, “This is Nellie” and you know, Nellie responded to her straight away. And she [the coach] said, “Come over girls, come meet Grace’s little sister.” And almost invited them – hey, come meet this person. Whereas they probably wouldn’t normally come up and go over to her. Typically society, kinda . . . holds back. And, um, Nellie loves that attention; she loves people talking to her. And all the girls came over and she [coach] said, “This is Nellie, and she’s Grace’s little sister, and she’s here watching the game . . .”

So the next game came along, and at the very beginning of the game, you know how they get together and do a little chant? The coach came over, and brought the girls over, brought all the girls over, and said, “Nellie, we just want to tell you that we’ve all talked about it, and we want you to be our team mascot.” And I was just overwhelmed, you know? That they had just kind of included her. And Nellie just beamed. They all got around her, and did their little chant before the game. And I said, you know, I said to the coach, “Thank you so much for that.” And Nellie knew exactly what was going on. She knew it, she totally got that . . .

And I said to her [the coach], “that means more to me, that day, that you asked Nellie to do that, and to be a part of it, than it really even would have if she were a typical kid and she had made the team.” That was so much more important. And realizing how much she impacted all those other girls, that for the rest of their lives, they might feel differently about seeing someone who’s different, or in a wheelchair, or whatever, because they’ve already experienced Nellie.

As can often be true with teens, it took another trusted adult, rather than her own parents, to transform Grace’s attitude towards her sister. Kate reported that Grace (and even baby sister Julia, three) are now ferociously protective of Nellie. Like Kate’s daughter Grace, Edith and Jesus’ son David, even while dealing with his own disability (autism), was the consummate big brother. Edith said,

They interact, she looks at him but they don’t converse since she does not understand him. He is very protective of her. He does not let any other children who might hurt her or hit her get close to her . . . Yes, he does love his sister.

Grandparents

Beyond marital and sibling relationships, grandparents can also be powerful stanchions for parents of children with disabilities. In the twenty-first century, family members can be far-flung; our mobile society is not conducive to having multiple generations in the same household, or in the same zip code for that matter. But when elders are close by, their guidance and love can be a vital element of a family's web of support (Correa, Zobeida, & Reyes-MacPherson, 2011; Dowling, Nicole, & Thomas, 2004; Simons, 1987). Naseef (2001) explains this bond:

When something is wrong with your child, you often feel like a little child yourself, and you want your mom and dad to help you—to rescue you and protect you from the hurt that you are feeling. My mother and father would counsel me to be patient and tell me that things would work out. (pp. 196-197)

Others concur that grandparents provide an invaluable safety net for families. Correa et al. (2011) identified practical supports such as babysitting, household chores, and help with finances, along with emotional supports (a listening ear, acceptance of the child “as they are,” and affirmation of the parents’ competence). Yet it should be conceded that grandparents are not immune from stressors themselves:

It becomes clear that grandparents can have as hard of a time accepting a disability as parents do, or even harder, and the acceptance can take longer. They face the double grief of their grandchild's disability and their own child's pain . . . This second level of grief often renders the grandparents powerless to offer the support that their son or daughter longs for. (Naseef, 2001, p. 201)

The research of others in the field bears out Naseef's reservations concerning grandparents' capacity for support. When Janicki, McCallion, Grant-Griffin, and Kolomer (2000) conducted interviews, focus groups, and surveys with 164 grandparents caring for 208 children with disabilities, three trends emerged: "(1) caregiving was an all-consuming role, (2) their lives were fraught with uncertainty and they could not access sufficient formal and informal supports, and (3) they were constantly worried about the future" (pp. 35–36). So, while grandparents are for many families a critical factor in coping with challenges, they are prone to some of the stressors that affect their adult children.

True to the literature, many of my research participants' extended families were geographically-scattered, and hence unavailable for day-to-day support. (Kate's mother is in her native Australia; all of Edith and Jesus' immediate family is in Mexico.) John, in his sixties, lost his parents years ago. But some caregivers told stories of how their mothers and fathers did indeed provide high levels of support, especially during the most medically trying times. Kristin's parents, more than most, literally "dropped everything" to support her when Marc and his twin were born.

Once we had the boys, and they were so early, I relied on my mother. She is an early interventionist. She stacked all her kids [patients] on Tuesdays, Wednesdays and Thursdays, so she pretty much, probably three weekends out of the month, she would come here on Thursday night or Friday morning, and she would be here for the weekend, and she would go to the hospital and visit Marc, or she would keep Owen so that I could go visit Marc . . . And so Dad obviously gave up his wife for big chunks of time so she could do that.

Kristin's parents, in the same state and just a couple of hours' drive away, have now purchased a second home in Kristin and Larry's hometown so that they can come for extended stays at a moment's notice to help with the three boys' care. Larry's parents, on the other hand, are illustrative of the flip side, fearful of Marc, and holding to antediluvian attitudes toward disability:

Marc is terrifying to them. I mean, all of it is terrifying to them. And they're constantly using inappropriate words, and they're kinda . . . I feel like everything with them is a constant education session, as to what is appropriate to say, and what is not appropriate to say . . . They're coming around. As he is healthier, he's less scary. And I think that, you know, we still have to, I still have to caution them against words like "retarded" and things like that, that always make my skin crawl and bristle.

Brenda's mother helps financially by allowing Brenda to work for her cleaning business in return for gas money and car insurance. Since Brenda is so young, even her own grandparents are spry enough to take on caregiving duties. And while Carter's biological father has abdicated responsibility for his son, *his* mother and father, happily, have maintained a close relationship with Brenda. They dote on their only grandson. ("Yeah, they actually take him almost every weekend, so that I can have a break," Brenda marvels.)

His grandpa is his buddy . . . So, it's funny because his grandma told me yesterday, she goes, "Jake [Carter's grandfather] mopes around all week, and then Friday when Carter's comin' over, he perks up a little bit!" And he's so excited, whenever Carter comes over. They play all weekend.

When grandparents are geographically accessible, they can be a source of great support, both as caregivers and confidants. They may, however, need gentle nudging to abandon their sclerotic preconceptions as they learn to function in the world of disabilities.

Parent-to-Parent

The social and emotional supports derived from family are invaluable tools for the parent who is navigating the world of disabilities. But durable family connections are not consistently available to all parents, and previously solid friendships can be strained to the breaking point by the transformative events facing a family with an exceptional child. Simons (1987) describes one mother's disengagement from her friends with healthy children thus: "They worry when their kids fall off their bikes and don't get A's in school. I don't have much in common with them anymore" (p. 19). Forming relationships with parents who experience similar challenges is a well-documented strategy for support (Boyd, 2002; Brinker & Howell, 1991; Strnadova & Evans, 2007; Solomon, Pistrang, & Barker, 2001). Parent support groups have time and again proven to be one of the strongest salves, scaffolding families to a place of stability. In a grounded qualitative study based on fifty-six parents meeting in six groups, Solomon et al. (2001) found parent-to-parent support to be helpful in three domains: sociopolitical (gaining a sense of agency in the outside world), interpersonal (feeling part of a larger community), and intra-individual (changing one's own attitudes and opinions). A qualitative interview-based examination of a support group for 25-30 Latina mothers in the United States conducted by Mueller et al. (2009) revealed three major benefits: "(a)

feeling like a family, (b) having a source of information, and (c) receiving emotional support” (p. 116). Pizzo (as cited in Turnbull et. al., 2006), captures the parent-to-parent bond in this excerpt from a support group discussion:

Family and friends fell by the wayside in a fantastic pattern of despair . . . like a chain of dominoes . . . Pillars of strength and guidance drifted away like straws in the wind . . . I knew from that day forward my whole life must change if [my son] were to survive. His vulnerability frightened me. I knew what I must do. I could no longer go it alone. I needed other mothers, other fathers to relate to. (p. 214)

Sometimes the group model for parent support is narrowed to just a partnership between two individuals. This can and does happen on an informal basis, but since 1971 a program called *Parent-to-Parent* has been “a core resource for families with children who have a special health care need, disability, or mental health issue. Through a one to one ‘match,’ experienced parents commit to providing emotional support to families and assist them in finding information and resources.”⁶⁸ Having a “veteran” parent who has walked a similar path provides a mode of emotional empathy and practical guidance that may be beyond the capacities of well-intentioned family members and friends. And like many volunteer programs, the happy denouement is that both mentee *and* mentor are the better for it. Experienced parents who act as guides see their own parenting and coping skills grow, and have the satisfaction of shepherding someone through what can be a tangled morass of demoralizing challenges.

⁶⁸ (<http://www.p2pusa.org>)

With the advent of web-based communities of concerned parents and professionals, access to information and interaction for home-bound parents has become less problematic. A parent can connect with someone else experiencing similar life circumstances across the country or literally across the globe through websites, blogs, wikis, Skype or other applications (Gabbard, 2001). This avenue of support removes not only barriers of distance, but also can provide a measure of anonymity and privacy for parents not comfortable in face-to-face meetings. The issues of transportation and scheduling are minimized as well. Of course, for parents in poverty and without Internet connectivity, this option is likely out of reach.

The caregivers in my study were a diverse group in regard to their reliance on parent support groups. No one volunteered information about encouragement from non-family sources in the first round of interviews; any information linked to this topic was elicited by my specific questions later on. With the demands of caring for a child with serious disabilities, a majority of caregivers did not appear to have carved out time to explore and develop close friendships or seek out a mentor to guide them through the caregiving experience.

Jackie did take the time to investigate the Internet, looking for other foster or adoptive parents raising children with Shaken Baby syndrome (see Footnote 14), and met with some success.

Now I did find a lady online, who lives in Arizona. And she adopted her son Michael. She got him when he was seven months old. His story is almost parallel

to Troy's. And, um, he died at twenty-two . . . So, she's been a good . . . she's like, "Call me any time!"

Ken, our foster worker, he ran into a lady in Florida, who was a nurse, and adopted a special needs child. He was shaken. And now he's seven . . . seven or nine, I can't remember . . . Yeah, it seems like we're kind of a triangle! [laughing] But maybe we'll eventually meet in the middle and cover . . . the entire, the continent there!

Kristin iterated that her female friends from her pre-parenting days drifted away as a result of both her lack of free time, and the awkwardness that people in the able-bodied world often feel around those with disabilities. She said,

I think that they don't always know what to say or to do, or what's appropriate or not appropriate . . . there was a long time when I was off the grid. I wasn't having cocktails with the girls around the corner . . . I wasn't doing that, because I was, you know, if I wasn't at home with Owen, I was at the hospital with Marc, or I was at work . . .

Fortuitously, Kristin found a kindred spirit in Marc's teacher, a young woman near her own age with two preschoolers at home. They had been acquaintances previously, but the relationship grew once Marc was placed in her class for infants and toddlers with special needs. Here was someone who "got it" with no explanation needed.

I would certainly say [teacher's name] and I are really good friends. And so, you know, she's always been, she's always been a good resource for me, too. We were hanging out at the pool this weekend, and I said, ". . .he's chewing on his shirt all the time, it's driving me crazy!" And she's like, "Have you tried Chewelry?"⁶⁹ [laughing] "Have you tried . . .?" All that kind of stuff. She's plugged

⁶⁹ KidCompanions Chewelry functions as a chewable and wearable sensory tool for individuals who chew or fidget. Developed by a parent for her child, it is a discreet, age-appropriate alternative to traditional

into all that kind of stuff, which is nice. And I think it's . . . my kid with special needs is nothing new to her.

Of course Kristin's high-profile position as the spokesperson for the March of Dimes was not only an act of advocacy (discussed later in the chapter), but a collateral channel into the community of mothers dealing with issues of prematurity and birth defects.⁷⁰

Brenda, the youngest of all the caregivers, turned to social media to seek friendships with other parents of children with disabilities. Since Carter's syndrome is exceptionally rare, accessing a wider geographic area (much as Jackie did) increased Brenda's ability to make personal connections.

Yeah, um, actually I'm a part of a group on Facebook for, uh, parents of kids with schizencephaly, what Carter has . . . a lot of good support people on there. And a lot of people who go on there, that look for, you know, hope, really, I guess. I've gotten on there and told people about Carter, and they're like, "Thank you so much, that's helped so much."

Brenda mentioned that she frequents a web-based support "village" created just for families of children with schizencephaly.⁷¹ This website, like many other niche groups

oral motor and fidget toys. Chewelry is marketed to parents of children with ADHD, oral/motor issues, and autism. <http://kidcompanions.com/store/#.UEHbg8FIS7o>

⁷⁰ This term has been largely discarded in the disability rights community, but the March of Dimes still clings to it.

⁷¹ <http://Schizkidzbuddies.com> is dedicated to supporting families of children with schizencephaly. The site maintains a Facebook group and a Yahoo email group, and includes over 2,000 members worldwide. Many parents have posted pictures of their children.

that are specific to a lone disability or syndrome, provides factual information, opportunities for connecting with others, and current breakthroughs in research.

Kate has become a frequent contributor to CaringBridge,⁷² a web-based community for people facing serious illnesses or chronic health problems. CaringBridge allows patients (or their relatives) to create a network for medical updates and messages of support. The act of writing itself is, of course, cathartic and cleansing. But additionally, after each of her posts, Kate receives copious on-line feedback from friends and relatives who follow her CaringBridge page. Physical distance (her family is in Australia) does not thwart the development of emotional bonds with others.

At one point in his life, John, father of Johnsie, 20, was very involved in Rett syndrome support groups, even attending national meetings on a regular basis:

. . . the conference is going on right now in New Orleans; I missed it this year. I've been . . . I went to the first eleven after Johnsie got diagnosed. Every year, I looked forward to it more than anything in the world. Learned about a lot of stuff there, things that really helped Johnsie . . . Still involved in a lot of the stuff. But I've paired it down.

Perhaps tantamount to how parents of children without disabilities scale back their level of involvement as their children become young adults, John has abridged his participation in parent groups as his daughter has aged; his own work obligations and responsibilities for his second, late-in-life family may play a part as well.

⁷² Learn more about Caringbridge at <http://www.caringbridge.org/about>. Pass-protected and free of advertising, it is now has over 500,000 users.

Edith and Jesus, with no computer in the home and little family support (all are in California or Mexico), relied on a trusted friend who helped them access online resources:

They [the doctors] told us about a diet that they told us was very good . . . They told us we could buy a movie about the diet that a child had used. We bought it. It was hard to find, but we found it and we bought it.

We could not find it in any store to buy it, but we had a friend. Well, we lived in some apartments. He was the manager there, and he was a very good person. He has the Internet, so we went to him to get help, and he said yes, that we could buy it . . . That movie talks about a child who has the same illness as our child. It is in English and I do not understand much English, but yes, we watched it. The idea was for us to understand more about that special diet.

So after watching it and understanding more, we decided to try the special diet for the child. And yes, up until now we are seeing many good results.

Luckily this family had a faithful ally to act as advisor when they needed guidance while exploring pathways for Veysa's treatment. He piloted them through what must have been an unfamiliar and intimidating process.

Overall, the caregivers in my study spent very little time with friends, and did not rely heavily on parent support groups. While there are a great many organizations in place for parents of children with Down syndrome, autism, and other commonly-occurring disabilities, I would assert that my caregivers had two strikes against them when it came to developing friendships. First, since all of the children in my study had severe and profound disabilities requiring round-the-clock care, the caregivers were tapped out both in terms of energy and leisure time. Also, because many of their

children had exceedingly rare syndromes or multiple disabilities, cohort caregiver groups were sparse or unavailable.

Spirituality

Beyond the supports of community agencies, family, and parent-to-parent groups, qualitative studies regularly cite religious affiliations and connections as a bedrock of support for parents of children with special needs (Bayat, 2007; Dowling et al., 2004; Greeff & van der Walt, 2010; Naseef, 2001; Pitchlyn et al., 2007). As expressed by Dowling et al. (2004),

A strong belief in a higher power can be of benefit to people grappling with a wide range of emotional issues . . . The fact that ‘bad’ things can happen to ‘good’ people is not necessarily easily accepted, and some families may need considerable support to help them understand that a special-needs child is nobody’s fault. (pp. 195–196)

(It should be noted that the authors borrow the phrase “bad things can happen to good people” from the title of Kushner’s (1981) small but powerful tome on maintaining religious faith in the face of personal calamity.) First, one must tease out differences between succor derived from the *institutions* of religion, and the comfort that may come from personal, inner spirituality. When dealing specifically with the assistance offered by “bricks and mortar” faith communities, such as churches, mosques or synagogues, parents in previous studies weigh in with mixed reviews. Speraw (2006), in a phenomenological study seeking to illuminate the lived experiences of parents of exceptional students in relation to spirituality, found that “while church could at times

be a source of both social and spiritual support, church staff displayed avoidance toward the disabled” (p. 215). Other parents in her study had more uplifting epiphanies; witness the tale of this father of a non-verbal 13-year-old:

In church she loves to dance in the aisles to the music. People tell her that she reminds them of angels. Most of the time people take to her dancing positively; they go out of their way. I don't know how much she understands, but she is so good in church that I think she knows that something reverent happens there, she has a place in the community, she is valued. (Speraw, 2006, p. 221)

Caputo (2001) reasons that people often find God at precisely those moments when they are most challenged and stretched by the circumstances of human existence. Caputo labels these moments “unhingedments.”

. . . When we come unhinged, when our powers and our potencies are driven to their limits, when we are overwhelmed, exposed to something we cannot manage or foresee, then, in that limit situation of the possibility of the impossible, we experience the limits, the impossibility, of our own possibilities. Then we sink to our knees in faith and hope and love, praying and weeping like mad . . . The religious sense of life awakens when we lose our bearings and let go, when we find ourselves brought up against something that exceeds our powers, that overpowers us and knocks us off our hinges, something impossible vis-à-vis our limited potencies. (pp. 12–13)

Caputo goes on to talk of the transformative experience of “letting go” when our best-laid plans are thrown askew by the realities of the human condition. As he says, “Our only recourse is to hang on by our teeth, that is, to have faith and hope, and to love this possibility of an impossible and unmasterable future which is not in our hands” (p. 14). He proffers that as humans we are brought to our knees, both literally and

figuratively, when faced with the realization that our lives will include random and chaotic events beyond our control. The birth of a child with serious disabilities would qualify as a spot-on exemplar of Caputo's unhinging episodes.

The caregivers in my study, predictably, were a sundry lot in terms of their reliance on religion and spirituality for support, ranging from devout, to indifferent, to atheistic. Many echoed Caputo's sentiments, albeit framed in an expansive range of religious traditions. Some participants sprinkled their speech liberally with references to God, while others, even with prompting from me, skirted the matter or were outright dismissive.

Anna was the most overtly religious of the eight caregivers, citing God thirteen times in one interview alone. Born and raised in a church-going family, her experiences as Alex's mom solidified and deepened that faith:

I can honestly say, yes, I went to church all my life; yes, I was a good Christian. I had religion—now I have a *relationship*. And . . . that's been very important for me . . . I can hear God whispering in my ear, "It's going to be OK." Um, and there are some days when I'm like, "Lord, I'm not feeling it!" [laughing] I had a great relationship with my *earthly* father. So, somebody tells me that God loves me and it's gonna be OK? I'm like, "OK, I *believe* it!" [laughing again]

As her son faced crisis after crisis as a premature infant, Anna said she "realized how small I was, and how big God was." When she was sure that he would not survive, yet he pulled through time and time again, her rationale was, "the Lord's got a different plan."

While raised in the Baptist faith and maintaining a membership in a small African American Baptist congregation locally, Anna and her family now attend a church of another Protestant denomination, not wholly by choice:

We go to a church where, although we're not members of that particular church and it's a huge church, we go to the church because it is very wheelchair accessible. The choir sings, Alex sings. The choir stops singing . . . Alex doesn't! [laughing] So we have to come out in the hallway, and they have screens out there. So that's how we go. So that is a little bit harder for me, because I'm more relational; I like to have that sense of community.

Anna is willing to bend her own desires for an intimate worship experience so that Alex's wheelchair can be rolled into a barrier-free sanctuary. She can shift him to the lobby when he becomes boisterous, and still participate in the worship service via television monitors. She and her family have adapted to Alex's needs, finding a workable way to still be part of a faith community.

Anna openly avows that Alex's disability was divinely planned, and counts her family as "very blessed" to be chosen to raise Alex. "God just meant for us to have a child who had a difficult start. And that's just when you have to understand God's sovereignty." Later she returns to that refrain:

It just happened. It, it was just supposed to happen, and that's all there is to it. Again, when all of those other families had kids, and they had typically-developing children, it was just supposed to happen . . . You have to understand, you are simply the conduit for God's provision.

Kate, mother of Nellie, age eleven, echoed Anna's sentiments almost verbatim, saying, "Maybe I was 'specially picked out. Maybe there was a reason for that." She saw her daughter as having a special purity of spirit that touched others in profound ways.

You realize that she will never harbor hate, she will never harbor jealousy, you know, resentment. She'll never have those things in her heart. How many people can say that? That is a true special soul, that we can all learn from, you know?

Kate saw her daughter as a vessel for love, put in the world to remind others to slow down and look for God's grace in quiet places and unpretentious acts. Kate related this episode:

You know, there was a lady one time on the plane, when we were going somewhere, and she had cancer, little did I know. And Nellie just started, almost communicating with her, although she has no way of talking. And the woman came over to me, and she put something in my hand, and it was this little angel medallion. And she said, "You have a true angel there." She said they had been talking together. And they literally hadn't been talking, but they were.

Kate held to a personal dogma that Nellie had a mystical, shaman-like ability to help others, relating another story about how she brought healing and peace to someone who was suffering:

Another girl, at Whole Foods . . . Really rough, tough gay woman, with lots of tattoos, was serving the coffee. And I stopped there with Nellie, to get a coffee. And Nellie reached out and touched her one day. And the girl's whole demeanor just changed, and she said, "What's her name?" And I said, "Nellie." And she said, "What's wrong with her?" And I said, "She has a seizure disorder."

Well, it ended up that every time we'd come in, we would make this connection. And finally, about six months later, she said, "I just want to tell you something." I said, "What?" She said, "Your daughter saved my life." And I said, "How . . . how is that?"

And she said, "I have been a drug addict all my life. Bad one." She said, "I almost died several times. . . I'd never had the strength to get it together." And she said, "I've watched your daughter for six months, come and go. The day your daughter touched me," she said, "I felt love. I felt something powerful, from your daughter, when she touched me." And she said, "Do you know I've been clean since the day that Nellie touched me?"

Kate admits that her own faith has wavered at times over the last eleven years, watching Nellie endure countless painful procedures and violent seizures. On one particular night, Kate was feeling overwhelmed by the Sisyphean demands of caring for both Nellie and her two-year-old sister. She was irate with God and with what he had put on her plate. She shared a metaphorical description of what transpired on that night when she reached her spiritual nadir:

I thought, "How am I going to do this? How could God do this??" And I remember, it was storming. It was absolutely pouring rain. . . She just had her, like fiftieth seizure, and I remember thinking [whispered] "I can't do this." And I had walked by this window a thousand times. There was a tree right in the window. There was a nest, with a mother bird, full of about five babies. And she had puffed all her body up, and her feathers, and she had her head like this [head bowed down]. And she was completely puffed up.

And the water was just pounding down. But it was going over her, and not getting the babies. And it hit me. It hit me. God was answering my question of "How am I going to do this?" Was that mother bird sitting there, going "How am I going to do this, it's raining?" She was just doing what she *had* to do. She was a *mother*, she looked after them. She could do it. And it was very profound to me.

And I realized instead of sitting around going “Why me? Poor me,” *just do it*. She’s mine; I was given her. She’s got a lot of challenges. “Just do what you’ve got to do. You’re her mother.”

Kate’s faith was grounded in a belief that God sends us signs and symbols, if we are amenable to seeing and hearing them. Her daughter’s ability to touch others, a mother bird’s protective instincts—these talismans, for Kate, informed how she saw her caregiving role, and how she made sense of Nellie’s challenges.

Edith and Jesus, akin to Kate and Anna, volunteered that their strength came from their fervent faith—Catholic, in their case. Sprinkled throughout their interview were allusions to God’s place in their lives. Jesus credited God with putting “good people”—doctors, teachers—in Veysa’s life. Due to Veysa’s health issues, their attendance at Mass was often sporadic. (“Most go to church every week, but we go when we can. Sometimes we cannot go; there are weeks when we cannot.”) Asked if she had advice for parents who are just learning that their child has a significant disability, Edith responded, “I would tell them to have much faith and be strong, because God is always there to help you and He will find a way.”

Not all caregivers were as diehard their beliefs as Anna, Kate, Jesus and Edith. Janet did not mention religion as a source of support at all during our first interview. When I met with Janet and husband Raul in their home and asked direct questions about religion and spirituality, she equivocated:

We attend meetings. We go out. We have people that . . . I think that's where we get our support from, definitely . . . I think as a whole, that's kind of what keeps us strong, and keeps us happy, and hoping. It definitely is.

I continued to probe for specifics; neither spouse was forthcoming with religious details.

Raul filled in a few more blanks.

For our religion, you know, attendance is an important thing. You know, showing up for every meeting. It is an indication that you're serious. But because, you know, you never know what the situation is going to be with Anne Marie . . . it means we don't show up as often as other people.

And what the congregation has done, is like, they haven't been, "Well, you need to pick up your attendance." They haven't been like that. "Here's a number you can call." And we can call in and listen to the meeting so, we're able to call in if she's sick, or one of us is sick, we can call in and listen, or whatever, and they'll call to see how we're doing. Not to be critical, just to check on us and see how she's doing.

With questions phrased in a number of ways, I was finally able to draw out from Janet and Raul that they are members of a Jehovah's Witness congregation. It is unclear whether their reticence was born of a desire for privacy on the topic, fear of judgment on my part, or some unknown reason. While Jehovah's Witnesses were themselves a persecuted sect at one time in history,⁷³ other researchers have noted that the denomination has a history of secrecy, insularity, and subjugation of women (Braasch, 2010; Scelfo, 2002). The question must at least be raised: Could the Jehovah's Witness congregation (and by extension, Raul) be responsible for Janet's isolation from all

⁷³ See "Travel Advisory: A Holocaust Memorial," March 28, 1993, *The New York Times*.

outside support groups? Given her gregarious, bubbly nature, and with seven years having elapsed since Anne Marie's diagnosis, it is a disturbing riddle.

Both Brenda (Carter's mother) and Jackie (Troy's foster mom) came from families that attended church, and they enjoyed being part of church communities. Yet neither was able to carve out time to attend on a regular basis. Jackie, with her blended family of five children, found that time and exhaustion were the nemeses of habitual church attendance. With her usual candor, she made her confession:

Well, you know I wake up, roll over, look at that clock. "Oh . . . sorry, God! [laughing] Uh, missed that again!" Yeah, we have a strong faith, Art and I both, um, believe in God. We don't always present the best example to our children, but we try.

Yet Jackie's family does indeed have solid support from a faith community. Jackie's younger children spent a week at vacation Bible school just before our home interview, and she is grateful for church support.

Our church knows all about Troy. Troy's more popular at our church than we are. They know *Troy*, but they don't know *our* names. "Hey, Troy!" Everybody who comes by—"Hey, Troy!" "Has he been sick again? Haven't seen ya'll in a while."

Similar to Anna, Jackie indicates that she has a relationship with God that is personal and ongoing. As she is making the decision to bring Troy home to her family, she turns to her faith for answers:

“God, am I doing the right thing?” And I put that to prayer: “Lord, am I? Is this really what you want me to do?” And you know what? If this is the door that God wants me to open and go through, then I shouldn’t be worried about in ten years, he weighs 120 pounds, how I’m gonna handle it. If this is what God wants me to do, then He’s going to handle those things.

Given the onerous nature of Troy’s injuries at the hands of his biological parent, and the equally horrific rape of her daughter, Jackie is not willing to wholeheartedly accept her husband’s mantra that “everything happens for a reason, and that there is a purpose for everything.” She does see God’s hand in the positives that eventually flowed from the physical abuse visited on Troy, and the sexual abuse her daughter suffered:

I believe that God has a hand in those things. Now, that’s not to say that I think God approved of what happened to Troy. But I think that He is using that situation to show . . . that He is still here.

Brenda’s sparse church attendance (resembling Jackie’s) was not surprising, given her serious financial constraints. When queried about church, Brenda said,

Uh, I go to church when I can. [laughing] You know, since my mom owns a cleaning business, I kinda have to *work* . . . just when she *tells me* I have to go to work. Sometimes I don’t get to go. I actually have went to the church right across the street a couple of times . . . My dad’s always inviting me to go to his church. And my grandma is inviting me to go to her church.

Brenda’s lack of a handicapped-accessible van also turns any trips outside the home into back-breaking, time-consuming ordeals. Beyond the lack of church affiliation, Brenda does not seem to draw upon an inner spiritual center. She did not mention faith in any

of her responses; seven years of juggling parenting, schooling, and working, from her mid-teens onward, seems to have left her with little inclination for reflection.

While Kristin's life of financial security was outwardly the antithesis of Brenda's, they seem to be quite similar in their dismissal of an interior spiritual life. Kristin, just like Brenda, made no mention of religion until questioned during the second interview. She was complementary of the tangible supports given by their church when the twins were born. ("They did meals, and our minister would come by and visit, and all that kind of stuff.") But their church affiliation seemed to be driven by her husband's interest, not hers:

Larry is much, you know, he's much more involved than I am . . . So I think he seeks far more, he looks to religion far more than I do . . . So it's a much bigger part of his relationship. Certainly it's something I, um, can get behind, and I can expose my children to. But it's not part of what keeps me going, or provides me solace or gives me strength.

A church affiliation is something that Kristin will buy into, more for her husband's gratification than her own. She does appreciate the kindnesses that flowed their way from the minister and congregation when her babies were very small and sick. And for her boys, she sees value in offering the experience of a community of believers as they are growing up. But she firmly declared that a relationship with God is not a part of her daily sustenance.

As might be imagined, John, always a renegade, was an unabashed non-believer. He was not part of any church community, nor did he hold out belief in a higher power.

("Nah, I'm agnostic.") He even took delight in telling a story about his ex-wife's

abandonment of her faith soon after Johnsie was found to have Rett's syndrome:

I remember about six months after Johnsie got diagnosed, in 1994. I remember Annette, my ex-wife, who was brought up a good Southern Baptist girl. As was I—I was a product of the Southern Baptists. I rejected that, and became agnostic when I was about nineteen or twenty. But Annette had never said, "I don't believe anymore; I'm agnostic." But after Johnsie got diagnosed, the subject of God came up one day, and I'll never forget, she said, "I'm not speaking to the son-of-a-bitch right now." [laughing heartily] "Well, then! I've never even said that!"

But I understood completely. She was very angry with God, and I don't . . . I don't assign any blame or credit to God. If He exists, I'm sure He's got more to worry about than this. Or *She*. [chuckling]

But I'm not too worried about religion. And that drives me crazy when I hear people assign . . . say things like, "This was God's will, that my child can't speak," and "blah, blah . . ." I want to . . . it's all I can do not to . . . to *strangle* them! I hate that stuff really bad. This is not *God's will*.

John was on quite a roll; he was passionate about his beliefs – or, rather, his right to freely choose to be a *non*-believer, and to eschew the canon that Johnsie's disability is part of a divine plan:

And I just get angry whenever I hear people say, "I wouldn't change a thing about my child." I have to go away when I hear that. Because I'd change *everything* about my child. She didn't ask for this. She might be happy. She's a lovely little girl. But . . . she's so deficient in so many areas; it's so horrible. And anybody who can't face that, just needs to get a grip.

But you hear that a lot, and I, I stay quiet, when I hear 'um. I just . . . roll my eyes. And the whole religion thing, I just kinda roll my eyes on that, too. It's not about religion. *God* didn't do this, the devil didn't do this. Whether He exists or not, I'm not too concerned with right now. . . A *genetic mutation* did this. And I'm pretty

sure God did not say, “Yeah, I think I’ll punish . . .” Yeah, I *hate* that. I want to . . . I get annoyed.

Faith communities are without dispute mainstays for a considerable number of families who have children with disabilities. When those communities value and welcome—even celebrate—these parents and their children, the fellowship and spiritual communion can be a lifesaver. For other caregivers, it is not so much the fellowship in a specific building that is sustaining, but an inner spiritual life of prayer or conversation with God that provides nourishment. Some are candid enough to share that God is not part of their “toolbox.” The “unhinging” and subsequent conversion to faith described by Caputo is not universally experienced; perhaps no system of support is more intensely personal than this one.

Self-Care

Humor

One of the best uses of humor is its value in handling the stress of our crazy world. Laughter is a non-fattening, contagious, pleasant tranquilizer without side effects. It can help people live longer, healthier lives, and recover more quickly from stress-related illnesses. Humor provides counterbalance. It is an “inner upper,” a “mental recess,” an ever present safety valve, and one of the most effective stress breaks available. (Paulson, 1989, p. 65)

Anyone who has ever enjoyed belly laughs watching an old comedy rerun can attest to the healing, cleansing power of humor that Paulson extols. Building on research in other fields, disabilities scholars have examined how families of children with disabilities

employ spontaneous humor as not just a coping mechanism, but as a “decidedly positive human trait” (Jarzab, as cited by Rieger, 2004, p. 96) that allows caregivers to discern what others might automatically presume to be dismal circumstances in a positive light (Jarzab, 2004; Melnick, 1989; Rieger, 2004).

Finding levity in disability is a precarious endeavor. Albrecht (1999) reminds us that it “raises a hidden paradox that makes many people feel uncomfortable. What is so funny about having a disability when others think that it is a tragedy?” (p. 67) Yet he goes on to aver that disability humor can convey solidarity (“social glue”) within the special needs community, and redefine the tragic as inherently valuable.

What is humorous and accepted by disabled people in their inside world may not be understood by people in the outside world. Also, inside jokes add to disability culture by providing a bond to this minority or marginalized group; hence ‘crip humor.’ What they accept from their peers, they may not tolerate from others because of the perceived intent of the language or joke. (p. 73)

Those with disabilities, and by extension their caregivers, thereby have “insider status,” affording them the privilege of using humor as a cultural touchstone and a unifying language.

Rieger (2004) honed in on the use of humor in six different families that contained an aggregate thirty members. Through a series of home interviews and observations over the course of a year, she logged over a thousand pages of text, tallying nine different functions of humor in the participating families (all of which included a child with a disability). These included stress release, problem-solving,

learning, connecting, communication, defense, control, optimism, and playfulness. One parent put it succinctly: “You should make humor one of the commandments. You know? Thou shall always laugh, or something like that” (Rieger, 2004, p. 205).

Rieger noted as one of her study limitations the fact that her participant families were all highly educated, articulate, and financially secure. My research, then, built upon that of Rieger, as my participants were in fact quite diverse in these three dimensions. Humor did not have to be explored as its own question; in fact, humor seemed to course through the veins of the caregivers I interviewed. (I endlessly typed the word “laughter” as a descriptor throughout my transcripts.) Parents told funny anecdotes about their children; they laughed at their own foibles as caregivers; they even found humor in the darkest moments of their stressful lives.

Jackie, with meager financial means and the twin tragedies that befell Troy and Ashley, might seem least likely to find life humorous. Yet she exuded jubilation throughout both interviews. The futility of attempting to cram five children plus all of Troy’s equipment into their van for an overnight trip sent her into peals of laughter:

We went to [amusement park]. And, you know, [it’s] not far from us. But just to pack up, the first time we went, we had to pack the Pack N Play, and we had to pack the suction machine, and the feeding pump, and the . . . [She begins laughing.] You know, all of these things, and then the kids come out, and they go, “Where’s *our* stuff gonna go???” [She laughs harder.] There’s only so much you can fit in a minivan!

When she and Art tried to steal away for a camping weekend, leaving Troy with friends, he became ill with a fever. They immediately packed up the campsite and returned to town. Jackie turned it into a joke: “Troy didn’t like that [a romantic getaway]—No!! He decided he wanted *me* to come *home*!!” Jackie laughed repeatedly during both interviews at her lack of time, her disheveled house, and her limited funds; she radiated positivity.

Janet, similar to Jackie, punctuated her sentences with laughter. Her memory of an insult delivered by a thoughtless stranger who thought Anne Marie was “too old” to be diapered sent her into hysterics: “I just said, ‘Get the F--- out of my face!’” What must have been a hurtful encounter is turned risible, and recalled with mirth. She was amused at how people could be alarmed by such an innocuous child.

You don’t have to shield yourselves from them; they’re not diseases! [laughing]
It’s not catching! [more laughter] If DNA started catching, then, you know, we’ve got a problem for *everybody*, let me tell you! We got bigger issues! [yet more laughter]

When our second interview ended with seven-year-old Anne Marie precariously pulling herself to a standing position for the first time, Janet and Raul laughed adoringly. Yes, she could have easily fallen, and they now have an entirely new set of safety worries, but they chose to delight in her unexpected emerging skill.

Both Janet and Jackie dealt with tight finances. Anna, the study’s most financially secure participant, mirrored their positive outlooks and tendency to laugh at every turn.

A proud, strong-willed woman, she poked fun at her own aggressive behavior with doctors (“I don’t care if you put him in the parking lot, just figure out what’s going on!”), and her loquaciousness (“The Lord blessed me with a child who is not able to use words to speak, but He gave him a mother who *never shuts up!*”) She found an occasion to cleverly inject insider or “crip” humor into disability when she said that “Alex’s contribution is, he helps us with parking!” since their family can utilize “handicapped only” spaces thanks to his wheelchair.

John, who had children with both his ex-wife and his ex-girlfriend, relished poking fun at his own checkered romantic history. (“Little bit of a scandal!”) He admitted that humor aids him as a public defender:

Each trial lawyer has a certain style. And I’ve honed this style . . . over the last thirty-one years of practicing law. It’s kind of irreverent, but I kinda do a little . . . my style in court is sort of a stand-up shtick. Sometimes, even though it can be a serious matter, I’m a little light-hearted . . . I’m a bit of a joker, not a practical joker, but a quipper. Yeah, I try to be a funny man, a wiseacre, a smart-ass.

This devil-may-care attitude is uncanny, coming from a man charged with defending what some might describe as the worst that society has to offer: murderers, rapists, armed robbers. He approaches life with Johnsie in the same way, poking fun at his financial losses in the divorce. (“When we were married, we had a house in [vacation resort]. And after we *weren’t* married, *Annette* [ex-wife] had a house in [vacation resort]!”). He found humor in remembering a plaintiff in a disabilities trial. (“If you asked her what time it was, she would take forty minutes to tell you how to make a watch!”),

but more than any other catalyst for humor, he reveled in Johnsie's antics. Whether she "bellowed" in delight at a Broadway Lion King performance ("To the uninitiated, it can be something!") or starred in a July 4th parade as honorary beauty queen ("They had a sign that said, 'Miss Johnsie of [hometown] and [resort town]!'"), John found her enchanting at every turn.

Brenda spontaneously shared three stories about how Carter kept the both of them laughing:

He thinks cleaning is hilarious! He thinks that's the funniest thing in the world. Most kids are scared of the vacuum, and he thinks it's hilarious. I'll pull out the vacuum, and he starts squealing, and gets all excited! [laughing] Yeah, he . . . he definitely is a different kid!

He was laying [*sic*] on the living room floor one day . . . and he got his legs up on the corner of, on the edge of the coffee table, and just pushed. And he turned the entire coffee table over, with everything on it! [laughing] And laughed, the entire time I was picking it up, and I was like, "Carter, why are you laughing?" But I couldn't help but to laugh with him, because he was laughing, and it was so cute!

He was sitting in the back seat one day, and I didn't have the windows locked, and I was driving through [downtown]. And he, he reached over, and hit the button, and the window went down, and I thought somebody was trying to get in my car! [laughing] And I turned around and I was like [imitating a shocked, scared expression], and then I was like "Ohhh!! *You* did that!" [laughing]

Behaviors (squealing, turning over furniture, opening car windows) that would likely be annoyances for parents of typically-developing children are grounds for Brenda to rejoice; these behaviors are indicators of Carter's developing skills and increased interactions with the world around him.

Humor, for my research participants, was a stress-reliever and a safe outlet used to displace what could have been wrath or sadness in pernicious situations, cutting across all income levels and family configurations. More broadly, smiles and laughter were visible indicators of the positive mindsets that caregivers held toward their children with disabilities and life in general. In describing Norman Cousins's work exploring laughter's effect on physical pain, Naseef (2001) showed how humor can provide a bulwark against our psychic ills as well. He described laughter as "a metaphor for the full range of positive emotions including hope, love, determination, purpose, and a strong will to live" (p. 218). In the toolkit of caregiving, it appears to be indispensable.

Hobbies and Personal Pursuits

Caregivers' needs for leisure activities away from caregiving duties should not be trivialized in a discourse on support. Mainstays of personal respite can be uncommonly different in nature; some parents have found release in the act of recording their experiences in memoir form (Berube, 1996; Brown, 2009) or in collecting and editing the stories of other caregivers (Kamata, 2008; Soper, 2007). Others use physical exercise for emotional and/or physical rejuvenation, sometimes even incorporating their children into marathon, duathlon or triathlon activities.⁷⁴ For others, hobbies or other pursuits apart from the caregiving role (or special outings shared with a spouse, family member, or friends) provide a needed break from what can be mind-numbing work, even for the

⁷⁴ Dick and Rick Hoyt are perhaps the most famous example of this. The father and son have completed over 1,000 races, with Dick pushing son Rick (who has spastic quadriplegia and cerebral palsy) in a specialized running/biking stroller, or pulling him in a rubber dingy in swimming competitions. See <http://www.teamhoyt.com/about/index.html>

most dedicated and loving caregiver. Unlike other supports, there is little information in the literature about specific self-care behaviors, making this a noteworthy topic for discussion with my interviewees.

The participants in my research study did not initially volunteer information about their self-care activities. Whether it was their intense focus on their caregiving role or a desire to appear single-minded about these responsibilities, they needed specific verbal prompts to explore this topic. Most could identify one or more strategies they employed to ease their angst, although more than one readily admitted to neglecting his or her own personal needs due to time or financial constraints, or the perennial parental bugaboo, guilt.

For the caregivers in my study with demanding full-time professions, outside activities were rare at best. Neither John (public defender) nor Kristin (private school development director) had notable outside pastimes beyond work and their children. Yet both cited work as immensely rewarding and fulfilling in and of itself. John said,

I'm not going to be retiring! And I can't imagine doing it anyway. I'm a *young* sixty-three-year old, I believe . . . I like what I do. I run a good office, and I want to keep doing that. I couldn't imagine just sitting home.

His facility as a trial lawyer helped to fuel his passion for disability rights, allowing him to use his vocation to successfully defend (on a pro bono basis) families of children with disabilities seeking redress through the courts. Kristin admitted without inhibitions that work provided welcome respite time:

Being around kids with special needs all the time . . . three children under three isn't easy! Add into the mix, the whole, "I need to do this therapy and we need to practice eating now, and we need to be doing this, and we need to be doing that." And . . . that's a lot.

And I have to say, I don't have any interest in doing it twenty-four hours a day. I need that break. And I need to be able to, as much as I love my children, I need to be able to step away from the . . . For me, at least, I need that. I love the time I get to spend with my kids, I love my weekends, with them, but, on Monday? I'm . . . I'm ready for us to go our separate ways . . . So for me, I would say that work is somewhat therapeutic and restorative.

Other parents had decidedly quirky hobbies and interests that soothed their nerves and revived their energies. Jackie, as always, in a jocular mood, shared her unusual self-care secrets:

There's a couple things I do. I have a, a large aquarium that I maintain, that's got freshwater plants and fish in it. [laughter] And the fish don't yell, and they don't argue, and they don't . . . "She's not touching me!! She is touching me!! She's in my seat!!" [raucous laughter] They don't do that! So the fish and I can spend quality time together.

Also, video games. My husband says that, uh, people ask him, "Well, how do you maintain your sanity?" "I shoot zombies!" [laughter] You know, and the whole family, that's something that most of the whole family can get in on, play a video game together.

Even with her tight budget and the demands of single parenting, Brenda took time for herself, unwinding with exercise and sewing.

I have lots of hobbies and stuff I try to do. I learned how to sew when I was real young, so I, you know, sew stuff. And I . . . I bought a bike not too long ago. I like to go out and ride my bike, and I go to [local public trail] a lot, to just walk around. It helps me think, clear my mind, stuff like that.

Janet discovered reading to be an effective self-care strategy; she allowed herself to disappear into books for a short time, leaving her day-to-day concerns behind.

I usually don't tell a lot of people, but I'm dyslexic, but I have found that through trying to learn to read more, I can kinda escape my world a little bit, and imagine, and then kinda come back to reality. I mean, that might be odd, but that's just a way I can find things.

Kate says that looking after herself "is not my strongest point." But like Janet, she loses herself in reading, especially reading other caregivers' stories:

I really like to try and learn from what other people have gone through. I love to read, quotes and things about people who have gone through some sort of adversity, and made it to the other side.

As touched upon earlier, Kate also found a measure of serenity through writing about her own experiences. With her permission, here is an excerpt from a recent post on her CaringBridge (see footnote 72) page, in which she describes writing as a path to lightening her mood and burden:

There has been so much on my mind and so much going on ,that it's been hard to think much less write . I think taking the time to sit and write, actually helps me organize, sort through and clear out things that have been stressful or worrying. Writing isn't exactly an easy process. . . . I often avoid it, or feel self-conscious. If I try to sit, plan out or give a quick light hearted update it just doesn't come out . . . I go blank. When I continue to avoid it, things seem to continue to build and go round and round in my head and heart. I do find that if I just sit down and just let it flow out. . . . not think too much, that it does seem to ease /clear up things for me.

A very gifted writer once told me that your best writing is usually something you just do without much thought, when you don't hold back. When I have taken the time to write . . . everything seems to be lighter and brighter afterwards.

For other caregivers, travel is a form of emotional and physical hiatus. Anna and her family tapped into the Make a Wish Foundation⁷⁵ for a Disney World trip for the family as a maiden voyage.

It was a great vacation. It was the first time we'd done something like that. So, wow, we went to Florida! . . . We had front row seats to all the performances; we were first in line. And we haven't stopped since.

More road trips followed. Family treks centered on the boys' sports pursuits, and visits with relatives in neighboring states. As they gained confidence in their travel skills, the family began to take cross-country trips by plane.

So we learned how to run with things through the airport. So now when I ask for equipment [for Alex], I tell the people, "You have to make it so I can run through the airport with it. Not too cumbersome . . ." [laughing] I mean, it's like, if we're going from gate to gate, we have to be able to do this. And so with that, we now have this great wheelchair that does collapse!

Anna found travel to be an activity that could be shared by the whole family, with Alex snagging choice seating and parking as his special contribution. And by dint of Anna's tenacity with wheelchair and other equipment vendors, Alex's disabilities did not derail their efforts to see the country.

⁷⁵ Since 1980, the Make-A-Wish Foundation® has enriched the lives of children with life-threatening medical conditions through its wish-granting work. <http://www.wish.org/about>

Conclusion

Reading, writing, biking, traveling, studying tropical fish or “shooting zombies”—caregivers found strategies that renewed their spirits so as to approach their roles refreshed and energized. The array of tools in caregivers’ kits ran the gamut; whether it was the structured aid of medical, educational, or financial services, or the informal yet crucially-needed help provided by family and friends, caregivers’ emotional and physical stamina was buttressed by multiple supports. A spiritual axis (whether in community with others, or practicing a solitary faith) was salvific for more than a few. The underpinnings of humor were present in each and every case, without exception. Sources of support were as individual as the participants themselves. For some caregivers, a satisfying career provided reprieve from caring for their children; others found delight in idiosyncratic hobbies or communal activities. The common essence seemed to be that supports were accessible and utilized. While Kristin saw her toolkit as “chock-full,” and was disquieted by the plight of caregivers without her education and financial means, in actuality all of the caregivers had manifold supports that transcended traditional rubrics of security; no one stood alone. The bountiful backing of the community at large allowed all to thrive in their caregiving mission.

CHAPTER VII

PERSONAL AND COMMUNITY DYNAMICS: CHALLENGES AND TRANSFORMATIONS

Introduction

Chapter V introduced the eight individuals and couples in the study, offering a snapshot of their caregiving experiences. The mosaic of supports accessed by these parents was delineated in Chapter VI. In this chapter, I explore a farrago of systemic obstructions encountered by the caregivers, and how they responded to these challenges.

Safety nets can and do act to diffuse the difficulties inherent in parenting children with severe disabilities. Yet caregivers and their charges still, unquestionably, face a quagmire of personal and societal hurdles. Even though the eight caregivers (and caregiving couples) in my study self-identified as resilient, hopeful, and as agents of advocacy, they were not spared hardship. Some of these trials have already been identified within the support systems themselves; medical professionals, educators, religious groups, and even family members can be both hindrance and anodyne to caregivers. This chapter will explore some of the endemic realities that confront those whose lives are entwined with disability through caregiving: intersections of race, class and gender with disability, societal fascination with bodily norms, and the “dark days” experienced when planning for a future often adumbrated by fear of the unknown. The

chapter will close by illuminating how caregivers rename what many would label tragic circumstances as opportunities for agency and transformation.

Intersections of Race, Class, and Gender with Disability

Progressive and concerned citizens have, over the last half-century, entered into thoughtful discussion about how minority groups are marginalized or oppressed by those who seek to define them by (perceived) common attributes. The ability of gender, race/ethnicity, class, and sexual orientation to render individuals and entire groups as “other” has received copious attention in the academy (Cochran-Smith, 1995; Collins, 2003; Freire, 1970; McIntosh, 1988; Rich, 1986; Weber, 1998). Coursework and entire departments devoted to serious discourse on feminist theory, queer theory, and critical race theory have flourished, producing written and oral theses exploring these groups singly, as well as the multiple interstices of these positionalities.

Yet textual and literal conversations around the topic of disability, and how membership in this specific group above all others elicits negative societal responses, remain comparatively sparse and covert. As Garland-Thomson (2006) says,

There has been no archive, no template for understanding disability as a category of analysis and knowledge, as a cultural trope, and as a historical community. So just as the now widely recognized centrality of gender and race analyses to all knowledge was unthinkable thirty years ago, disability is still not an icon on many critical desktops. (p. 257)

Davis (2006b) likewise opined that “disability has continued to be relegated to hospital hallways, physical therapy tables, and remedial classrooms” (p. xv).

Even more than race, gender, sexual orientation or class, disability remains veiled, vaguely frightening, and somehow unmentionable. Much in the vein of Britzman's (1995) characterization of queer identity as something we "cannot bear to know" (p. 218), disability is out of the mainstream, a phenomenon marking others—not ourselves. Yet disability theorists are wont to quote this unsettling aphorism: "*We will all become disabled, should we live long enough.*" Many would snicker when we hear a person say something like this, considering it the ultimate in political correctness; it also happens to be true," says M. Johnson (2003, p. 67). Siebers (2008) couches this fact in even blunter terms:

In no other sphere of existence . . . do people risk waking up one morning having become the persons whom they hated the day before. Imagine the white racist suddenly transformed into a black man, the anti-Semite into a Jew, the misogynist into a woman . . . (p. 26)

The unique place that disability occupies in our common psyche means that it trounces all other identities; disability becomes the "primary defining characteristic" or "master status" (Couser, 2006, p. 399). The Latina woman using sign language, the gay man in a wheelchair, or the Black teen with a cane and service dog are marked, first and foremost, as disabled. But we would be prudent to heed the reminder from Crutchfield and Epstein (2000) that "the disability experience comprises continuums of various individual experiences among other spectrums of difference and identity—notably

those of race, class, and gender—that over the last few decades have recharged our national politics, universities, and art” (p. 8).

While I chose not to overtly address sexual orientation in my interview questions with the caregivers in my study, it can be incidentally noted that all of them were in stable, long-term relationships with someone of the opposite sex. For that reason questions surrounding GLBT⁷⁶ issues were not posited. The participants in my study did hail from a number of different racial or ethnic groups, but of the eight families involved, five were made up of White parents caring for White children. One couple (Raul and Janet) was interracial (Latino and Black) with a mixed-race child. Another couple (Jesus and Edith) was Latino, with three birth children. One caregiver (Anna) and her husband were both Black, also with three birth children.

Jesus and Edith did not openly address their status as Latinos, but their language barrier came up multiple times in the interview: attempts to communicate with doctors about Veysa’s seizures, their difficulties in buying a camera to record them, and barriers to obtaining a recommended medical video. Inimically reminiscent of Fadiman’s (1997) acclaimed non-fiction account⁷⁷ of a Hmong family’s inability to communicate with

⁷⁶ One of the most commonly accepted acronyms for Gay, Lesbian, Bisexual and Transgendered individuals. An excellent source of other frequently-used terms is available at <http://internationalspectrum.umich.edu/life/definitions>

⁷⁷ *The Spirit Catches You and You Fall Down* is a must-read for anyone concerned with barriers of culture and language in the medical world. It details an immigrant couple’s struggle to be understood and heard as their child’s severe epilepsy went undiagnosed and mistreated. (See references for detailed information.)

medical professionals due to language and cultural barriers, Jesus and Edith also fought to be taken seriously by Veysa's doctors.

Anna was galled by (bogus) assumptions about her poor attention to prenatal care, conjectures which she avers were based on her diminished status as a woman of color:

I'm walking in, and people initially judge me, because they say, "Oh, she has a child who is sick." How many times did I hear, "What did you do when you were pregnant?" "I didn't do anything!" and . . . and that's normal. I understand that.

As a Black woman in the upper echelons academically, socially and financially throughout her life, Anna wrestled with the implications when Alex's astronomical bills required their family to rely, for the first time, on government subsidy programs:

I grew up as a colonel's daughter. Being the child of an Army colonel taught me to command respect. I watched men salute my father – men of all races – and so I've never had a problem commanding that sort of respect for myself. And I . . . grew up well-provided for. So for me, as an African American woman, to have a child on Medicaid . . . was . . . humbling doesn't even quite describe it. So, whatever pride issues I had, I just had to let it go.

In Anna's case, race, class and disability intersected in jarring new ways. Her status as an educated woman of formidable means and confidence was trumped by the disability card, which can send financially secure families to the brink of poverty.

Janet and Raul experienced disparaging glances when out in public with Anne Marie. But Raul believed that the stigma of being an interracial couple in the southern

United States was actually a greater ignominy in the eyes of the majority culture than their daughter's disability:

People look at her, but I . . . I don't observe people as closely as you do [speaking to Janet]. And you forget, we're an interracial couple, so we never know why we're getting stared at [grinning]. If I see an older white guy, or an older white lady, I know why they're looking at us! [laughing] I feel like going, "You know I'm *Mexican*, right?" [He and Janet have a good long laugh.]

Raul (whose complexion is very light, and whose speech is unaccented) found humor in unexpectedly adding his own Latino heritage to the mix, making the specter of the interracial couple even more odious to any bigoted onlookers. Janet and Raul preferred to think that curious stares were not meant for Anne Marie, instead using their own minority status to absorb prejudicial looks that were, more than likely, also aimed at their daughter.

Passing . . . Or Not: The Myth of the Melting Pot

America has long been romantically described as a melting pot of cultural groups. This anachronistic notion of merged cultures, say Adams, Bell, and Griffin (1997), might have held sway when waves of German, Irish, Italian and Scandinavian families were arriving on our shores, but "ignores the continued exclusion of non-white groups . . . [and] automatically marginalizes those who can never 'pass' into the dominant culture by virtue of their race, gender, or other noticeable difference" (p. 10)

Blending in is not necessarily a straightforward task for many groups. Perhaps more critically, it is not, a priori, a desirable outcome, nor is it accomplished without heavy

repercussions for those who attempt to do so. Siebers (2011) talks of the “psychological and physical price paid by those who pass.” While passing may provide freedom from “curiosity, prejudice, economic disadvantage, and violence . . . these maneuvers may also exact a heavy toll on individuals, both mentally and physically, leading to psychological crises and secondary health problems” (p. 117). Siebers was speaking from a disability perspective, but her words could just as easily address others on the fringes of the mainstream: the closeted gay teen passing for straight who bullies gay classmates to avoid detection, or the light-skinned Black man who sees a swift path to promotions at work by abandoning his preferred corn-rowed hairstyle and African dashiki for conservative dress and grooming. Rich (1986) tenders this litany of passing strategies:

Change your name, your accent, your nose; straighten or dye your hair; stay in the closet; pretend the pilgrims were your fathers; become baptized as a Christian; wear dangerously high heels, and starve yourself to look young, thin, and feminine; don't gesture with your hands; value elite European culture above all others; laugh at jokes about your own people; don't make trouble; defer to white men; smile when they take your picture; be ashamed of who you are. (p. 142)

Rich ticks off her list addressing gender, race, and ethnicity, yet is eerily silent on disability. But in her defense, her words were penned as the disability rights movement was in its infancy, a full four years before the passage of the ADA.⁷⁸ Garland-Thomson, writing two decades later and through her own lens as a woman with disabilities, exposes the philosophical occlusions inherent in passing as able-bodied with this story:

⁷⁸ Americans with Disabilities Act <http://www.ada.gov/>

Some of my friends . . . have measured their regard for me by saying, “But I don’t think of you as disabled.” What they point to in such a compliment is the contradiction they find between their perception of me as a valuable, capable, lovable person and the cultural figure of the disabled person whom they take to be precisely my opposite: worthless, incapable and unlovable. (2006, p. 35)

In the twenty-first century, other minority groups are (mostly) spared this sort of banal rhetoric; it would be rare these days to hear the public declaration “I don’t think of you as Black.” Another phrase commonly used just decades ago—“He/she is a credit to his/her race” (Linton, 1998, p. 18) has been put to bed as similarly trite. But it is still acceptable, even high praise, to tell a disabled person that they don’t look, act, or appear to be . . . themselves. Shapiro (1993) recalls attending the funeral of a friend (who happened to have polio and used a wheelchair), at which more than one person commented from the pulpit that he “never seemed disabled.”

More than a few heads bowed with an uneasy embarrassment . . . It was as if someone had tried to compliment a black man by saying, “You’re the least black person I ever met,” as false as telling a Jew, “I never think of you as Jewish,” as clumsy as seeking to flatter a woman with “You don’t act like a woman.” (p. 3)

Passing has historically taken on many forms, what M. Smith (2006) calls “aesthetic and medical deceits,” or attempts to

pass as, or pass from, say, being a man to being a woman, or vice versa, from being straight to gay, or vice versa, from being black to white, or vice versa, and so on. . . . for the most part moving in a not unexpected direction: from a category of exclusion to a community of inclusion, from being an abject pariah to an object of desire . . . (p. 312)

For those with disabilities, these medical deceits can take the form of prosthetics designed for beauty rather than utility, so as not to offend the sensibilities of the able-bodied. Imagine, for instance, a woman who chooses to wear a rubberized, immobile arm instead of a more functional but visually jarring metal hook. For the Deaf, the desire to pass might compel someone fluent in the nomenclature of signing to attempt spoken English and lip-reading so as to assimilate into the dominant (hearing) culture, or to endure what some see as the mutilation of a cochlear implant. Brueggemann (2006), who herself passed in the hearing world until middle age, says,

I knew that there was a price for passing, that the ticket cost more than just a pretty penny, that the fear of always, at any moment, being “found out” was far worse than just telling at the outset. (Like telling a lie and having to remember who you told it to, who you didn’t.) (p. 328)

Passing confers privilege upon those who normally would be subjected to the prejudices of the dominant culture. People with hidden impairments, such as learning disabilities, epilepsy, AIDS, or a variety of syndromes or diseases may chose *not* to disclose their status, so as to retain able-bodied privilege. As the ADA states, you can be *considered disabled if people think you are*. Ponder this hypothetical from A. Johnson:

If you don’t have a sense of what privilege is, I suggest that you go home and announce to everybody that you know—a roommate, your family, the people you work with—that you’re a queer. Try being queer for a week. When it comes to privilege . . . it doesn’t really matter who we really are. What matters is who other people think we are, which is to say, the social categories they put us in. (2005, p. 35)

The promise of the metaphorical melting pot may have held true for waves of white European immigrants over a century ago, but for groups who can never pass as members of the dominant culture “by virtue of race, gender, or other noticeable difference” (Bell, 1997, p. 10), it is no more than a myth. At its worse, passing fosters an inner self-loathing, a buy-in to the notion that, in fact, the dominant culture is somehow intrinsically superior. Whether the normative culture is white, male, wealthy, straight, or able-bodied, the oppressed can and do internalize a desire to shed their skins, and belong.

For most of the participants in my study, passing (or, rather, helping their children to pass) was not a viable option. When dealing with severe disability, unmistakable markers such as wheelchairs, helmets, leg braces, and ventilators verify the handicapping condition for the able-bodied viewer. In two cases, however, parents spoke candidly of the momentary relief that could be purchased through passing. Kristin, with two-year-old Marc, was still able to present him in the public sphere as typically-developing.

I think it's easier to be the parent of a special needs child who's little, because one, *lots* of little children can't walk. And *lots* of little children can't talk. Or all two-year-olds throw temper tantrums, or throw things across the room, or hit the kid next to them, or do whatever. The “socially unacceptable” behaviors that often-times come with kids with special needs . . . get more obvious to the general public, the older the kids get. So, um, you know, at two and a half, yeah, he may not climb up the stairs quite as quickly as other kids, but I don't think it's . . . that glaring.

Since Marc's doctors are nonplussed when asked to predict where any particular child with 22-Q deletion will plateau, Marc may very well still be non-verbal, tantrumming, and unsteady on his feet as a grown man. But for now, while she can help Marc to pass as a typical toddler, Kristin is happy to do so, while at the same time realizing that the charade is temporal.

Janet, mother to seven-year-old Anne Marie, admits to propagating a faux picture of normalcy when she does not have the emotional energy to deal with a barrage of probing questions. Anne Marie, similar to Marc, has fewer physical markers for disability than some children.

Anne Marie has this face, where when you look at her, you don't immediately think she is disabled. 'Cause, you know, some disabled children will show it in their facial features. Like Angelman's [*sic*] syndrome,⁷⁹ or Rett's [*sic*] syndrome (see Footnote 19). There's distinguishing characteristics. "Oh, they have a disability." "Oh, that child has Down syndrome" (see Footnote 10). And you can tell by just looking. Anne Marie? She might fool you for a few seconds . . . or more.

Janet can only fully conjure this idealized picture of Anne Marie for others when her daughter is not physically present. She admits, with some glee, to at times creating a mendacious depiction of Anne Marie's functional level.

I mean, I hate to say this, and I'm sure every parent has done it, but there has been times I've just went to a place, and they'll ask me about my daughter, and

⁷⁹ Angelman syndrome (AS) is a neuro-genetic disorder that occurs in one in 15,000 live births. AS is often misdiagnosed as cerebral palsy or autism. Characteristics of the disorder include developmental delay, lack of speech, seizures, and walking and balance disorders. <http://www.angelman.org/understanding-as/medical-info/>

. . . I'll just play like she's normal, and that she's doing things, and there's nothing wrong with her . . . just to not have to tell my story. And I know it's a lie, but it feels so good! [laughing]

Sometimes I just don't want to explain the story. 'Cause you know the first thing, they're all like, "I'm sorry about that, what's this, and this?" [Looking at her wheelchair and braces] And sometimes I just act like, like it's normal. Like everything's normal. There's nothing wrong. She's seven, and she's really cute, and she's liking the boys, and yeah, she's being really picky right now, and she's being picky about what clothes she's wearing, and what clothes she has to wear to school.

I mean I just have these feelings sometimes. And sometimes if I'm not around them [gesturing toward Raul and Anne Marie], and I'm meeting somebody for the first time, and I know I'm not gonna see them again? I'll do that. And it feels so good.

The challenges of living with a disability are not unlike those faced by other marginalized groups. Whether it is stereotyping a Black mother as irresponsible in her prenatal behavior, stigmatizing those who must rely on public assistance, or bowing to the temptation to pass so as to circumvent disapproving glances, caregivers of children with disabilities, acting as proxies for their sons and daughters, experience the selfsame discriminatory practices as others who are on the periphery of privilege.

The Stare: Our Fascination with the Body

While disability theory rightfully questions and exposes the hegemony of able-bodiedness, we in fact live in a culture that worships at the totem of the body in its most flawless form. This reality puts those with disabilities, perhaps more than any other group, at a disadvantage when it comes to outward appearances. Feminist theorists have long held similar claims:

Women in sexist society are physically handicapped [and are] inhibited, confined, positioned, and objectified . . . It is possible to read the differential and pejorative treatment of women, as if it were a disability, on the surface of their skin, in muscle mass, in corporeal agility. (Siebers, 2011, p. 23)

How telling and disheartening that when searching for a synonym for “flawed,” the word “disability” was this author’s choice. The disabled body, much like the female corpus but to an even greater degree, is judged with disapproving eyes. Garland-Thomson (2006) states “both women and the disabled have been imagined as medically abnormal—as the quintessential sick ones” (p. 262). Just as impossible beauty standards lead women to seek a perfect form through cosmetic surgeries or self-regulation (starvation), the disabled person might seek reconstructive interventions to normalize his or her body in the eyes of the public, striving to eliminate disability or, at a minimum, disguise its manifestations. Davis (2006c) maintains that in our consumer-driven society, care of our somatic selves has become an industry unto itself, involving

a vast number of products for personal care and grooming, products necessary to have a body in our society . . . deodorant, hair gel, sanitary products, lotions, perfumes, shaving creams, toothpastes, and so on. In addition, the body is increasingly becoming a module onto which various technological additions can be attached. The by-now routine glasses, contact lenses, and hearing aids are supplemented by birth-control implants, breast implants, penile implants, pacemakers, insulin regulators, monitors, and the like. (p. 239)

It is intriguing that Davis co-mingles strategies for achieving attractiveness with those undertaken for health purposes. These twin ideologies—beauty and normalcy—mark both female and disabled bodies, sending members of both factions on an

inevitably futile mission to attain physical perfection in the eyes of men and/or the able-bodied, questing to be “nondisabled, deracialized, de-ethnicized” (Garland-Thompson, 2006, p. 263). We must, however, be on guard not to hastily dismiss the reality that some disabilities *do* in fact produce acute or chronic pain and suffering, which can at times be moderated through prophylactic or surgical interventions.

Though historically held up as an object to be admired and perfected, the female body—reminiscent of the disabled one—is seen as an inferior, atrophied version of the male figure. Dykstra (2001) recounts the story of Alice James, sister to famed 19th-century writers Henry and William, and her life spent in a sickbed despite an absence of evidence that she suffered from any concrete illness. Her story is representative of many:

The hallmark symptoms of neurasthenia—exhaustion, inertia, and hopelessness—in women . . . were linked to a susceptible feminine biology and thus became a problem not of society or civilization but of women’s bodies. The medical community deemed women susceptible to nervous exhaustion expressly because their unpredictable uteruses rendered their bodies especially vulnerable to disability. A woman was particularly at risk for neurasthenic symptoms when she overtaxed a fragile nervous system with intellectual pursuit. (p. 116)

James evidently had potential for literary greatness herself, but was cloistered in the sickroom to placate her brothers’ jealousies, Dykstra conjectures. Sadly, this bromide of “the weaker sex” has not yet been fully retired. Thus women (and people with disabilities) naturally share a healthy distrust of the medical community and how it deals with the body as inherently flawed. Women’s normal reproductive functions and natural

life cycles are treated as anomalous and unclean; pharmaceutical companies stand at the ready to treat pre-menstrual syndrome, post-partum depression, menopause, and any number of “ailments” that are routinely problematized.

Feminists also recognize the lack of privacy in medical settings as “a source of gender and sexual oppression” that “reifies gender differences and disempowers women” (Siebers, 2011, p. 143). Those with disabilities, too, find their bodies to be open season for public exploration and discussion by the medical community. Siebers (2011) goes on to describe the experiences of a disabled person at the hands of a variety of physicians:

Male and female doctors alike have experimented on me, and I never knew that experimentation was happening until later, sometimes years later. Rare is the doctor who explains procedures, let alone allows patients to question them. There seems to be no protected realm, no private sphere, into which the medical establishment cannot reach. (p. 144)

Whether the body is seen as a plastic entity in constant need of refinement, or as a site for illness and weakness, females and those with disabilities share in the fallout that results when others dictate the standards of beauty, normalcy, and health.

While the children themselves were not of an age or cognitive ability to be mindful of the disdain that their different bodies attracted, the caregivers in my study were uber-aware of the dyspeptic attention garnered by their sons and daughters. Many parents spoke at length about the unwelcome stares that were an unavoidable part of daily living. (“Mommy, what’s wrong with that baby? Mommy, look at that

baby!” is the refrain Jackie heard most often.) Brenda, a young single mom, aired her complaint:

It’s like one of the things that kinda aggravates me about when we go out in public, the kids that stare. And I’m like, “Parents should teach their kids that there are other kids that are different and not to stare at ‘um, and make ‘um feel different . . . They are kids, and they don’t know, but their parents should take some initiative, you know, to teach them.”

Kate, mother of Nellie, is in her twelfth year of dealing with public reaction to her daughter. She is quick to note, however, that incidents of staring and avoidance can be transformed into opportunities to educate.

The first thing that people do is, they don’t want to offend. Or they don’t want to say the wrong thing. So they tend to avoid you, um, and I think . . . I’ve learned it’s my job to make them comfortable with the situation. And realize, it’s OK to come over and talk to us. There are ugly stares, you know, and . . . I realized over time, when people stare, that I can be hurt by it, or I can use it as an opportunity to, to do something about it.

John, always the realist, knows that Johnsie (who at age twenty is diminutive, frail, and non-verbal but very vocal) is instantly recognized as having a disability. He deals with stares head-on, usually with good humor, but at times striking back stridently.

I’ll go out with Johnsie to restaurants, and to shopping, and stuff like that. And people will stare, and so far I’ve never had anybody offend me doing that. I know they’re curious, especially kids. I got mad at one teenager who turned around and looked at her a couple of times too many in a movie . . . well, Star Wars . . . I

did say something kinda rude to that fella, and I regretted it, and I thought, “I’d better get out of here before I do something bad!” [laughing]

I understand why people would, uh, look at her funny. She does get looked at funny, I mean, people are naturally curious. You see pity looks . . . I mean, people can tell. It’s noticeable, it’s visible, that there’s some kind of really bad . . . something wrong. And so I think folks are naturally curious, and naturally feel sorry.

John is generally not offended by stares; he sees this as a natural human reaction to being confronted with something or someone out of the ordinary. He finds no reason to squander energies by drumming up conflict with the curious and, with his penchant for forthrightness, prefers honest stares to sanctimonious smiles.

“The Trifecta of Suck”: Fears, Struggles, and an Obscured Future

All of my study participants chose to volunteer their time because they self-identified as hopeful, resilient, and as advocates for their children. Yet it must be recognized that even caregivers who seem to “have it together” experience hours, days, or even years-long periods of struggle. In the face of frequent stares and pitying looks, with disability as a social stigma stronger than any ethnic, socio-economic, or gendered class, these parents admitted to dark moments. (The group suicide plan suggested by John’s ex-wife after Johnsie’s Rett syndrome diagnosis comes to mind as a prime illustration.) Until recent decades, those dealing with disability were roundly described in the jeremiads of medical professionals and researchers as merely coping with a tragic set of circumstances (Guetzloe, 1991; Maes et al., 2003; Michelson, 2001; Parrish, 2010; Pipp-Siegel et al., 2002; Trute et al., 2007). In reality, this construct of disability as an

abyss of tragedy is now contravened by a robust number of studies to the contrary. But to paint a true and complete picture of the experience of caregiving, my study participants' dystopian dimensions must be included in the palette.

Kristin coined the phrase "The Trifecta of Suck" with acerbic humor, as she was absorbing the triple blow of Marc's premature birth, heart defects, and his genetic anomaly (see Footnote 31). She sought professional help early on while wrestling with the disappointments of failed fertility treatments, and continued to see a psychologist to ward off stress and depression after the twins' birth. Her greatest challenge was in dealing with the unknowns that lay ahead. There were anxieties about heart surgeries to come; the vagaries of the 22-Q prognosis gnawed at her. ("Yeah, I mean, nobody knows what our kids are going to do.") Janet, ever-smiling, off-handedly admitted "I missed out on a lot when I was depressed for the first [pause] three or four years of [Anne Marie's] life. I missed out on *a lot*."

Jackie, famously happy-go-lucky, admitted that it was at times a fragile façade. ("I don't always feel happy. I think that when I lived some of these experiences . . . it's not nearly as funny as when I tell it.") She divulged nagging doubts about her ability to maintain her current level of care for Troy. A non-mobile two-year-old is manageable; the notion of an older child in the same condition gave her pause:

He's getting harder to hold, and handle. And for lack of a better expression, dead weight. He is dead weight. And as he grows, it's going to be harder to do that. Everywhere we go, he goes. Can we maintain that? Can we continue that? Um

. . . I don't know, I don't know. And I've had so many questions about it, and I've had so much anxiety about it.

I question, sometimes, whether I can continue the level of care I give him, at the, um, I don't want to say consistency [pause] but at the, the pace, maybe? Or the intensity—that's the word. The *intensity* I put into it. You know, can I continue at that, at that intensity for the rest of his life, and not back down for the things he needs? 'Cause it's wearing! It's mentally tiring.

Jackie's concerns centered on her ability to handle burgeoning caregiving responsibilities as Troy invariably moves from toddlerhood, through childhood, and into adolescence. The knowledge that children with Shaken Baby syndrome oft-times do not survive to adulthood only compounded her worry. A reduction of family income as Troy's status changes from being fostered to fully-adopted amplified her unease.

Anna, as the seasoned parent of a teenager with disabilities, also fretted about the next steps for her son.

Now that Alex is getting bigger, we do have to think about things differently. Um, we just recently found out, a friend of mine, who is by training a social worker . . . she said to me, one day, she said, "What are you going to do when Alex graduates from high school?" And he was eleven at the time. And I said, "Well, I don't know. I've got plenty of time."

So last year, when he was fourteen at the time, last year we put in our paperwork with our CAP worker⁸⁰ and everything, and applied to the [adult care center] to get on their eight-year waiting list. And the next month we got a rejection letter. They said his needs were too great . . .

⁸⁰ Community Alternatives Programs. These programs provide home assistance in the hopes of keeping people with disabilities in a home setting, and out of institutionalized care. See <http://info.dhhs.state.nc.us/olm/manuals/dma/abd/chg/MA2280.pdf>

I read an article, I guess, I don't know if it was Ladies Home Journal or whatever, but it had an article about "Forever Parents."⁸¹ And it was a good article for me to read, because I said, "I know that there are other people like us out there . . ."

Anna and her husband are up against Alex's looming high school graduation, with no placement for him afterwards. They must grapple with a paucity of programs for adults with severe disabilities. Warehousing in nursing homes is the ultimate fear, and it is a realistic one.⁸²

John, by far the oldest of the caregivers, expressed the most heart-rending concern: that his daughter will outlive him. For able-bodied parents, this is generally a *fait accompli*, and a comforting fate at that. Yet for parents of children with disabilities, it is a reality that can induce abject fear. In a culture that clings to an oath of *omerta* when it comes to end-of-life issues, John's admission is both shocking and brave:

There's a significant possibility she could die tonight. But there's a larger possibility—probability—that she won't, and that she will live to be in her forties, and maybe beyond. Both . . . both those worry me, 'cause I'm 63. And, um, the last thing I'd want to see is her have to be institutionalized. And Annette [ex-wife] is not much younger than me, so it's worrisome to us.

I hope this doesn't sound too harsh, but it's my biggest fear that she will outlive me, rather than die before me. . . . I am one of the parents . . . I would be sad, but I would be OK.

⁸¹ I was able to locate this article in *Ladies' Home Journal*, November 2011. It can be read online at <http://www.lhj.com/relationships/family/raising-kids/forever-parents/>

⁸² See Swarns, R. L. (2013, September 30). After a Lifetime in Institutions, a Rocky Trail to a Group Home. *The New York Times*, pp. A1, A28.

John would rather deal with the pain of losing his daughter than worry that she might live on without his, watched over by caregivers with no more than a perfunctory interest in her wellbeing.

While John feared that Johnsie might outlive him, Kate was imbued with trepidation over the prospect of Nellie's death. Like Kristin, she sought the help of a counselor to sort out her fears.

Just recently, not long ago, I went to a counselor, because I thought, "Well, things are a bit rough, and I'm having a bit of sadness and stuff." I just felt like something was not quite right. I don't know, I guess I had a feeling of anxiety all the time? All of a sudden it just came out of nowhere. And I started thinking, "What if something bad happened to Nellie?" I was feeling that.

And I went to a counselor, and she predominantly works with children, with people who've either lost their children, or who have very sick children. When I first walked in, she just put me on the spot right away, and said, "Well, why are you here?" And I said, "Well, uh, I'm having a hard time." And she goes, "What . . . what's your biggest fear? What are you scared of?" And I said, "What am I scared of?" And she said, "I just want to know, right now, what are you scared of?" And I said, "Of Nellie dying. Of living without her. Because she is so much of my life. The thought of not having her . . ."

And she looked at me and said, "You're scared of her dying." And I said, "Yeah." And she said, "Well, let me tell you, she is going to die. I don't know when, but she is. It could be tomorrow, it could be ten years from now." And she said, "And you're going to die, and I'm going to die, and we're all going to die. That's out of our power. You can sit there, and worry yourself silly about when that time is going to come."

. . . And you know what? It almost gave me permission to go, "Yeah, she will die someday. But it's OK. Worrying is wasted energy. *It's wasted energy.* You can't say, "Don't ever worry." That's not, that's not even possible. But what I do is, I give myself a little time. "I'm going to worry about this, and then I'm going to get past it." And just be realistic with that.

Every parent's "Trifecta of Suck" took on its own form. One parent dreaded the inevitable death of her child, while, ironically, another feared that his child could potentially outlive him. Planning for a nebulous future brought on stress as parents realize that "forever parenting" was not just a magazine catch-phrase, but a likely scenario. Lack of quality community programs when severely disabled children age out of public school posed a dilemma, as did the physical challenges of daily caregiving when a growing child becomes a less-manageable adult. Looming operations and health care crises were additional stressors. Debunking the romantic canard of the eternally chipper and sainted caregiver, these parents acknowledged that they experienced dark moments. Yet all of the parents returned time and again to the positives that flowed from their caregiving role, circling back to a central theme of strength and joy.

Resiliency: "I Do What I Have to Do"

Resiliency has been conceptualized as "relative resistance to environmental risk" (Broberg, Blacher, & Emerson, 2009) and "the ability to withstand hardship and rebound from adversity" (Bayat, 2007). Researchers working with seriously disabled veterans have labeled optimism in the face of great physical and emotional challenge "post-traumatic growth" (Rendon, 2012, p. 43). Yet resiliency under trying circumstances is a phenomenon so ubiquitous that it is oft taken for granted. "The idea that people grow in positive ways from hardship is so embedded in our culture that few researchers even noticed it was there to be studied" (Rendon, 2012, p. 40). Some researchers in the field of disabilities have attempted to unravel this Moebius loop of a question: Are resilient,

positive caregivers hardwired for hardiness, or did the caregiving experience grow the trait? In a number of studies (Gerstein, Crnic, Blacher, & Baker, 2009; H. R. Hall, Neely-Barnes, Graff, Krcek, & Roberts, 2012; Heiman, 2002) salient factors for resilience were teased out (covered in Chapter II). Researchers acceded that resilience and adaptation are multi-dimensional constructs “complexly determined by a number of factors” (Gerstein et al., 991). So, apart from the overt supports that enhance coping skills, are there habits of attitude or qualities of spirit inherent in resilient caregivers, and do they (like the injured soldiers Rendon described) find their trauma experience to be uplifting and transformative?

Time after time, the participants in my study exemplified the transformative growth model that is now supplanting the specious argument that families of children with disabilities are damaged or traumatized by their experiences. Jackie, unique in that she actively chose to bring a child with a disability into her family, expressed her views on the matter:

As time goes on, and life still happens, you realize that your view on some things was changed. You realize that some things just aren't as important [pause] as they were before. And I try to hold on to that reality when dealing with Troy, and all of his stuff. And he grounds me . . .

For some caregivers, moving forward in a proactive manner involves accepting a new normal. Kristin stated it this way: “Our family's been dealt the cards it's been dealt. And [pause] it is what it is. We can't do anything to change it. All we can do is make the best

of it for ourselves.” Her second point was also echoed by others in the study; she refused to allow Marc’s disability to define their family: “Everything in our lives cannot revolve around Marc and his special needs . . . I think it’s really important that our family learn how to co-exist with Marc’s disabilities, as opposed to letting them direct everything we do.”

Janet said that raising Anne Marie “taught me a lot.” She related that “it [has] opened my eyes, for me to learn things. From other people, from other kids, what’s going on.” Like Janet, Kate found that her daughter taught her to celebrate small victories, and to never take her child’s milestones for granted.

Whether it was something so miniscule and small, it was just a huge joy for us. And I would start to look at other parents, who had typical children, how they were taking things for granted, the amazing things their children were doing, and they’re just like “Oh, they’re walking, oh, they’re doing that.” [spoken in imitation of a bored monotone] You know what I’m saying?

Whereas for us, it was a time to celebrate, “Oh my gosh, she sat up by herself!” “Oh my gosh, she put a spoon up to her mouth!” So I really think we were getting so much more out of having a child like this, than anyone else could ever imagine . . . So our whole perspective was changing, that we were really lucky. It wasn’t easy. But, that we were *lucky*.

Kate described her proclivity towards distilling joy from her circumstances. She made a conscious and deliberate decision to embrace Nellie just as she was.

You know, you choose your attitude. You do have power over that. You don’t have power over much in your life, but [pause] you know, you can choose that. And it’s not always easy, but you just have to keep doing it. And I don’t think I’ve ever, really, ever thought, “Oh my God, how am I going to deal with this?” Or,

“She’s never going to be able to do anything.” Never! You know, I’ve always strived much higher than that.

John explained how another (younger) lawyer in his office was unable to comprehend how he handled the stressors of caring for “a child like Johnsie” as a single parent.

John’s answer echoed Kate’s words about choices, as well as Janet and Kristen’s advice on playing the hand you’re dealt.

I have a good friend of mine, he just started having kids. He’s fifteen years younger than me, a young lawyer, and now that he has little kids, and he’s consumed with doing that, it’s just killing him to do that, he’s just, um, to see, [pause] to think what I [pause] to think about my daughter . . . And I was the same way. It seems impossible, but it’s not. It’s not even hard. Maybe it’s hard . . . Single, married, whatever you just [pause, voice choked with emotion] it’s your child . . . it’s not that hard. You just deal with what you have to deal with . . . I’m her daddy, and I’m in charge of making sure she has a decent life.

Parents spoke of how their children with special needs had positively impacted their lives and the lives of others. They spoke about paring away the trivial and treasuring life’s joys. They viewed themselves as the arbiters of their own attitudes, not victims of circumstance. And they reiterated the need to simply move on with the business of living their lives, rather than coveting someone else’s parenting or caregiving reality. Whether resilience is ascribed to the crisis event itself (and labeled as post-traumatic growth) or is born from a resoluteness of spirit, caregivers found that their roles were not just manageable, but utterly fulfilling.

Agency: Caregivers Fight Back for their Children and Others

A comprehensive discussion of caregiver agency and advocacy must include a provenance of past efforts. Prior to the 1960s, parents of children with disabilities were deeply influenced by the conventional wisdom of the day concerning protocol for care; expert opinion told them that these children were better off in residential facilities. While many acquiesced to the status quo, a subversive minority chose to raise their children at home, rooted in the community. Schwartzberg's (2005) narrative study of these few families who bucked the trend includes this account:

Lance was born in 1955. The pediatrician said he'd never progress, never learn anything, and I should put him in an institution . . . I couldn't have put him in an institution – I don't care how bad he was. Lance did learn things—to walk, and feed himself . . . He would surprise us with the things he would come out with. We were encouraged that this child could learn. (p. 86)

Beyond accepting their children as full, participating family members, parents also rallied to form charitable organizations, usually organized around specific disabilities. The Arc, for example, founded in 1950 by parents of children and adults with mental retardation, "has served in a pivotal position in terms of spearheading the national advocacy movement" (M. Wang, Mannan, Poston, Turnbull, & Summers, 2004, p. 144).

As the civil rights movement gained momentum in the late 1960s, parents realized that they too could conflate forces to insist on opportunities for their children with disabilities. The "normalization" or, more correctly-named "valorization" movement, first popularized by Wolfensberger, stated "not that their children would be

changed and made ‘normal,’ but that society would learn to accept, include, and appreciate their kids for who they were” (Schwartzberg, 2005, p. xii). Parents adopted the Wolfensberger model as their battle cry, initiating advocacy efforts aimed at creating a place at the table for their offspring in the public schools. This grassroots movement took a ground-up approach, as parents in individual communities and states fought for educational access. Witness this first-person account by a resolute Seattle-area parent of that era:

Yes, we’d go when [legislative] bills were being discussed that might provide more money for the handicapped. If we wanted something, someone in the group would write up a proposal and present it. Through the mother’s guilds we got as many people as possible to come. We had a calling committee. We would call people and bake a batch of cookies for a committee meeting at the same time. You just worked and ran after your kid and called people. I mean, it was chaos all the time. But it wasn’t too hard to get people to attend things because within our group of parents our lives were so hard; we all agreed it had to get better. (Schwartzberg, 2005, p. 95)

Baby steps toward rights for children with disabilities were indeed occurring, piecemeal, at the state and federal levels due to relentless parental pressures. But even though the Bureau of Education for the Handicapped was established in 1967 to train special education teachers and advance research in the field, the overarching ideology was still one of segregation and minimal services.⁸³

With impetus rising due to parents’ grassroots efforts, savvy parents were beginning to understand that a sea change in educational policy for children with

⁸³ Read more about this at <http://catsedu.org/earlychildhoodteaching/36.pdf>

disabilities would best be achieved through the courts. Building upon the transformative 1954 *Brown v. Board of Education* case clarifying that “separate cannot be equal” (Friend, 2006, p. 9), parents instigated a plethora of suits against public school systems inhospitable to children who did not fit the norm. This patchwork quilt of rights was finally stitched into a cohesive whole in 1974 with the passage of the landmark Education for All Handicapped Children Act (EHA), which directed states to create “full educational opportunities” for children with disabilities, and increased federal spending toward this end (Friend, 2006, p. 10). But it was the set of amendments to this law, Public Law 94-142 (passed in 1975), that became and continues to be the basis for comprehensive special education reform and practice throughout the United States.

Precipitously, parents had a potent mandate, an assurance that their children would receive a public education, gratis and tailored to their individual needs, in an inclusive environment. Additionally, they would have a voice in designing and refining the educational plan for their children. Parents were, for the first time, regarded as “persons who could insure that professionals would provide an appropriate education . . . No longer were parents expected to passively receive professionals’ decisions. Now, they were expected to make educational decisions and to monitor professionals’ decisions” (Turnbull et al., 2006, p. 109).

This legislation, coupled with Section 504 of the Rehabilitation Act of 1973, suddenly put parents on solid legal ground as advocates for their children with disabilities. (The Americans with Disabilities Act (ADA), passed in 1990, would later

increase this leverage exponentially.) Yet, as expected, prejudice, stigma, segregation and paternalism did not automatically “go gentle into that good night.” Parents’ efforts, out of necessity, now morphed; pressure was brought to bear upon schools reluctant to comply with these new laws. Obstacles to success were frequent and demoralizing. Reminiscent of the ugly laws of the early 1900s, one Wisconsin school system excluded a student with cerebral palsy from public education on account of his “depressing and nauseating effect on the teachers and schoolchildren” (M. Johnson, 2003, p. 181). Incredibly, the policy was upheld by the Wisconsin Supreme Court—a full *fifteen years* after the passage of EHA. In the face of such resistance, parent advocacy continued to be a clear and present need.

Not surprisingly, school districts and their employees at many levels were wary of the requirements of EHA. Boyer (1979) summed up a variety of professionals’ misgivings.

Alarm bells went off just about everywhere when Congress passed the act, Public Law 94-142, in 1975. Many school officials said the legislation asked too much too soon. Some feared that their regular classroom teachers would not be ready for handicapped children. There was also widespread concern that already tight budgets could not be stretched to provide the comprehensive services mandated by the act. (p. 298)

Right out of the gate, as children with special needs entered the schoolhouse doors, the relationship between parents and schools had the potential to be adversarial and even volatile. Teachers and administrators often balked at this strange paradigm of shared

control, with parents qua authoritative members of the educational team. And, to complicate matters further, parents were anything but a monolithic entity. As Kidder (2011) judiciously remarked, “Parent advocacy is a complicated beast” (p. 1). Some parents had financial and social capital, and some did not. Some came from groups either privileged or disadvantaged by their race. Trainor (2010), for example, speaks of “frustration resulting from disrespectful and prejudicial treatment among immigrant and African American parents” (p. 36). Other adults came to school with emotional baggage wrought by poor school performance or labeling in their *own* childhoods. Kidder (2011) reminds us that only a handful of mothers and fathers

speak the language of the education world—either literally in the case of English . . . or figuratively in the case of understanding the million and one acronyms that come with special education (i.e. “After your IPRC we might be able to provide you with an EA who will be able to deliver the support suggested in the IEP for your ASD child. If you’re not happy with that you could go to the SAC, or even MACS for more support or information.”) (p. 2)

Parents bombarded by this foreign tongue of educational jargon could rapidly reach overload. As an added challenge, the demands of raising a child with special needs (along with the law’s emphasis on individualization in instruction and planning) could mean that there was little opportunity for families to bond together in the interest of addressing shared problems as a collective advocacy group. As one parent in Nespor and Hicks’s (2010) study reported, “As a parent you’re so busy, you know, you really can’t go to war for anybody else” (p. 310).

Yet in spite of these barriers, parents persevered in pursuing the best interests of their children. An ever-growing assemblage of parents, working on behalf of their sons and daughters with disabilities, has been instrumental in the fight for justice and acceptance. The battle to have their children in inclusive classrooms is still one of intermittent skirmishes that have produced disparate results. And so, the push to enter the schoolhouse doors was won; now the fight continues to preclude the insidious process of “separating and then warehousing millions of young people that the culture has no need for” (Charlton, 2000, p. 33). Parents’ efforts to advocate for their children, built upon strategies of others who fought for disability rights (and, even earlier, civil rights), have been key in furthering social justice for these young people.

The caregivers in my research study all self-identified as advocates for their children with disabilities. Their chosen platforms and methods were as diverse as the participants themselves. John, as a practicing attorney, was the most imbedded in the legal processes of change. He served on a state-wide board which examined and prosecuted cases of discrimination. John retold the story of representing a family seeking a regular education setting for their daughter with a disability:

I can tell you about the time I sued the [south eastern district] schools on behalf of a little girl with Down syndrome. And the only issue was inclusion. And the position we took—this was 15, 16 years ago now—the position that we took is just so obvious now.

They didn’t . . . they were the new [name of school]. And they thought that was inappropriate [inclusion]. The judge decided it was quite appropriate . . . These people wanted their little girl, their little six year old girl to go to school with her

playmates. And, uh, I was amazed. This was 1996 or '97. I was hurt, shocked, I don't know what the word is. I couldn't believe the animosity in the courtroom between the family of this little girl and the school folks . . . I had done dozens of murder trials—death row cases! And I've seen the victim's family and the defendant's family in the same courtroom. And they didn't act like they disliked each other as much as I saw in that courtroom . . .

I couldn't understand, I couldn't understand why there was such a "circle your wagons" mentality about the whole deal. Anyway, it came out [the decision in favor of the family]. I thought the result was good.

While John had the skills and credentials to work for change in a courtroom setting, Kristen found her outlet as the local spokesperson (ambassador) for the March of Dimes. She explained how she felt called to advocate for others by raising funds and awareness for birth defects:

I think that when you've got a kid who's really sick, or has major developmental disabilities or something like that, all of a sudden you become this "accidental advocate."

. . . My family has had to circumvent this medical insurance, or this horrible NICU stay, or this whatever, and if I can make it so that another family doesn't have to do that [pause]? It's not just, you know, that I think it's a *good* thing for me to do, but I think it's really *my job* to do it. If I can help some other family from having to go through the same thing that I've had to go through, so be it. Or, if I can help make their journey a little bit easier, then it's kind of my responsibility to do that.

. . . Yeah, it's about my family, and it's about doing what's best for my kid. But if I can, if I can pave the way for somebody else while I'm at it, more the better.

Although Kristen's forte was polished presentations in public venues, Jackie was working behind the scenes in her own way for families of children with special needs. She did not

let the cap on her financial means or the time constraints of raising five children hinder her plans to advocate on behalf of other caregivers.

I quickly realized that, you know, there's a lot of equipment, a lot of clothing, a lot of things that the foster parents are having just to come up with. If you're called for a child, and you don't have a crib, you know [pause], you've got to go find something. And in my mind, I said, "You know that is just not acceptable! [laughing] 'Cause as many babies are born, and as many people who have clothing and equipment that they are willing to donate, um, we need a place that we can store that, and keep it organized, and have it available.

. . . So, you know, I'm trying to get, you know, someone to either cut me a deal at cost for a storage shed, or donate one to our cause . . . I'm all the time looking on Craig's List, for good deals. "Hey, I found us a shed!" [laughing] So, yeah, to me, that's a need in the community that needs to be filled. I wear many hats.

HIPAA⁸⁴ and FERPA⁸⁵ laws surrounding foster parents are currently stymieing Jackie's desire to share Troy's story publicly, but when the adoption papers are finalized, she has plans to take his story to as many people as possible:

Especially with Troy being a foster child, I have to be careful what I tell people at this point. But, once he is adopted, we have a plan to create a presentation, and start going to churches and schools, to educate about Shaken Baby [syndrome]. Once people realized that he was injured, that someone *did this* to him [her voice fades away].

A lot of times, the question is, they're like, "What's wrong with him?" And I say, "He has non-accidental head trauma." And it takes a few minutes to process that, and you can see the change in people's faces. It's like "You mean, he was

⁸⁴ The Health Insurance Portability and Accountability Act of 1996 (HIPAA) protects the privacy of individually identifiable health information. <http://www.hhs.gov/ocr/privacy/index.html>

⁸⁵ The Family Educational Rights and Privacy Act is a Federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education. <http://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

born OK?" [long pause] "Yes." "And somebody *hurt* him?" "Yes." And you can, you can see the wheels turning when you talk to people about that. Most people just can't fathom that somebody hurt that child. So I think there's a lot of education that's needed there. About how easy it is, especially a small baby like that, to hurt them.

While John, Kristen and Jackie were involved in community outreach efforts, all caregivers in the study were staunch advocates for their own children's welfare. Parents seemed particularly disposed to share stories of standing up to those in positions of power—most often doctors and other health care professionals. After a year of experience with the mechanics of Alex's care, Anna did not brook condescension from medical residents still wet behind the ears.

I would tell them when they walked in, with their confidence, I'd say, "I've been in the NICU longer than you have. If you want to impress somebody, go call your mother. 'Cause this is how we're gonna do this." And they were just like, "Oh, my gosh." I'd be like, "You're my third hospital. In less than a year. I've been out there more than you have."

. . . And I say, "No, no, no. Your job is to read his file before you walk in. I will tell you what's happened from his last appointment to today. And then, if you need more information, then you need to go do your homework." And it takes people aback, because, "How can she say this?"

Anna's fractious style may not have won her any civility points, but her goal was to secure the finest care possible for her son, and she did so. Much in the way Anna did, Brenda, just twenty-four, challenged doctors who had placed her son Carter on a dosage of seizure medications that had left him lethargic and unresponsive.

Well, at one point, he was put on a, kinda a new medicine . . . And it was making him very, like, zombie-like. He didn't, you know, move his arms a lot, he didn't do much. And, um, I mean, I did not like the way it was makin' him, and his seizures just kept gettin' longer and longer.

. . . So, um, they put him actually in the seizure unit, and wanted to see his seizures. And he didn't have a seizure. They made me *not* give him his medicine, because they were trying to get him to *have* a seizure. And he didn't have a seizure all day. And I was like, "*Hellooo?* [laughing] Is this not a sign that, you know, that maybe the medicine is causing, at least causing the seizures to be *worse?*"

. . . He didn't have a seizure for two weeks afterwards. And I told his doctor, "I don't care, he is *not* going back on that medicine. And after that [his teacher] saw it, everybody saw it. He just, like, came back to life. He started playing, and moving his arms, and he was more awake and aware, and he was watching people, and watching things, and [pause] it was just *amazing!*"

While some might doubt the acumen of a tyro with no formal training who seemed to blithely override the decisions of experts, Brenda's instincts were correct, and Carter was a "brand new child" after the seizure medication was eliminated.

Every caregiver had an advocacy story to tell; some have been shared in previous chapters. Edith and Jesus were relentless in securing quality care for both of their children with disabilities, despite language barriers and the strains of a cross-country move. Kate (with her older daughter's coach) educated an entire team of adolescent girls about disability and inclusion. John, a lone male in the female-dominated world of support groups, lent his talent for persuasion and oratory to the Rett syndrome foundation for years. Anna, ever the outspoken one, told one last story of stepping up

to educate the public about preserving wheelchair accessible parking at sporting events for its intended purpose:

We are out and about. We're helping other families that have typically developing children to see how a family with special needs can make it. And we tell people, clearly you know, when we go to these ball fields, and they meet Alex and what have you, and we say, "This is the reason why we need for things to be wheelchair accessible." When we see somebody park on the lines, we stop them, and we say, "Do you know what the lines are for?" And they say, "Well, I didn't park in the space." And I say, "Well, no, but if somebody needs a ramp to come out for a wheelchair . . ." So, we just walk around, kind of educating people in our own way.

And so the caregivers in my study, and others who are raising children with special needs, will continue, *must* continue, to "make noise." Some will contact their legislators or school boards, some will join advocacy organizations, create blogs, sit on boards, or raise funds. Most—comparable to this mother interviewed by Hess, Molina, and Kozleski (2006)—will be tireless advocates, day in and day out, for their children.

You will see me frequently, you may come to the point where you hate to see me. But if you need something, let me know. I will go to bat to get whatever you need. If it's computers for your room, if you need help, whatever you need, I will be there helping. I will stand up on the table and scream until somebody hears me. (p. 153)

We whose lives intersect with disability—whether professionally, personally, or both—must remember above all to listen to those dedicated parents who are "standing on the table screaming," asking that we bring their children into the schoolhouse and the larger community as full and valued members of the human family.

Conclusion

About a year ago, a local reporter was invited by a non-profit director to visit my building and write a story about a dedicated educator with a career that spanned forty-plus years teaching children with disabilities. A quiet and reserved woman, the teacher was reluctant to participate but finally assented, since it would mean a chance for her students to shine in the city newspaper. On the crisp October morning that the story was published, I stood in my driveway scanning the front-page text and photographs, with a building sense of horror and rage.⁸⁶ The children were described as having “wild and wobbly spasms.” One child’s “contorted face” was cited; another’s “grunt-scream” was highlighted. Worst of all, this esteemed educator was called out as having “a twisted hand and an awkward gait”—information that was gratuitous and superfluous. The aftereffects of the teacher’s childhood stroke had never impacted her distinguished career.

How does this disturbing story relate back to the challenges faced by caregivers of children with disabilities? It illustrates with mind-boggling clarity that some of those who live in the able-bodied world stand ready to reduce children with disabilities (and their caregiving teacher as well, in this case) to their “defective” parts. All of the challenges outlined in this chapter were there, wrapped up in the reporter’s warped vision of what he *thought* he saw: bodies outside the parameters of expected norms, as well as children and instructor unable to pass, portrayed as cultural curiosities. (The

⁸⁶ The article, entitled “They Have Become My Family,” can be accessed at <http://www2.journalnow.com/news/2011/oct/23/wsmain01-they-have-become-my-family-special-needs--ar-1528823/>

teacher was thrown a misogynist curve ball to boot; the reporter objectified her as a barren, lonely spinster.)

Caregivers and their charges, even in an environment rife with supports to boost their efforts, must still move about in a world that subjects them to stares, pity, and a charitable mindset. It demands tremendous resilience and a heart for advocacy to push back against this troglodyte of a reporter and those like him, so that children with disabilities and those who love and care for them can go about the business of leading joyful, productive lives.

As a coda, I should share that I made my own stabs at advocacy. I called the reporter, and explained to him calmly and rationally why the article was offensive to those of us who work in the world of disabilities. My entreaties fell on deaf ears; he was smug with a colonizer's apocryphal confidence that he had presented these unfamiliar "natives" accurately to his readership. I took my concerns to the human resources department of his employer, with no immediate results. But I have noticed, over the last few months, that this reporter's byline no longer appears in the local paper. Perhaps I was not alone in my complaint.

Sadly, there is much work still to be done; challenges remain in unlocking minds and doors. But there are parents, caregivers, and others in the community up to the task of pushing back against the ignorance and ugliness of exclusion.

CHAPTER VIII

NARRATIVE AS IMPETUS FOR ACTION: NEXT STEPS

Introduction

Without a doubt, the central thrust of my research was to bring a constructivist's head and heart to the telling of caregiving stories. Through narrative inquiry, I sought to cede these mothers and fathers center stage, where they could share (with as little interference from me as possible!) their tales of hope, resilience, and advocacy.

While I believe that these stories stand on their own as guideposts for medical and educational professionals as well as for other families of children with disabilities, I would be remiss if I did not tie the recurring themes voiced by the participants to larger issues at hand today. Ethnographic research undertaken without at least a nod to critical research runs the risk of being no more than a tourist's souvenir, shelved and forgotten. If the researcher's aim is only to describe things as they are, there is a missed chance, as Merriam (2002) says, to "critique, and challenge, transform and empower" (p. 327). Sandlin (2002), like Merriam, urges the researcher to "point to positive possibilities and articulate a better, more just, vision of the world" (p. 371).

Recurring topics surrounding both supports and challenges echoed throughout the narratives of my participants, and were recapped in Chapters VI and VII. To ask the questions alluded to by Merriam, Sandlin and others (Glesne, 2011; Hatch, 2002;

Lichtman, 2010), some of these issues bear revisiting. It is one thing to privilege the stories of caregivers. It is finer and bolder ambition to add a call for social justice to the research aims.

Health Care and Social Safety Nets

The eight caregivers and caregiving couples highlighted in my story were all able to access, to varying degrees, federal and state health care and financial aid programs. In a political climate increasingly unfriendly to social programs, these parents were prime examples of how tax dollars strategically spent “upstream” save money in the long run. It is noteworthy that all eight participants were gainfully employed. In the narratives involving married caregivers, either husband or wife worked full-time, and in two cases both partners worked forty hour weeks. Caregivers’ ability to work was, in many cases, dependent upon the home health care services provided through CAP-C or CAP-MRDD. Without these nurses or CNAs in their homes, John, Brenda, and Kate would have been forced to either institutionalize their children or quit working; either prospect places added burdens on government safety nets. Yet Congress continues to insist that Medicaid benefits should be the purview of the states, essentially issuing unfunded orders that lead to the inevitable gutting of services.

Supplemental Security Income (SSI) payments helped all families in my study to offset the financial strains of raising a child with a disability. For Brenda, these monthly checks kept the lights on and the pantry stocked. Yet Congress continues to place this

particular program on the chopping block. Shriver (2011) gives an impassioned argument for maintaining these funds:

SSI is not glamorous. But it is necessary. It's a critical lifeline for children with severe disabilities and their families. What's at stake in cutting it is nothing less than our core values—not to mention our nation's commitment to providing a full quality of life to those who face the most significant challenges. (para. 4)⁸⁷

Other funds specifically targeting children with special needs—early intervention dollars for infants and toddlers, stipends for the fostering and adoption of children with exceptional needs, respite care programs, and the like—may appear to be low-hanging fruit to legislators. But decisions to keep or cut such programs are, as Shriver pointed out, measures of our moral valence as a society. Early intervention has proven time and again to be a critical factor in ameliorating a variety of disabling conditions (Friend, 2006; Jimenez & Graf, 2008; Turnbull et al., 2006). Respite and fostering/adoption assistance could only be considered “frills” by the most hard-hearted of legislators.

Affordable and reliable health insurance (the bane of financial stability for millions of Americans), was an unremitting worry for the caregivers in my study. Even the most financially secure participants—Kristin and Anna—spoke of juggling policies when their children's surgeries pushed the tab for their care past lifetime deductibles. Worse still, families told of being summarily dropped from their companies' rolls. For caregivers of more modest means, Medicaid filled the insurance gap for their child with disabilities (and their siblings), but left adults uncovered. Edith and Jesus along with

⁸⁷ The full article is available at <http://www.politico.com/news/stories/1211/70439.html>

Janet and Raul chose to spin the roulette wheel and remain uninsured, finding the costs of their coverage in the private sector prohibitively steep. If Americans *without* disabilities are uneasy about a health care system whose “free market” underpinnings have left scores uninsured or underinsured, with no promise of continuous coverage, imagine the anxiety of the parent who counts emergency room visits and surgeries as normative, not the rare exception. Those who disparage universal health care likely have not considered the medical and financial realities of a family dealing with disability. This alone is reason to take up the banner to maintain and expand the Affordable Care Act.⁸⁸

Medical insurance and government social programs are not the only safety nets under attack. America’s public schools, charged with educating *all* children but specifically called to provide a free and appropriate education (FAPE) for children with disabilities, are increasingly vilified by conservative factions. Charter schools and vouchers that allow families to opt out of the public system erode the current public model, drawing off critically-needed dollars for each student enrolled in a private setting. Perhaps even more unsettling than the financial costs of the push to privatize education are the human costs. The diversity that is a hallmark of the public schools (if not always perfectly executed) is undermined when families abandon settings where children of all

⁸⁸ The federal Patient Protection and Affordable Care Act (P.L. 111-148), signed March 23, 2010, as amended by the Health Care and Education Reconciliation Act, signed March 31, 2010, is also referred to as the Affordable Care Act (ACA), or simply as “federal health reform.” Provisions included in the ACA are intended to expand access to insurance, increase consumer protections, emphasize prevention and wellness, improve quality and system performance, expand the health workforce, and curb rising health care costs.

ethnicities, income levels and abilities learn together. All of the children in my study, ages three to twenty, were enrolled in public schools; their educations were comparatively expensive because of the low teacher-student ratios and therapies (occupational, speech, physical, hearing-impaired, visually-impaired) that were needed to help them access the curriculum. A public school system increasingly stripped of funding as tax dollars are siphoned off by private and parochial ventures cannot preserve quality education for all. As Shriver earlier implied, it is an ethical question—a marker of our fundamental values. Does “every man for himself” become our national slogan, or do we believe that we are, in fact, our brother’s keeper?

The Inclusion Conundrum: Segregated Spaces

A discussion of the inclusive nature of public schooling (versus private options) leads to another quandary with no simple answer. While America’s public schools are under legal directive to welcome and educate all students regardless of disability, many times these students are housed in segregated spaces. The “separate but equal” race polemic that was officially discarded after *Brown v. Board of Education* lives on in our public schools for children with disabilities. All of the children in my study were in settings that provided for few interactions with typically-developing peers. The preschool/elementary site had a small “reverse inclusion” program, but for preschool and kindergarten only. The middle school children were in a building adjacent to “regular education” and gifted children in the middle grades, but sustained, meaningful contact between the groups was not reported. Similarly, the high school students in my

research study were on a newly-minted state-of-the-art campus that also served teens without exceptionalities, but students with disabilities were housed in a detached wing.

While many parents work hard to change these divisive practices, the caregivers in my study were earnestly supportive of separate schools. Brenda moved across county lines because the students in Carter's first class were *too* high-functioning; she did not feel his teachers understood his severe disabilities. John liked Johnsie's protected setting among other students with multiple disabilities.

Let's face it. They're separate schools. And that's fine . . . She's in a class with nine disabled kids, and three teachers, and she's had a very good year . . . I wouldn't want her at a high school with gangs and boys, all that crap going on, 'cause I'm her daddy and I want her to be safe and happy.

An inclusive experience is of less consequence to these parents than safety and specialized instruction. The solidarity and camaraderie found in a community of like-minded families is reassuring. This stance, while to some a puzzling koan, is not without precedent; many other minority groups within and outside of the world of disabilities cherish their separate status. Deaf culture especially stands as an avatar of the yearning to maintain a unique identity (Baynton, 2006; L. H. Cohen, 1994; Longmore & Umansky, 2001). But there is a difference between *choosing to be apart*, and *being placed apart*. The sticky question of how and when to include children with profound disability into all classrooms has not been fully explored.

Segregated special needs education tucked away within a system of “schools for all” is only one piece of the inclusion maze. The caregivers in my research study continually ran up against other public spaces that only welcomed their children if they could conform to normative behaviors and appearances. John’s ex-wife brazenly fought back, taking Johnsie to a Broadway performance of *The Lion King*. Other parents ventured to Disney World, religious services, restaurants or movies, and were consistently met with stares or even verbal reproaches. How do we begin to extend the promise of full societal inclusion to people who may not look, sound, move, eat or even breathe like “the rest of us?” It is only through continually pushing against comfort zones that these antiquated notions of restricted access and acceptability can be put to rest. Compounding the task, ADA requirements for full physical access to public spaces are only satisfied when court challenges are mounted.⁸⁹ Many arenas of public life remain out of bounds to the disabled due to the passive resistance of those with the power to create the access; stores, movie theatres, restaurants, amusement parks – these and other spaces often are off-limits, and will remain so until taken to task by concerned citizens.

Redefining “Normal”: Can a “Cure” Mentality Truly be Discarded?

Chapter III told the story of the gradual transition from a charity mindset of disability (“those poor people”), based on a medical model, to a social model, in which the environment, not the person with a disability, is seen as deficient. Disability

⁸⁹ See M. Johnson’s (2003) excellent treatment of ADA challenges, *Make Them Go Away: Clint Eastwood, Christopher Reeve & the Case Against Disability Rights*. (Reference list contains complete information.)

theorists' swelling body of literature insists that those with disabilities are not incomplete, but simply part of a celebrated array of human difference. The caregivers in my study would likely have a heated and volatile discussion if gathered together to debate the merits of these models.

For some caregivers, such as Brenda and Anna, imagining their children free of disability is unthinkable; they believe them to be perfect as they are. For others, notably John and Kate, disability is not seen as an illustration of diversity, but through the medical model. Given the choice, they would trade their children's disabilities ("in a heartbeat," John says) for normalcy. Much in the same way that the fight to cure cancer is not questioned by society, these parents see their sons' and daughters' conditions as unfortunate, life-limiting afflictions to be remedied if at all possible. Barnbaum's (2008) blunt assessment captures this ethos: "Heart disease kills, and paralysis prevents you from moving—nothing about society will change these facts" (p. 153). While it is tempting to glom onto the theorists' social model perspective, I would argue that no one has the right to speak for an individual parent on this issue.

Larger ethical questions come into play as medical technologies advance. We tend to bristle self-righteously at the eugenics policies of the previous century, yet geneticists today can identify many disabilities in the womb, allowing parents to screen for (and eliminate, if they desire) "defective" offspring. Would the world be a better place without disability? What would be lost, for example, if Down syndrome disappeared? Davis (2006c) points out that

it is possible to imagine a world in which disability decreases from 15 to 20 percent of the population to just 2 or 3 percent . . . Indeed, political issues aside, the possibility does exist of cures for many impairments that now define a group we call 'people with disabilities.' (p. 238)

Whether one adheres to a cure model or embraces disability as the new normal is a highly personal decision. Davis (2006c) concurs, calling disability an “unstable category” (p. 237), more slippery than gender or race (although admittedly categories involving human diversity are rarely, if ever, static). The decision to embrace or rail against disability is best left to those doing the “heavy lifting” each day: the eight caregivers and caregiving couples in my study, and those like them.

Embracing an Ethic of Care

These convoluted societal enigmas of inclusion and equity surround those who live with disability, and hence impact their caregivers as well. Questions of access to affordable, guaranteed health care, along with educational and social safety nets, will continue to be debated. Philosophical and ethical schisms will perhaps become even deeper as medical knowledge (deciphering the genetic code, for instance) grows more sophisticated. But at the crux of policy debate rests an essential question: what innate value do we collectively place on those with disabilities, and on the act of caregiving? More critically, what do our responses to the call for care for the disabled (whether with our tax dollars or our own energies) say about us as citizens and as human beings?

There is a community that presents a most surprising rejoinder to the question of how we valorize disability. Siebers (2011) relates the unusual story of a Belgian city which, in 1430, created an infirmary for the treatment of mental disability:

. . . the facilities soon proved inadequate to the influx of people seeking a new home, and the arrivals began to board with the people of the city. In this way the population of Geel became accustomed to the mentally disabled and accepted their presence among them as a point of pride . . . The presence of mentally disabled people was so common that mental impairment lost its stigma, and the people of the town embraced the boarders as citizens of Geel.

. . . the disabled people were not only Belgian; among them were found Dutch, French, English, Spanish, and Russian boarders. Others came to Geel from Chile, China, and the United States . . . In 2003 there were 516 boarders living with 423 families.

In the psychological literature . . . Geel has become a model for community-based mental healthcare. Though the number of boarders is now small compared to previous years, Geel continues to display practices and attitudes that make it a community ideally suited to receive fragile, vulnerable, and disabled people. Inhabitants of the city acknowledge and accept the human needs of the boarders, respond to those needs rather than act on unfounded fears, and recognize new arrivals as members of their community. The townspeople know the boarders by name and know where they live. The entire population protects, apparently without regard for its own interests, the members of their community least likely to be accepted elsewhere. (p. 186)

Geel, a haven for people with disabilities even to this day, provides a roadmap for how societies should respond to members least able to care for themselves.

A number of ethicists, philosophers and others (Appiah, 2006; Bauman, 1995; Belenky, Clinchy, Goldberger, & Tarule, 1986; K. Q. Hall, 2011; Rorty, 1999) point to our treatment of the poor, elderly, and disabled as the central measure of our ethics.

Bauman (1995) labels this as “being for,” or a “frame of sympathy, of the willingness to serve, to do good, to self-sacrifice for the sake of the Other” (p. 60). This is similarly upheld by Appiah (2006) as “cosmopolitanism . . . the notion that we have obligations to others, obligations that stretch beyond those to whom we are related by the ties of kith and kind” (p. xv). Rorty (1999) sees moral progress as “a matter of increasing sensitivity, increasing responsiveness to the needs of a larger and larger variety of people and things” (p. 81). All of these perspectives place caring for others—*the Other*—at the nexus of moral behavior, just as the citizens of Geel have quietly done for centuries.

Feminist literature provides another abundant critique of the ethic of care. While on one hand Belenky et al. (1986) somewhat derisively maintained that “women are drawn to the role of caretaker and nurturer, often putting their own needs at the bottom of the list, preceded by other people, husband and children” (p. 77), the authors also recognized that women “strengthen themselves through the empowerment of others,” in knowledge of the fact that “it is the act of giving rather than receiving that leads them to a greater sense of their capacity for knowing and loving” (p. 47). More recently, K. Q. Hall (2011) espoused the “feminine ethic of care,” whereby “caregiving is a moral benefit for its practitioners and for humankind” (p. 29). It is no accident that eight of the ten participants in my research study were females. Our society (and societies worldwide) has largely relegated the caregiving role to women, both in the home and the workplace, with a low- or no-pay return and a low societal valence. But if

we turn to the philosophers who position caregiving as the pinnacle of moral behavior, the role is transmuted into the highest of callings.

Without exception, the caregivers in my study drew joy and satisfaction from their responsibilities. Like the denizens of Geel, they saw nothing remarkable or saint-like in their behaviors; they neither complained nor boasted. Some drew connections between their faith and altruism—“the least of these” in Biblical terms⁹⁰—while others simply spoke of doing the “right” thing. All would concur with Sieber’s (2011) challenge to us in our dealings with disability:

What difference to human rights would it make if we were to treat fragility, vulnerability, and disability as central to the human condition, if we were to see disability as a positive, critical concept useful to define the shared need among all people for the protection of human rights? (p. 180)

Conclusion

How society responds to those with disability, whether through financial supports, educational opportunities, or medical interventions (or perhaps craving the elimination of disability altogether) returns us to the example of Geel. What is our collective philosophy on the worth of the individual, apart from of his or her capacity to “contribute” to the economic base? Those whom we elect to local, state and federal office hold varying viewpoints. Some would have us emulate Geel, allocating resources to provide for those who can never “repay” the debt. Others, harkening back to Galton’s

⁹⁰ Matthew 25: 44-45: They also will answer, ‘Lord, when did we see you hungry or thirsty or a stranger or needing clothes or sick or in prison, and did not help you?’ He will reply, ‘Truly I tell you, whatever you did not do for one of the least of these, you did not do for me.’

world view, would seek to husband capital for those who are able to contribute most fully to their communities in a traditional sense, through their labors, talents, and ideas. Lest the reader take as fact that these issues fall out neatly on party lines, with conservatives playing the role of villain, it must be pointed out that the tangled issues of selective abortion and in vitro fertilization techniques (to select for or to reject embryos with particular traits) are often in accord with liberal policy.

The eight caregivers and caregiving couples who shared their stories with me do not claim to speak for others, and likely their own public policy positions vary widely. Yet they are unified in their belief that their children's lives have great value and that they have much to offer to their own families, and the greater community. Claiming that a child who is dependent upon others for all aspects of daily living is a contributing member of society may seem radical to some. Suffice it to say that how both villages and countries choose to answer these questions of care are indicators of whether, like the people of Geel, they place value on *all* human beings.

CHAPTER IX

CONCLUSION

Research Questions Revisited

The very things that drew me to qualitative research—and to a narrative study in particular—were the uneven borders and “messiness” inherent in dealing with personal stories. To that end, my original research questions seem painfully narrow when contrasted with the wealth of information and perspective shared around the kitchen tables and on the playroom carpets of “my” families. Research questions were not overtly answered; they were organically embedded in one parent’s parable of a mother bird shielded her young in a rainstorm, or in another’s creative compellation of his daughter’s treasured “firsts” on a music video. Yet circling back briefly to the original aims of the study is warranted for the sake of summary.

- What proactive strategies do families (mothers, fathers, grandparents, and other caregivers) of children with disabilities use that enable them, when faced with challenging circumstances, to remain resilient and hopeful?

A number of formal supports were critical to families’ ability to function. Medical personnel (family physicians and specialists, home care nurses and CNAs) addressed the varied acute and chronic health issues of the children, while at times also bringing emotional support. Educational settings gave parents and caregivers a sense of security,

and a community in which they felt their children were valued as learners by teachers, therapists, and administrators. Government supports (programmatic and financial) funded essentials such as diapers, formula and suctioning equipment, while also underwriting nursing hours in the home, perhaps even keeping some children out of residential care, and some parents in the workplace. Non-profits and grass-roots support groups provided needed connections with other families facing similar circumstances.

Informally, caregivers found that a spouse or helpmate was invaluable in shouldering (physically and figuratively) a measure of the load. Siblings often took on caregiving duties, and even included their brothers and sisters with disabilities in community activities. Grandparents and extended families added to these supports, as did church affiliations. Other parents in similar situations, whether physically close-by or in the social media realm, became sounding boards and trusted allies.

- What stressors are common to the lived experiences of families of children with disabilities? When families *are* successful in building lives (or perhaps moments) of hope and resiliency, what ameliorates their stressors?

Without reiterating all of the positive supporting strategies above, suffice it to say that almost any supportive strategy can go awry, hence having a negative impact. Government assistance is not always fairly and uniformly administered, nor is it accessible when impediments of language or citizenship exist. The selfsame professionals charged with healing the corporal body can wound caregivers emotionally.

The ranks of teachers and administrators contain, sadly, insensitive members. Family dynamics, whether in marital or other familial ties, can become strained and broken. Friends can drift away, finding it uncomfortable to navigate the “new normal” of disability. The job of caregiver, while rewarding, is taxing on multiple levels. Worries about the future—even, ironically, about children outliving their parents—compounded anxieties.

Humor was a universal key to lowering stress; laughter and a sense of the absurd in the face of difficulty (and even the use of inside “crip” jokes) were common threads. Taking time for oneself, either through a fulfilling career or with hobbies and avocations, kept many caregivers on an even keel. All of the supports outlined in the first research question were at times part of the solution as well. Finally, parents consistently reported that their positive attitudes were *chosen*, not innate; they felt a strong sense of control over this standpoint of their lives. The ability to *decide to be hopeful* was a theme throughout the interviews.

- How do families navigate the dominant cultural stereotypes of “normal” behavior, intelligence, or able-bodiedness? For families that succeed in redefining normal, what are their strategies for replacing a “deficit” mindset with a paradigm of inclusion, acceptance and even celebration of the diversity of human ability and disability?

The caregivers in my study had multiple tales to tell regarding the challenges of public spaces and perceptions. Each sought to bring disability into the foreground by actively including his or her child in activities outside the home. Some faced the

intersection of cultural stereotypes about disability with their own minority identities (Black, Latino), or Southern cultural bias against “mixed” marriage. As (mostly) women, they had to redouble their efforts to be heard by male doctors sometimes younger and less experienced with disability than they were. They all experienced discriminatory affronts when their children did not conform to societal expectations behavior or ability, ranging from pity to outright disgust. Most verbalized their sense that the visual impression made by their children shaped public attitudes. Sons and daughters who could “pass” as being within the range of societal norms due to their affect, mobility, young age, or attractiveness were able to avoid stares and undue negative attention.

No matter what disability theorists would like to believe, caregivers were not a unified front on “normalcy” as a false concept. Some felt that their children were in fact simply part of the wonderful array of human variance, perfect as they were. Others expressed no shame in admitting that if able, they would spare their child from disability “in a heartbeat.” Often these sentiments were tied to quality of life issues, with those caregivers whose children suffered numerous surgeries, illnesses, seizures, and invasive and painful procedures being most eager to seek a transformation. For other parents, their assertions that their children were perfect as they were was spiritually based; if God made their child, then it was part of His plan that he or she be disabled.

- What specific advocacy strategies do families employ to move the needle of acceptance in the local community (neighborhood, school, medical settings) for their children with disabilities? How do parents lobby for fuller acceptance and inclusion of their children with disabilities into the mainstream of society

in broader terms (social justice work, state and national advocacy groups, political/government action)?

In general, the parents in my study, raising children with severe cognitive and physical disabilities, had little free time to devote to formalized advocacy issues. One father, an attorney by profession, happily parlayed his existing skills into pro bono work on disabilities issues, and served for years on the Rett Syndrome Foundation board. A well-educated and marketing-savvy mother brought her skills to bear in service of the local March of Dimes Walk for Babies campaign. But most parents' efforts were more subtle than overt, which, it could be alleged, is perhaps one of the most effective strategies of all. When met with stares or utter rejection, these parents were quick to educate others about disability. Most clearly, their custom was to teach through example. (Oh yes, there was Janet's "Get the F--- out of my face!" But those outbursts were rare.) On the ball field, in the concert hall, and at the playground, they could be found simply going about the mundane business of being a family. And if this excursions involved explaining a G-tube feeding or a piece of strange equipment to a curious child, all the better! While parents of children with disabilities have been at the forefront of the disability rights movement since its inception, the parents in my study, immersed as they were with high levels of daily care, did their best when and where they could to turn the tide of discrimination in their own "back yards" by seeking out the most caring schools, by challenging doctors on their own turf, and by integrating their children into the mainstream of the community whenever possible.

Critique of Study

Glesne (2011) warns researchers new to qualitative study that

The openness sets the stage for understanding as well as for ambiguity that can engender a sometimes overwhelming sense of anxiety: “Who else should I be seeing?” “What else should I be asking?” “How can I ever assemble all of the pieces into something meaningful?” (p. 25)

It should be some comfort, then, that the nature of qualitative research dictates that any study feels incomplete to some degree. Asking open-ended questions leads to even more questions. Exploratory rabbit holes seem to multiply; “Could I have asked more about religion?” “Did I miss opportunities to delve into sibling relationships?” “Were there more layers to uncover around the concept of normalcy?” Yes, yes and yes. Yet even after acknowledging the futility of turning over every stone, an examination of the study’s shortfalls can inform future efforts, my own as well those of other narrative researchers.

First, the blog portion of the study, which seemed to hold much promise for bringing caregiver voices to the table in a unique format was, bluntly put, a resounding flop. While eight of the ten original study participants (and six of the eight who continued with home interviews) enthusiastically agreed to share email addresses, a scant three of them posted comments to the site. I employed numerous strategies to remedy the lack of traffic: reminder emails were sent out on three occasions, the blog was maintained for an extra month, and participants’ posting rights were upgraded

from “member” to “author.” All this to no avail; a total of seven posts (beyond my own) were recorded over the four months that the blog was open.

I attribute the paltry postings output to a number of factors. First, all of the caregivers related that their free time was at a premium, and guarded it zealously. Most had little opportunity for leisure pursuits. Asking them to take on a continuing, add-on task in the midst of work and home responsibilities was perhaps not realistic. Second, while the interviews were bounded by time—two one-hour sessions, scheduled in advance—the blog was not a “calendar” event that required immediate attention. When these time constraints were coupled with the lack of any tangible compensation (no \$25 gift card), the attraction of blog participation became lower still. Even though all caregivers freely chose the option of having their fellow participants read their posts, this lack of privacy may have given some pause. Others may have been intimidated by having their writing skills (or lack thereof) on display, or may not have fully trusted that blog security settings protected them from exposure to a wider internet audience.

While narrative research is all about story, I suspect that my participants’ narratives could have been more powerfully relayed had I gathered more concrete data surrounding their demographics, support systems, and financial safety nets. My Study Participant Information Sheets (See Appendix F) collected the barest of statistics: names and ages of caregivers, children and others in the home, and contact information (phone and address). As I began to analyze the data (post-interview) and commonalities began to emerge, I realized that it would have been illuminating to have gathered

minutiae on such points as home health care nursing hours, SSI and food stamp payments, and insurance coverage levels on caregivers and children. The value of a well-developed, comprehensive Information Sheet became clear, unfortunately, after the fact. While it might have been an option to re-contact all of the participants to clear up ambiguities, I chose to chalk this oversight up to experience, and use the knowledge gained to inform future efforts. After immersing myself in qualitative research texts exhorting me to just “tell the story,” this gap in my study was a lesson in the ability of hard data—“facts and figures”—to inform narrative research. Realizing that quantitative and qualitative methods are not Janus-faced, but movable points on a continuum of practice, was an “ah-ha” moment for me.

The research questions in my study, related to concepts of caregiver hope and resiliency, normalcy, and strategies for advocacy, bubbled to the top in the interviews due to specific questions in the interview guide. Yet in hindsight, I believe that I did not give my participants enough credit when it came to speaking to thorny topics. My questions were “surface level”—designed, certainly, to elicit heartfelt stories (which they seemed to do)—but never delving into “darker” and controversial spaces. For example, there is much debate in the medical community and the political realm over the ethics of selective abortion, genetic testing and in vitro fertilization, with the objective of reducing or even eliminating live births of children with disabilities. I never ventured to ask any caregivers’ opinions on these controversial quandaries. And while we danced around the topic of normalcy, I did not prod my participants to share their

explicit reflections on the concept. I believe that I, like others who spend the bulk of their hours in the world of the able-bodied, must admit to experiencing some level of discomfort when talking about disability. Just as discussions of race and sexuality can be riddled with awkwardness for those outside group boundaries, I too found myself reluctant to “go there” without the authority accorded to those with membership. At what point would I have overstepped my bounds, becoming an intruder in these personal spaces? As researcher, I was by most measures an interloper in the caregiving world and hence was hyper-aware of the liminality of my position. Researchers who are caregivers or who have personal experience with disability could perhaps unpack these questions more incisively.

Recommendations for Further Research

There are plentiful possibilities for continuing to build a body of qualitative research involving caregivers of children with disability. The review of the literature reveals that narrative studies are greatly outnumbered by quantitative measures, usually survey-based. In addition, “disability” is an ambiguous descriptor at best; even though government-speak marks exceptional children with fourteen distinct metonyms, each child (and each child/caregiver relationship) is uncommon in his or her own way.

My particular study focused on caregivers who self-identified as resilient, hopeful, and as advocates for their children. Other than phone and email follow-up questions, no research-based strategies were used to determine which volunteers best met the study criteria. Future mixed-methods research that includes qualitative

preliminary screening tools to find the interviewees who best embody these characteristics might lend heft to the dialogue. Additionally, narrowing the focus of the study (looking at just advocacy and agency issues, for example) might be an improvement on my broader effort. Being a novice, I loaded my shopping cart with an overabundance of items. Restricting the topic would allow for deeper, more directed conversations.

The use of internet tools to connect caregivers of children with disabilities need not be abandoned as an area of study. My lackluster results in this enterprise, detailed earlier, beg a need for better-articulated surveys of how blogs, social media (Facebook, Twitter), and specialized sites such as CaringBridge shore up families' avenues for support in an increasingly mobile society. Rather than "starting from scratch," as I attempted to do by creating a new blog, researchers might approach families *already* successfully using these tools, analyzing the nature and frequency of their online interactions. Luckily the blog was a sidebar, not the main thrust, of my research study; perhaps inquiry focused entirely on this method of communication would produce more prolific written narratives.

The diversity of my participants in terms of age, ethnicity, education, and socioeconomic level was at once a strength and drawback of my study. Having eight caregivers and caregiving couples with such diverse backgrounds allowed for comparisons across many different home environments. Future researchers, however, may choose to scrutinize a narrower band of participants, perhaps parsing out questions

and issues germane to single mothers, foster parents, caregivers in poverty, and so on. This advice must be paired with a caveat: just as children with disabilities are more different than they are alike, this study affirmed that stereotyping caregivers based on external criteria is a futile if not outright pernicious pastime. Any future researchers should be disabused of the idea that disabilities and caregivers exist in discrete silos. The far-flung diasporic web that is disability and caregiving should be approached without preconceptions.

No matter the methodology or area of study, the need for new research involving caregivers of children with disabilities becomes clear. While these dialogues are occurring daily in schools, internet cafes, and syndrome-specific support groups, these conversational flows, if captured by the researcher and shared, can inform the work of a host of professionals and lay persons who come into community with children with disabilities and those who care for them.

Final Thoughts

The narrative researcher is much like the proverbial mechanic who finds, after taking an engine apart and reassembling it, that there are unexplained nuts and bolts left on the concrete. Studying human experience is an exercise in examining selected moments, memories, and impressions, yet never fully perceiving the whole. Even when diligently heeding Lamott's (1994) advice to proceed methodically, "bird by bird," I found there were "nuts and bolts" scattered around my workspace. I have learned to deflect the predictable query "What will your study prove?" with a succinct thumbnail

sketch of what narrative research *isn't*. But what, then, does the sharing of these stories accomplish?

Glesne (2011) explains that the work of the qualitative researcher is “to accentuate complexity, not the norm, and to emphasize that which contributes to plurality rather than to a narrowing of horizons” (pp. 273–274). The caregivers in my study are not fodder for reductionism; rather, they present as a multifarious group, wielding a variety of tools that allow them to access services and supports. Anna and Jackie find solace in religion, June and John do not. Brenda gets by on nothing more than food stamps and a monthly SSI check, while Kristin hires a nanny and occasionally sips chardonnay. Jesus and Edith deal with the added pressures of cultural and language barriers that others need not abide. At first pass, the narrators of these stories seem more different than alike.

Yet if we listen, we hear evidences of their shared ability to bend, not break, when buffeted by unexpected challenges. We hear them insisting that caring for a child with a significant disability is not heroic, nor is it tragic: it just *is* (like your lives, and mine, *just are*). As Glesne (2011) says, “Many truths live side by side” (p. 274). These eight stories are multiple truths, or more accurately, fragments of truths. They bring the able-bodied world and the world of disabilities eight steps closer to full conversation and community; with luck, they begin to shift those living without disability from sympathetic outsiders to empathic listeners and advocates.

Even though the blog portion of my research study provided scant data, one post in particular cut to the heart of what I believe caregivers want “the rest of us” to know. I do not know whether Kate intended her words as poetry, but I believe they hold up as such. In closing, I’ve included her thoughts here with no editing other than punctuation.

**Positive way to Deal with our
(Parents of Special Differently-kids)
Daily , Monthly, etc. Challenges**

I have Bella, almost twelve,
with multiple *abilities*.
Yet she faces a lifetime of chronic illness,
and *Adventures*,
I like to call them.

I find strength
in reading others’ perspectives and experiences.
We have, to put it simply,
two options in facing this situation as parents.

One: Feel life is not fair,
blame, question, be bitter.
(Which only makes it harder.)

Or, Two: Do the best u can,
Find little things to triumph in.
And keep picking your feet up,
and your child's, if needed,
and keep going.
If the mountain seems too high,
take a break.

(Or look for a way around the bottom, if necessary!)

I chose Option Two . . .

Most of us, by way of accident, old age, or acute or chronic illnesses will spend part of our own lives dealing with a disability, or will care for someone who is disabled.

Remember, as Brueggemann et al. chided, “We are all TABs—temporarily able-bodied” (2001, p. 369). Continuing to look away from disability, then, is a fool’s errand. But more foolish still are the assumptions we make when we view disability with a smugness born of our own insular experiences. If we open ourselves to the stories of those who know disability best, those who have embraced their caregiving roles as joyful and meaningful, we can undergo a profound apostasy; we can cease to worship able-bodiedness as an ideal, and turn towards an ethic of inclusion, acceptance, care and celebration.

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APPENDIX A

LETTERS OF SUPPORT—FAMILY SUPPORT NETWORK AND THE CENTERS FOR
EXCEPTIONAL CHILDREN**FAMILY SUPPORT NETWORK
OF GREATER FORSYTH**

4505 Shattalon Drive • Winston-Salem, NC 27106

Chris Gentry
Program Director
4505 Shattalon Drive
Winston-Salem, NC 27106

Dear Dr. Villaverde,

It is with great enthusiasm that I am writing in support of the dissertation study to be completed by Carol Kirby, in which she will interview the parents of Forsyth County children with disabilities. The potential of this project to impact future work with families is exciting. My staff and I look forward to working cooperatively with Carol to help in any way necessary including assisting her to distribute flyers to prospective participants, and to provide meeting space for interviews as it is available in our schedule.

I understand the project proposal will be reviewed and approved by UNCG Institutional Review Board for Research Involving Human Participants prior to data collection.

If you need further information in support of this project please contact me at 336-924-5301 or CLGentry@wsfcs.k12.nc.us.

Sincerely,

A handwritten signature in black ink that reads "Chris Gentry". The signature is written in a cursive, flowing style.

Chris Gentry

Mike Britt
Executive Director
The Centers for Exceptional Children
2315 Coliseum Drive
Winston-Salem NC 27106

Dear Dr. Villaverde,

I am writing in support of the dissertation study to be completed by Carol Kirby, in which she will interview the parents of Forsyth County children with disabilities. The staff of The Centers for Exceptional Children and I are committed to working cooperatively with this researcher to help her distribute her flyers to prospective participants, and to provide meeting space for interviews as it is available in our schedule.

I understand the project proposal will be reviewed and approved by UNCG Institutional Review Board for Research Involving Human Participants prior to data collection.

Because of my movement between the two centers, the easiest way for you to reach me is on my cell phone, so if you need further information in support of this project please call me at 336-403-8614. You could also e-mail me at mbritt@thecfec.org.

Sincerely,

A handwritten signature in cursive script that reads "Mike".

H. Michael Britt

APPENDIX B

SIGNED TRAINING VERIFICATION STATEMENTS—FAMILY SUPPORT NETWORK AND
THE CENTERS FOR EXCEPTIONAL CHILDREN

I was provided with an electronic copy of the PowerPoint training entitled
“Protecting Research Participants” provided to me by Carol Kirby, as part of the
requirements of the UNC-Greensboro IRB (Institutional Review Board). I have
viewed the training materials and understand the elements presented in the
training.

Name Christera D. Gentry

Title Director, Family Support Network of Greater Forsyth

Signature Chris Gentry

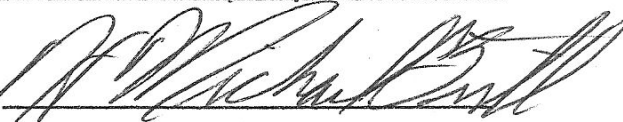
Date 6/22/12

I was provided with an electronic copy of the PowerPoint training entitled "Protecting Research Participants" provided to me by Carol Kirby, as part of the requirements of the UNC-Greensboro IRB (Institutional Review Board). I have

viewed the training materials and understand the elements presented in the training.

Name Mike Beith

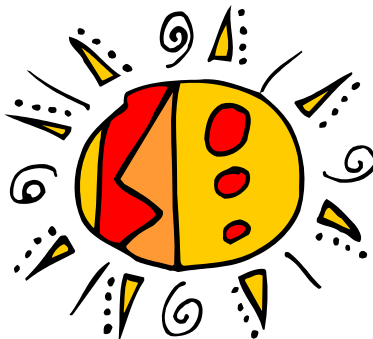
Title Executive Director

Signature 

Date 6-20-12

APPENDIX C

CALL FOR PARTICIPANTS—ENGLISH AND SPANISH

**Call for Parents and Caregivers to Participate in a UNC-Greensboro Dissertation
Research Study**

Are you the parent or primary caregiver of a child (birth through 21) who has a severe disability?

Do you feel that, in general, you are hopeful and resilient despite the challenges that come with raising a child with disabilities?

Do you act as an advocate for your child in a variety of community settings?

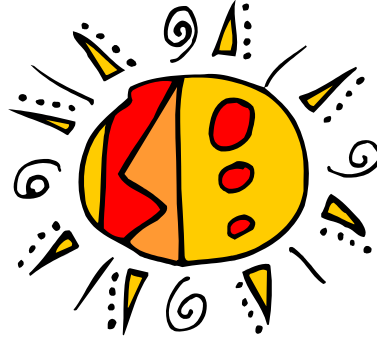
Participants will take part in a one-hour individual interview. Some participants will be offered the opportunity to participate in a second and possibly a third interview. You will be given a \$20 Target or Wal-mart gift card at the end of each interview session.

There will be an optional private and pass-protected on-line “blog” that you can visit to post written work. You may choose to share this writing with only the researcher, or you may choose a security setting that will allow you to share your writing with other participants, and read postings written by other parents interested in sharing. There is no compensation for participation in the on-line portion of the study.

Interested? Contact Carol Kirby at 336-462-1794, or 336-748-2297

Email: cakirby@wsfcs.k12.nc.us

**Una llamada para Padres y Cuidadores a Tomar Parte en
un Estudio de Investigación de Disertación de UNC-Greensboro**



- ¿Ud. es madre, padre o cuidador primario de un niño (el nacimiento hasta 21 años) quién tiene una discapacidad severa?*
- ¿Se siente, en general, que Ud. es optimista y elástico a pesar de los desafíos que vienen con levantar a un niño con discapacidades?*
- ¿Actúa como usted a un partidario para su niño en una variedad de ajustes de comunidad?*

Los participantes participarán en una entrevista individual de una hora. Algunos participantes serán ofrecidos la oportunidad de tomar parte en un segundo y posiblemente una tercera entrevista. Será dado un \$20 tarjeta de regalo de Wal-Mart o Target a fines de cada sesión de entrevista.

Habrà un "blog" opcional en computadora, privado y paso-protégido conectado que usted puede visitar para hacer el trabajo escrito. Puede escoger compartir esta escritura con sólo el investigador, o pueden escoger una colocación de la seguridad que permitirá usted compartir su escritura con otros participantes, y leer anuncios escritos por otros padres interesados en compartir. No hay compensación para la participación en la porción conectada del estudio.

¿Interesado? Contacte por favor Carol Kirby en 336-462-1794 (cell), o 336-748-2297 (casa) Correo electrónico: c Kirby@wsfcs.k12.nc.us

APPENDIX D

CONFIDENTIALITY STATEMENT—INTERPRETER/TRANSLATOR

RE: Training materials for community members

Page 1 of 3

RE: Training materials for community members

Baker, Carol P [cpbaker@wsfcs.k12.nc.us]

Sent: Thursday, June 21, 2012 8:49 PM

To: Kirby, Carol A [cakirby@wsfcs.k12.nc.us]

I have read the power point and understand my responsibility and the importance of confidentiality.

Carol Paguaga Baker
Pre-K 4-5 Year Old Teacher
The Special Children's School

From: Kirby, Carol A [cakirby@wsfcs.k12.nc.us]

Sent: Thursday, June 21, 2012 3:42 PM

To: Baker, Carol P

Subject: FW: Training materials for community members

If you could take a quick look at this PowerPoint, it is required viewing for any people assisting in my study.

Carol

Carol Kirby

Principal

The Children's Center

2315 Coliseum Drive, WS, NC 27106

School # - 336-727-2440

Fax # - 336-727-2873

NEW Cell # - 336-462-1794

www.thecfec.org or <http://wsfcs.k12.nc.us/Domain/3517>

From: Eric Allen [ecallen@uncg.edu]

Sent: Monday, June 04, 2012 1:04 PM

To: Kirby, Carol A

Cc: levillav@uncg.edu

Subject: Re: Training materials for community members

<https://by2prd0511.outlook.com/owa/?ae=Item&t=IPM.Note&id=RgAAAABZOsQodYb...> 6/22/2012

APPENDIX E**PARTICIPANT CONSENT FORM—ENGLISH AND SPANISH****Informed Consent Form****Project Title: Meeting Disability with Resiliency, Hope and Agency: A Narrative Study of Caregivers of Children with Cognitive and Physical Disabilities****Project Director:** Dr. Leila Villaverde **Student Investigator:** Carol Kirby**Participant's Name:** _____**What this study is about**

Carol Kirby has explained in the earlier verbal discussion the procedures involved in this research study. These include the purpose and what will be required of you. Any new information that comes up during the study will be provided to you if the information might affect your willingness to continue participation in the project.

What will you ask me to do if I agree to be in the study?

This research project will take about one to four hours of your time, and will involve one, two or three one-on-one interviews with Carol Kirby. The first interview will last from 45 to 60 minutes. Should you be asked to participate in one or two additional interviews, each one will last no more than 75 minutes. In addition there will be a secure, pass-protected on-line blog that you *may* choose to join. You can post written comments on this blog about your experiences raising a child with a disability. You may respond to other participants' postings if you [and they] have chosen this option. Participation in this portion of the study is completely voluntary. Length of time spent on the blog is at the discretion of the participant.

Why are you asking me?

You are being asked to participate in this study because you are the parent or caregiver of a child (age birth through 21) who has significant physical and cognitive disabilities. Additionally, you have self-identified as a person who is hopeful and resilient in this role of caregiver, and who acts as an advocate for your child in a variety of community settings.

Possible good things that may come out of this study

There are no direct benefits to the participants. However, families raising children with disabilities can learn from one another's stories, finding common ground while yet also discovering new strategies that they themselves might be able to incorporate into daily life. Physicians in a variety of disciplines (pediatrics, orthopedics, neurology), therapists (speech/language, physical, occupational), and educators (classroom and resource teachers, administrators) all benefit from a deeper understanding of the children they serve and the caregivers who support them. Research that actively involves the parents of children with disabilities can become a conduit for dialogue and support within their unique community.

Possible risks that may occur in this study

This study has a low possibility of risk. The topics under discussion in the interviews and blog will relate to your experiences caring for your child. There is risk that these topics may be emotional for you to discuss. Conversely, you may find that having an opportunity to share your opinions and feelings on this topic in a confidential setting is a positive experience. Your decision to participate in this study in no way affects the services that you might receive from either The Centers for Exceptional Children or the Family Support Network of Greater Forsyth.

Will I get paid for being in the study? Will it cost me anything?

There are no costs to you or cash payments made for participating in this study. A gift card in the amount of \$20 to either Target or Wal-Mart will be given to each participant as an honorarium after each interview session. There is no reimbursement for participation in the on-line portion of the study.

All of my questions

Carol Kirby has answered all of your current questions about you being in this study. Any other questions concerns or complaints about this project or benefits or risks associated with being in this study can be answered by Dr. Leila Villaverde who may be contacted at 336-334-3475, or by email at levillav@uncg.edu.

Leaving the study

You are free to refuse to participate or to withdraw your consent to be in this study at any time. There will be no penalty or unfair treatment if you choose not to be in the study. Being in this study is completely voluntary.

My personal information

Your privacy will be protected. You will not be identified by name or other identifiable information as being part of this project. Your identity will be protected in the published study through the use of a pseudonym, which will be selected by you. You will also be asked to select pseudonyms for family members or other people mentioned by name in the course of the interviews. The specific city will not be identified beyond "a medium-sized city in the southeastern United States." All references to school names, street names, identifiable locations (i.e. shopping malls, parks, etc.) will be absent from the published study. During collection of data, no specific names will be recorded on personal calendars or planners of the researcher. (Example: "B.S. at 10:00" rather than "Bob Smith.")

Confidentiality on the blog will be protected in a number of ways. First, the blog itself will be by invitation only. The researcher will ask for the email addresses of the participants, and only these participants (who have self-selected into the blog portion of the study) will be invited to participate. Hence, blog access will be limited to the researcher and the research participants. You are cautioned that your confidentiality can be maintained only to the degree that you maintain security on your home computer, or whatever computer you may chose to use while accessing the blog. Using Google "Blogger," as the platform for the blog, the highest security setting will allow for controlled access for only those invitees deemed members by the person controlling the blog. In addition, as blog editor, the researcher will add a second level of confidentiality for those requesting that only the researcher view their responses. Posts will be screened first by the

researcher, and posts will be viewed by the other blog members only if the participant wishes to share with the other participants. Otherwise, only the researcher will be able to view that particular post.

Study approval

The University of North Carolina at Greensboro Institutional Review Board makes sure that studies with people follows federal rules. They have approved this study, its consent form, and the earlier verbal discussion.

My rights while in this study

If you have any questions about this study, please contact Dr. Leila Villaverde, 336-334-3475, levillav@uncg.edu, 360 SOE Bldg., UNC-G, Greensboro, NC. If you have any concerns about your rights, how you are being treated or if you have questions, want more information or have suggestions, please contact Eric Allen in the Office of Research Compliance at UNCG toll-free at (855)-251-2351.

By signing this form, you are agreeing that you are 18 years of age or older. You also agree to participate in the study described to you by Carol Kirby.

Participant's Signature

Date

Witness* to Oral Presentation
and Participant's Signature

*Investigators and data collectors may not serve as witnesses. Participants, family members, and persons unaffiliated with the study may serve as witnesses.

***Signature of person obtaining consent on behalf of
The University of North Carolina at Greensboro***

Date

Forma informado de Consentimiento

Proyete Título: La Discapacidades de la reunión con Elasticidad, Optimismo y Apoyo: Un Estudio Narrativo de Cuidadores de Niños con Discapacidades Cognoscitivas y Físicas

Directora del Proyete: Dr. Leila Villaverde **Estudiante Investigadora:** Carol Kirby

El Nombre del participante: _____

Lo que este estudio está acerca Carol Kirby ha explicado en la discusión verbal más temprano que los procedimientos implicaron en este estudio de investigación. Estos incluyen el propósito y lo que será requerido de usted. Nueva información que sube durante el estudio le será proporcionada si la información quizás afecte su consentimiento para continuar participación en el proyecto.

¿Qué pedirá usted mí hacer si concuerdo en estar en el estudio? Este proyecto de la investigación tomará acerca de uno a cuatro horas de su tiempo, e implicará uno, dos o tres entrevistas de uno a uno con Carol Kirby. La primera entrevista durará de 45 a 60 minutos. Débale es pedido tomar parte en algunas entrevistas adicionales, cada uno durará no más de 75 minutos. Habrá además un blog por computadora, paso-protegido y seguro que usted puede escoger unir. Puede anunciar comentarios escritos en este blog acerca de sus experiencias que levantan a un niño con una discapacidad. Puede responder a los anuncios de otros participantes si usted [y ellos] ha escogido esta opción. La participación en esta porción del estudio es completamente voluntaria. El tiempo en el blog es a voluntad de los participantes.

¿Por qué me pregunta usted? Es pedido tomar parte en este estudio porque es el padre o el cuidador de un niño (el nacimiento de la edad por 21) que tiene discapacidades significativas, físicas y cognoscitivas. Adicionalmente, tiene auto identificado como una persona que es optimista y elástico en este papel de cuidador, y que actúa como a un partidario para su niño en una variedad de ajustes de comunidad.

Las cosas buenas posibles que pueden salir de este estudio No hay beneficios directos a usted. Familias que levantan a niños con discapacidades pueden aprender entre sí historias, encontrando los puntos comunes al todavía también descubrir nuevas estrategias que ellos sí mismos quizás puedan integrar en la vida diaria. Los médicos en una variedad de disciplinas (la pediatría, la ortopedia, la neurología), los terapeutas (el

discurso/idioma, físico, profesional), y los educadores (maestros de aula y recurso, los administradores) todo el beneficio de una comprensión más profunda de los niños que sirven y los cuidadores que los apoyan. Investigue que implica activamente a los padres de niños con incapacidades pueden llegar a ser un conducto para el diálogo y el apoyo dentro de su comunidad extraordinaria.

Los riesgos posibles que pueden ocurrir en este estudio Este estudio tiene una posibilidad baja de riesgo. Los temas bajo discusión en las entrevistas y el blog relacionarán a sus experiencias que cuidando de a su niño. Hay riesgo que estos temas pueden ser emocionales para usted discutir. Opuestamente, puede encontrar que teniendo una oportunidad de compartir sus opiniones y los sentimientos en este tema en una colocación confidencial son una experiencia positiva. Su decisión de tomar parte en este estudio afecta de ninguna manera los servicios que usted quizás reciba de The Centers for Exceptional Children o Family Support Network of Greater Forsyth.

¿Seré pagado por ser en el estudio? ¿Me costará algo? No hay costos a usted ni los pagos en efectivo causaron tomando parte en este estudio. Una tarjeta del regalo en la cantidad de \$20 de Target o Wal-Mart será dado a cada participante como un honorarios después de cada sesión de entrevista. No hay reembolso para la participación en la porción de computadora del estudio.

Todas mis preguntas Carol Kirby ha contestado que todas sus preguntas actuales acerca de usted estando en este estudio. Cualquier otras preocupaciones de preguntas o quejas acerca de este proyecto o beneficios o riesgos se asociaron con ser en este estudio puede ser contestado por el Dr. Leila Villaverde que puede ser contactado en 336-334-3475, o por correo electrónico en levillav@uncg.edu.

Para salir el estudio Usted está libre negarse a participar o retirar su consentimiento para estar en este estudio en cualquier tiempo. No habrá pena ni tratamiento injusto si escoge no estar en el estudio. Ser en este estudio es completamente voluntario.

Mi información personal Su privada será protegida. Usted no será identificado por nombre ni otra información identificable como formando parte de este proyecto. La hoja informativa proporcionó detalles los métodos que es utilizado para proteger su intimidad. Su identidad será protegida en el estudio publicado por el uso de un seudónimo, que será seleccionado por usted. Usted también será pedido seleccionar

seudónimos para miembros de la familia u otras personas mencionados por nombre en el curso de las entrevistas. La ciudad específica no será identificada más allá "una ciudad mediana en el EEUU del sudeste". Todas las referencias para educar nombres, nombres de calle, las ubicaciones identificables (es decir centros comerciales, los parques, etc.) estará ausente del estudio publicado. Durante colección de datos, ningunos nombres específicos serán registrados en calendarios ni planificadores personales del investigador. (Ejemplo: "B. en 10:00" antes que " Bob Smith".) La confidencialidad en el blog será protegida en varias maneras. Primero, el blog mismo estará por invitación sólo. El investigador pedirá las direcciones correo electrónico de los participantes, y sólo estos participantes (que tiene auto seleccionado en la porción de blog del estudio) será invitado a participar. De ahí, "blog" acceso será limitado al investigador y los participantes de la investigación. Es advertido que su confidencialidad puede ser mantenida sólo al grado que mantiene la seguridad en su ordenador doméstico, o en lo que computadora usted puede escogió utilizar al conseguir acceso al blog. Utilizando Google "Blogger," como la plataforma para el blog, la colocación más alta de la seguridad tendrá en cuenta acceso controlado para sólo esos invitados creyeron a miembros por la persona que controla el blog. Además, como redactor de blog, el investigador agregará un segundo nivel de la confidencialidad para esos solicitar que sólo el investigador ve sus respuestas. Los postes serán investigados primero por el investigador, y los postes serán vistos por los otros miembros de blog sólo si el participante desea compartir con los otros participantes. De otro modo, sólo el investigador podrá ver ese poste particular.

Estudie aprobación La Universidad de Carolina del norte en Greensboro, Institucional de Revisión se asegura de que estudia con personas sigue reglas federales. Han aprobado este estudio, su forma de consentimiento, y la discusión verbal más temprano.

Mis derechos mientras en este estudio Si tiene cualquier pregunta acerca de este estudio, contacta por favor a Dr. Leila Villaverde, el 336-334-3475, levillav@uncg.edu, 360 Ed de SOE., UNC-G, Greensboro, NC. Si tiene cualquier preocupación acerca de sus derechos, cómo es tratado o si tiene preguntas, desea que más información o tiene sugerencias, contactan por favor Eric Allen en la Oficina de Conformidad de Investigación en UNCG gratuito en (855)-251-2351.

Firmando esta forma, concuerda que es 18 años de la edad o más viejo. Usted también concuerda en tomar parte en el estudio descrito a usted por Carol Kirby.

Firma de Participante _____ La Fecha _____

El Testigo a la Presentación Oral y la Firma del Participante *

_____ * Los que estaran conductando este studio no pueden ser testigos. Membres de familia, otros participantes, o personas afuera del studio pueden ser testigos.

Firma de persona obteniendo concuerda por la Universidad de Carolina del Norte, Greensboro _____ La Fecha _____

APPENDIX F

PARTICIPANT INFORMATION SHEET

Dissertation Study Participant Information Sheet

Your name _____ age _____
 (Pseudonym*) _____ Marital status _____
 Do you work outside the home? (if so, type of work, hrs. per week) _____
 Child's Name _____ (pseudonym*) _____
 Age of child _____ Brief description of disability _____

Others who live in the home, with pseudonyms* if
 desired _____

Email Address: _____

Gmail Address (if different): _____

Home Address: _____

Phone numbers: _____

Choose one of the three options below:

- Yes, I would like to participate in the blog ckirbyresearch.blogspot.com, and would like to have my comments published on the blog for other study participants to read.
- Yes, I would like to participate in the blog ckirbyresearch.blogspot.com, but would like for my comments to be seen only by Carol Kirby.
- No, I am not interested in participating in the blog. (You can opt in later if you should change your mind.)

Choose one of the three options below:

- Yes, I would like to participate in a second and possibly third interview, and I am willing to have these interviews in my home.
- Yes, I would like to participate in a second and possibly third interview, but would prefer that these take place in the Children's Center conference room.
- No, I would rather end my participation with today's interview.

*First name only needed for pseudonyms. **

APPENDIX G

INTERVIEW GUIDE—ENGLISH AND SPANISH

Interview Guide – First Interview

- *Ask for permission to conduct the interview, and permission to use a recording device.*
 - *Confirm that the interview will last 45 minutes to an hour.*
 - *Open with time for rapport-building. Chat about the day, plans for the weekend/summer, events at school, etc.*
 - *Check for comfort of the participant, privacy of room, offer water/coffee.*
1. Would you share with me the story of [child's name]? What are the best parts about being [child's name] parent/caregiver? What are the challenges? Talk about what life is like as _____'s parent/caregiver.
 2. You answered the call for participants in this study because you identify yourself as someone who is resilient and hopeful. Talk about that, in light of [child's name]'s disability.
 3. Have there been particularly stressful moments along your journey as a parent/caregiver? What do you do to relieve stress?
 4. Where do you look to find your support? What “feeds” your hope and resiliency?
 5. Are there things that you wish you could do that you are not able to do as a family? What are the barriers that prevent you from doing these things you'd like to do? Do you ever resist when you meet barriers? In what way?
 6. Do you have any pet peeves – things you wish people would not say or do around your child? If you could say something to the person who looks at your family at Wal-Mart, then looks away, or looks a little too long, what would it be?
 7. In what ways do you act as an advocate for your child? Where do you find that you must stand up on his or her behalf?
 8. Is there anything you'd like to add, stories you'd like to share with me about life as [child's name]'s parent/caregiver?
 9. Can you think of anything else you would like to add before we wrap up our conversation?

Note: Questions for participants selected for second and potentially third interviews will be structured based on researcher notes from the first interview, and from areas not fully explored in the first interview.

Interview Guide – First Interview – Spanish Version

- *Ask for permission to conduct the interview, and permission to use a recording device.*
- *Confirm that the interview will last 45 minutes to an hour.*
- *Open with time for rapport-building. Chat about the day, plans for the weekend/summer, events at school, etc.*
- *Check for comfort of the participant, privacy of room, offer water/coffee.*

1. ¿Compartiría conmigo la historia de [name of child]? ¿Qué es las mejores partes acerca de ser padre de [child's name]? ¿Qué es los desafíos? Hable de qué vida está como [madre/padre/guardian] de [name of child].

2. Contestó la llamada para participantes en este estudio porque usted lo identifica como alguien que es elástico y optimista. Hable de eso, relativa de los discapacidades de [el nombre de niño].

3. ¿Ha habido momentos especialmente estresantes por su viaje como un padre? ¿Qué hace aliviar sus tiempos difíciles?

4. ¿Dónde mira encontrar su apoyo? ¿Lo que "alimenta" su esperanza y la elasticidad?

5. ¿Hay cosas que usted desea usted podría hacer que usted no puede hacer como una familia? ¿Qué es las barreras que previenen usted de hacer estas cosas que usted querría hacer?

6. ¿Tiene cualquier cosas que se molestar – cosas usted desea que personas no digan ni harían alrededor de su niño? ¿Si podría decir algo a la persona que mira su familia en Wal-Mart, por ejemplo, entonces miradas lejos, o mira un poco demasiado largo, qué sería?

7. ¿Hay algo que usted querría agregar, las historias que usted querría compartir conmigo acerca de la vida como padre o madre de [el nombre de niño]?

8. ¿Puede pensar en otra cosa que usted querría agregar antes que terminamos nuestra conversación?

Note: Questions for participants selected for second and potentially third interviews will be structured based on researcher notes from the first interview, and from areas not fully explored in the first interview.

APPENDIX H**EXAMPLE OF FOLLOW-UP QUESTION SHEET****(Brenda – Interview #2)**

- Are you able to get on the blog?
- Does your husband want to get on the blog? Or talk in the interview?
- (We can do his paperwork)
- Any on-line parent support groups or websites you go to? Do you belong to any local groups, go to any meetings?
- So you've had no outside nursing help, and you're thinking of looking into it. What do you see as the pluses and minuses of that?
- You mentioned that you see Mahagony getting more independent. When you think about the future, what do you see for her – after high school, for instance?
- You mentioned that family members think that there's going to be a miracle cure one day. Tell me how your religious beliefs, your faith have gotten you through the challenges – or if religion and/or faith are not a part of your belief system, tell about that, too.
- You mentioned that the doctors have always underestimated Mahagony. Tell a story about when you stood up to a doctor or therapist, or challenged them about their low expectations.

- You get SSI, but have no school insurance for her – she’s on Medicaid? Did you ever have a social worker, or anyone else to help you navigate all the doctors’ visits and other stuff?
- You mentioned the frustrations of not being able to do things like fly on an airplane, or go to Disney World. What sorts of changes in the way people treat those with disabilities would make your life better?
- What would be your biggest piece of advice to a parent who has just found out that their child has a disability?
- What is your biggest advice to the “world out there” about understanding your child, and your life?

APPENDIX I

SAMPLE BLOG PROMPTS

(Note – should any Latino caregivers opt into the blog, all prompts will also be provided in Spanish)

1. Read the story below, written by a mother of a child with Down syndrome. Can you relate to her story? Do you have your own “Holland” story to tell?

(“Welcome to Holland” 1987 by Emily Perl Kingsley. All rights reserved)

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting. After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay. The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts. But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss. But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

2. *“People watched us . . . often couldn’t help themselves from peering at Walker’s lumpy face, his just-off features, his squirming tight body. They had a number of ways of looking. There was the glance-and-look-away; that was the most common. Then there was the look-and-smile, to assure us we were accepted, that no stigma existed. Some people were openly horrified . . .”*

This quote is from a memoir by Ian Brown, The Boy in the Moon, about raising his son who has a genetic disorder. Can you relate to his description of the “number of ways of looking?” Share an experience with “lookers” and how you reacted to it.

3. In his book *Life As We Know It*, Michael Berube spoke about how hurtful and ridiculous the concept of “normal” can be for parents of children with disabilities:
“Anyone with any kind of “delayed” child knows how irrelevant and how indispensable are the standard charts of ‘normal’ child development. It wasn’t long before we realized that this paradox would be with us for the rest of our lives.”
 Talk about what the word “normal” means to you. Does it have meaning at all? Is there such a thing as inventing a “new normal” for families of children with disabilities?

4. *“Pushing my daughter in her wheelchair to the grocery store sometimes feels like a political act. Here, look at her, I want to say. I refuse to hide this kid. She is beautiful and smart and friendly. If you look at her enough, you will get used to legs that don’t work, the magnet sticking to her head, the hearing aid nestled in her ear.”* (Suzanne Kamata, mother of Lilia, in *Love you to Pieces: Creative Writers on Raising a Child with Special Needs.*)
 Respond to Kamata’s statement that taking her child out in public can be a “political act.” Do you think this will ever change in our society? If so, what will be the forces that will create change?

5. *“The disabled and their parents do not escape caricatures . . . Overwhelmingly, parents of the disabled are portrayed as little less than saints or martyrs, people endowed with endless patience, love, and compassion and happy to share their poignant insights with others.”*
 (from *A Different Kind of Perfect: Writings by Parents on Raising a Child with Special Needs*, edited by Dowling, Nicoll, and Thomas)
 Respond to this quote. Do you ever feel this way? How do you cope when you don’t live up to this (unrealistic) model of what some might think the parent of a child with a disability should be?

6. *“Speaking is a powerful healing act that can transform individuals and society. Encouraging mothers to tell their stories not only gives voice to their experiences; it brings disability into the dominant discourse and helps to dispel the stigma.”* (Barringer, 1992)
 Do you agree with Barringer’s statement ? Talk about how the process of participating in this study has, or has not been, transformative for you. Do you have ideas about how more of these stories could reach the ears of others?

APPENDIX J

GLOSSARY OF TERMS, ABBREVIATIONS, AND ACRONYMS

ADA Americans with Disabilities Act

ADAPT is a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom

AD/HD Attention Deficit/Hyperactivity Disorder

AS Angelman syndrome is a neuro-genetic disorder that occurs in one in 15,000 live births. Characteristics include developmental delay, lack of speech, seizures, and walking and balance disorders.

Apgar is a quick test performed at 1 and 5 minutes after birth. The rating is based on a total score of 1 to 10, with 10 suggesting the healthiest infant.

Apnea Monitor A home apnea monitor is a portable machine used to monitor a baby's heart beat and breathing after coming home from the hospital.

Apraxia is a speech disorder in which a person has trouble saying what he or she wants to say correctly and consistently.

Asperger's Syndrome is an autistic spectrum disorder. A qualitative impairment in social interaction, impaired communication skills, and a preference for routine and consistency are common characteristics.

Bolus feedings are G-tube feedings delivered four to eight times per day. Bolus feedings allow freedom of movement for the patient, so the child is not tethered to a feeding bag, as would be the case in a tube (pump) feeding.

CAP/C Community Alternatives Program for Children

CAP/MR-DD Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities

Case Management is the service of a Nurse or Social Worker, to help caregivers oversee and coordinate the child's health care as well as social, educational, and other services

CDSA Children's Developmental Services Agency (serving children birth through two with disabilities)

Cerebellum is the area of the hindbrain that controls motor movement coordination, balance, equilibrium and muscle tone.

Chewelry™ functions as a chewable and wearable sensory tool for individuals who chew or fidget.

CILs Centers for Independent Living, supporting fair housing, transportation, and employment practices for adults with disabilities

CNA Certified Nursing Assistant

CNA2 A Certified Nursing Assistant trained to a deeper and more specialized level

Cryptogenic epilepsy (from the Greek word “kryptos,” meaning “hidden”) is epilepsy with no obvious cause.

C-section Cesarean delivery is a surgical procedure used to deliver a baby through an incision in the mother's abdomen and a second incision in the mother's uterus.

DD Developmental Disability

DiGeorge syndrome (22q11.2 deletion syndrome) results in the poor development of several body systems, including heart defects, poor immune system function, a cleft palate, complications related to low levels of calcium in the blood and behavioral disorders.

Down Syndrome is a genetic condition in which a person has 47 chromosomes instead of the usual 46. The extra chromosome causes problems with the way the body and brain develop. Down syndrome symptoms can range from mild to severe.

EC Exceptional Children

EHA Education for All Handicapped Children Act

Febrile seizures are convulsions brought on by a fever in infants or small children. Children prone to febrile seizures are not considered to have epilepsy, since epilepsy is characterized by recurrent seizures that are not triggered by fever.

FERPA The Family Educational Rights and Privacy Act

FSN Family Support Network

GLBT Gay, Lesbian, Bisexual and Transgendered

Grand mal seizure also known as a tonic-clonic seizure, features a loss of consciousness and violent muscle contractions. It is the type of seizure most people picture when they think about seizures in general.

G-tube is short for gastrostomy feeding tube, which is the placement of a feeding tube through the skin and the stomach wall, directly into the stomach.

HI Hearing Impaired

HIPAA The Health Insurance Portability and Accountability Act of 1996

HUD The office of Housing and Urban Development

Hydrocephalus is a buildup of fluid inside the skull that leads to brain swelling.

ICU Intensive Care Unit

ID Intellectual Disability

IDEA Individuals with Disabilities Education Act

Intubation The most common use of this term in the ICU refers to placing a breathing tube into a patient's airway (endotracheal intubation). Endotracheal intubation is necessary when patients cannot cough and clear secretions or breathe on their own.

IV Intravenous (usually referring to medicine or nutrient delivered as a fluid into the vein)

Kyphosis is a curving of the spine that causes a forward bowing or rounding of the back, which leads to a hunchback or slouching posture.

Medical Model of Disability is the traditional way of viewing people with handicapping conditions. The person is considered in need of cure or “repair” so as to be more like the able-bodied norm.

MRI Magnetic resonance imaging is a test that uses a magnetic field and pulses of radio wave energy to make pictures of organs and structures inside the body.

MS or multiple sclerosis is an autoimmune disease that affects the brain and spinal cord (central nervous system).

Nebulizers are electric- or battery-powered machines that turn liquid asthma medicine into a fine mist that's inhaled into the lungs.

NICU Neonatal Intensive Care Unit

Nissen fundoplication is a surgical procedure that alleviates chronic reflux where the patient's condition cannot be controlled by medication or other means.

OR Operating Room

Orthotics are orthopedic appliances used to support, align, prevent, or correct deformities or to improve the function of movable parts of the body.

Person-First Language involves speaking of people with disabilities as people first, and their disability second. For example, say “a woman with Down syndrome” rather than “that Down syndrome woman.”

PICU Pediatric Intensive Care Unit

Pulmonary hypertension is abnormally high blood pressure in the arteries of the lungs. It makes the right side of the heart work harder than normal.

Pulse oximeter is a device, usually attached to the earlobe or fingertip that measures the oxygen saturation of arterial blood by transmitting a beam of light through the tissue to a receiver.

Rett Syndrome is a unique developmental disorder caused by mutations on the X chromosome, causing problems in brain function that are responsible for cognitive, sensory, emotional, motor and autonomic function. These can include learning, speech, sensory sensations, mood, movement, breathing, cardiac function, and even chewing, swallowing, and digestion.

RSV An infection with respiratory syncytial virus which manifests primarily as bronchiolitis or viral pneumonia, it is the leading cause of lower respiratory tract infections in infants and young children.

SBS/AHT Shaken Baby Syndrome or Abusive Head Trauma

Schizencephaly is an extremely rare developmental birth defect characterized by abnormal slits, or clefts, in the cerebral hemispheres of the brain.

Scoliosis is a sideways curvature of the spine. Scoliosis can be caused by conditions such as cerebral palsy and muscular dystrophy.

Septo-optic dysplasia (SOD) is a rare disorder characterized by abnormal development of the optic disk, and pituitary deficiencies. Symptoms may include blindness in one or both eyes

Shunting is surgery to relieve increased pressure inside the skull due to excess cerebrospinal fluid (CSF) on the brain.

Social Model of Disability locates the “problem” with disability not within the individual, but within the built environment, designed for the able-bodied majority, and with discriminatory societal attitudes

Spastic quadriplegia is the most severe form of cerebral palsy in which all four limbs and the trunk are affected. Children with this disorder usually have mental retardation, problems with muscles that control the mouth and tongue, and difficulty in speaking.

SSI Supplementary Security Income

Stridor is an abnormal, high-pitched, musical breathing sound caused by a blockage in the throat or voice box (larynx). It is usually heard when taking in a breath.

Suction Machine is a portable apparatus used for aspirating fluids and vomit from the mouth and airways.

TEACCH is an organization of community-based services, training programs, and research to enhance the quality of life for individuals with Autism Spectrum Disorder and for their families across the lifespan. TEACCH stands for teach, expand, appreciate, collaborate, cooperate, and holistics.

Tetrology of Fallot is a congenital heart defect causing low oxygen levels in the blood, leading to cyanosis (a bluish-purple color to the skin). The classic form includes four defects of the heart and its major blood vessels.

Tracheotomy is a surgical procedure in which a cut or opening is made in the windpipe (trachea).

Trisomies Almost any chromosome can be seen in trisomic form, but very few trisomies are compatible with life. Some chromosomes - 13, 18, X and Y- are seen in liveborn children, while trisomies of chromosomes 15, 16, and 22 are often seen in miscarriages.

Tuberous Sclerosis Complex is a genetic disorder that results in a variety of symptoms, including brain lesions that can cause seizures.

22q11.2 deletion syndrome can affect almost every system in the body, causing a wide range of health problems: heart defects, palate differences, feeding and gastrointestinal difficulties, immune system deficits, growth delay, kidney problems, hearing loss, low calcium and other endocrine issues, cognitive, developmental and speech delays, and behavioral, emotional, and psychiatric differences.

Vagus nerve stimulator (VNS) is a small device implanted under the skin near the collarbone programmed to produce weak electrical signals at regular intervals to help prevent the electrical bursts that cause seizures.

Ventilator A machine that supports breathing

VI Visually Impaired

APPENDIX K

IRB APPROVAL FORM



THE UNIVERSITY of NORTH CAROLINA
GREENSBORO

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To: Leila Villaverde
Ed Ldrship and Cultural Found
360 School of Education Building

From: UNCG IRB

Authorized signature on behalf of IRB

Approval Date: 5/30/2012
Expiration Date of Approval: 5/29/2013

RE: Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)
Submission Type: Initial
Expedited Category: 7.Surveys/interviews/focus groups,6.Voice/image research recordings
Study #: 12-0194

Study Title: Meeting Disability with Resiliency, Hope and Agency: A Narrative Study of Caregivers of Children with Cognitive and Physical Disabilities

This submission has been approved by the IRB for the period indicated. It has been determined that the risk involved in this research is no more than minimal.

Study Description:

This study investigates parents and other caregivers of children with disabilities who are hopeful and resilient and who act as advocates for their children.

Investigator's Responsibilities

Federal regulations require that all research be reviewed at least annually. It is the Principal Investigator's responsibility to submit for renewal and obtain approval before the expiration date. You may not continue any research activity beyond the expiration date without IRB approval. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.

Signed letters, along with stamped copies of consent forms and other recruitment materials will be scanned to you in a separate email. These consent forms must be used unless the IRB has given you approval to waive this requirement.

You are required to obtain IRB approval for any changes to any aspect of this study before they can be implemented (use the modification application available at <http://www.uncg.edu/orc/irb.htm>). Should any adverse event or unanticipated problem involving risks to subjects or others occur it must be reported immediately to the IRB using the "Unanticipated Problem/Event" form at the same website.

CC:
Carol Kirby
ORC, (ORC), Non-IRB Review Contact