

SOCIAL WORLDS OF LEARNING DIFFERENTLY:
A PARALLEL STUDY OF TWO FAMILIES

by

JOHN SHANE RAYBURN

(Under the Direction of JoBeth Allen and Patricia Bell-Scott)

ABSTRACT

This autoethnographic dissertation is a parallel study of two families at different points in time and yet timelessly bound by a similar experience of having a family member with a school-identified disability. The purpose of this research was to explore how two families use narratives as tools for defining and understanding themselves as they attempted to construct, participate, and navigate worlds of schooling and worlds beyond school. From a sociocultural perspective (Vygotsky, 1978, 1987) of language, narrative theory and narrative inquiry frame the research (Bruner, 1986, 1990; Coles, 1989; McAdams, 1993; Polkinghorne, 1988). Multilayered, rich narratives offer interpretations of experiences and the narratives offer data that elaborates upon Bronfenbrenner's (1979) ecological theory and explores how children with invisible differences and their families are positioned by competing Discourses (Gee, 1996). Adopting the definition of autoethnography espoused by Ellis and Bochner (2000), the researcher became part of the phenomenon under the scope of inquiry and traced his academic and personal life as a sibling of a brother who struggled to learn along with the narratives of other family members. Human lives are considered texts (Ricoeur, 1981) and language treated as data. Data from a parallel family was collected over six months through interactive interviewing (Ellis, Kiesinger, & Tillmann-Healy, 1997), email conversations, and participant observation. The researcher used a modified version of phenomenological hermeneutics (Van Manen, 1990) and Alexander's (1988) method of analyzing personal data as primary methods of analysis. Using narrative examples, the researcher offers new ways of understanding stigmatization from the perception of two families, explores possibilities of fostering more equitable and sensitive relationships with families, provides an elaborated discussion of human development as conceived through the writing of the narrative, and engages readers to consider their own developing responses to the narrative.

INDEX WORDS: autoethnography, narrative, disability, systems theory

SOCIAL WORLDS OF LEARNING DIFFERENTLY:
A PARALLEL STUDY OF TWO FAMILIES

by

JOHN SHANE RAYBURN

B.S.Ed., Georgia State University, 1993

M.Ed., Augusta College, 1995

A Dissertation Submitted to the Graduate Faculty
of The University of Georgia in Partial Fulfillment
of the
Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2003

© 2003

John Shane Rayburn

All Rights Reserved

SOCIAL WORLDS OF LEARNING DIFFERENTLY:
A PARALLEL STUDY OF TWO FAMILIES

By

JOHN SHANE RAYBURN

Approved:

Major Professors: JoBeth Allen
Patricia Bell-Scott

Committee: Martha Alleksaht-Snider
Mark Faust

Electronic Version Approved:

Maureen Grasso
Dean of the Graduate School
The University of Georgia
May 2003

For
Christopher,
I will always be your brother
and
Jacob,
I will always be your friend

ACKNOWLEDGMENTS

I am reminded of a verse from Proverbs 3:6 that my parents instilled in my academic, personal, and spiritual selves from the very beginning, “In all thy ways acknowledge him and he shall direct thy paths.” It is with God that I begin these acknowledgments. Thank you, God, for guiding my steps in life. And thank you for the people below who have so graciously held my hand and showed me the way. The narratives of the following people have informed and challenged this project in ways that transcend simple acknowledgment, but it is here that I want to honor them.

Dr. JoBeth Allen tenderly yet firmly guided me down the path of including myself within my research and never closed her door to my wonderings and my worries. She nurtured both my academic spirit and my narrative spirit. She was never pushy; although, I suspect that she knew this is where I would end up all along. Thank you, JoBeth, for shedding light upon my path so that I could travel it securely.

Dr. Patricia Bell-Scott metaphorically held my hand at every juncture, even when she was unaware, providing support through her gentle commentary and support of my work. She cared for me as a person and helped me remember to “keep on living.” Thank you, Pat, for contributing to this work in such significant ways.

Dr. Mark Faust, who is responsible for my fascination with John Dewey’s theory of experience, kept my attention on language and its power to shape who we are and how we live our lives. Thank you, Mark, for always being interested in my pursuit and supporting this hybrid dissertation effort.

Dr. Martha Alleksaht-Snider also challenged my thinking about families and our interactions with families and how we develop ways of facilitating better communication between homes and schools. Thank you, Martha, for always being in your office and always offering a smile and a hug just when I needed it.

I suppose I could blame Dr. Emilie Paille for all of this or perhaps she'd prefer the credit. Either way, I want to thank her for believing in me from the beginning of my educational career when I was student in her Language Arts Block course at Georgia State University. It was then that she saw something within and pushed me to follow that academic dream. Thank you for your friendship and kind spirit, Emilie.

Dr. Karla Moller, now an assistant professor at the University of Illinois, Urbana-Champaign, was my officemate and friend during our years of coursework. She and I had lively conversations about my narrative journeys, and those debates made me think deeper and consider alternative perspectives on any given issue. Thank you, Karla, for offering your support and friendship through the years. I am a better thinker because of you. I value and respect you greatly.

My Writing Group—Dr. Sara Angeletti, Dr. Terry Burns, Sharon Clark, Dr. Jane Rogers, and Cindy Truett—have been a lifeline for my work. They have read this research perhaps more than anyone, each time offering new and insightful feedback. It is better because of you. Thank you for sharing your work and your lives with me. You have been an academic support system and spiritual allies in times of trouble. We've been through so much together and I eagerly anticipate our future meetings together.

Teri Holbrook, you came along at just the time I needed you. I'm so glad our paths have crossed. I believe that our friendship will continue to develop as colleagues and research collaborators. Thank you for reading and responding to my work.

Dr. Karen Hankins, you paved the way for me to pursue such personal work. You have been and continue to be a major source of inspiration to me. You're fantastic.

Julie Hoff helped me immensely in the final stages of this work as she willingly offered her tech-savvy advice and time and ultimately her hand of perfection in the forming of my diagrams. She and her husband Michael have been encouraging friends. They have nagged me to stop and play in the sun from time to time. I am so grateful that they did. They have made me laugh and enjoy life. Thank you both.

Jacob and his family opened their lives to me and made me a part of their family and I learned so much about my self through them. Thank you for trusting me with your stories. I hope it is true to your experience and that you find strength and company within the pages of this dissertation.

My Parents, John and Cecilia, have always believed and supported my every learning adventure. Dad, your belief in me never faltered. I think you think that I can do anything! And Mom, you think I'm perfect despite my imperfections. Your love and trust in me ultimately allowed me to pursue this personal research. Thank you both for taking on the caretaker role for Trent so that Jennifer and I could be together and so that I could face the daunting task of finishing the last leg of this journey. I hope I have made you proud.

My Brother, Christopher, you may never fully understand the depth of your influence on my life—both my personal and professional lives. Your unconditional love serves as a constant reminder of how we all should interact with each other in the world—simply

caring and sharing our lives with one another. Christopher is and will always be my “best buddy.” Thank you, Christopher, for allowing me to share our story as siblings.

My son, Trent, you will not fully appreciate this experience until later in life, but your little life has kept perspective in my academic life, reminding me daily to laugh and play. You have filled my being with hope and worry. You are within the pages of this narrative, implicitly and explicitly. I will always be here for you as you make your way into the world. I love you so much.

Finally, I want to thank Jennifer, my wife and best friend. Our love is like none other. We have reached new milestones as I worked on my doctorate. We welcomed a new baby into the world, constructed a new office for Jennifer’s practice, currently are building a new home, will welcome our second child shortly after commencement, and will celebrate ten years of marriage this June. Jennifer, you have been my personal confidante and my cheerleader. You would not let me quit. I asked and every time you said, “No!” Thank you for insisting that I finish. I repeatedly cried during this difficult research and you held me, saying little but wrapping me in your arms of love. You made me feel safe; I loved it there. Thank you seems so insignificant in light of the depth of our relationship. You are my best friend and I love you always. At times, I have been far away emotionally, preoccupied with the narratives of this research. I’ve come to an understanding of this experience now, I’m beginning to heal, and I’m coming home.

TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS	v
CHAPTER	
1 HISTORY OF THE RESEARCH PROBLEM AND QUESTIONS.....	1
Introducing Christopher	3
Stories: An Introductory Argument	5
The Problem with Labeling	7
Learning in School – Learning at Home: Zones of Possibility.....	9
Purpose and Goals of this Research.....	12
Research Questions	15
Reader’s Overview.....	16
2 THEORETICAL/RESEARCH CONNECTIONS.....	18
Learning about Children’s Social Worlds: Opening the Possibilities	18
What Counts? Theorizing and Conceptualizing Experience	25
Narrative	30
Language.....	34
Concluding Thoughts.....	39
3 THE WRITING STORY	41
In the Field	42
Getting Acquainted with Autoethnography	43

Meeting the Research Face to Face	44
From There to Here.....	48
About Data and Theoretical Positioning.....	55
Preparing to Write—Data Summary and Analysis.....	62
Research or Therapy?	69
Narrative Truth?.....	70
Reliability, Validity, and Generalizability?	72
Proposed Evaluation Standards.....	74
A Reader's Guide.....	75
4 THE NARRATIVE WORK	77
Protecting Travis.....	77
Ability Questioned.....	91
False Reassurance	93
Protecting Jacob.....	95
We Love This School, But	104
Special Words	109
Being a Good Friend.....	112
Good Friend Expert.....	114
Facing the Inevitable Question—Why?.....	116
Losing Ground	117
From the Beginning: The Village Ogre	119
Time Out—Punished or Misunderstood?	120
Another Village Ogre.....	121

Surprises, More Revelations	122
Suspicious	123
The Whys—Blocking It Out.....	126
Worries.....	130
Being Put on the Spot—Seeking Competence.....	131
Compromises by Siblings	132
Travis is Travis, Jacob is Jacob, Christopher is Christopher	136
5 EXPLORATION OF TENSIONS	142
Challenging the Language of Disability	143
Revisiting Bronfenbrenner.....	146
Explaining Interactivity	149
Thematic Tensions	158
One Last Look at Me	180
6 COMING TO TERMS WITH THE NARRATIVE WORK	186
7 TAKING ACTION: TWO LETTERS.....	202
A Letter to Families	202
A Letter to Educational Professionals.....	205
REFERENCES	209
APPENDICES	
A Bronfenbrenner’s Ecological Theory of Development.....	230
B Interactive Interviewing: Possible Topics/Prompts.....	231
C Data Sources: Jacob and His Family.....	232
D Data Sources: Christopher and His Family.....	233

E	Overlapping Data Sources	234
F	An Extended Model of Ecological Theory	235

CHAPTER ONE:

HISTORY OF THE RESEARCH PROBLEM AND QUESTIONS

Dr. Kay Redfield Jamison (1995) recalled in *An Unquiet Mind: A Memoir of Moods and Madness*,

It was a gorgeous day, and, after having discussed a wide variety of topics, Mogens turned to me and asked me point-blank, Why are you really studying mood disorders? I must have looked as taken aback and uncomfortable as I felt because, changing tack, he said, “Well, why don’t I tell you why I study mood disorders?” (p. 188)

Jamison continued to recall how Mogens shared his family’s historical battle with the disorder. Finally Jamison conceded, “Feeling a bit trapped, but also relieved, I decided to be honest about my own and my family’s history, and soon the two of us were drawing our pedigrees on the backs of table napkins” (p. 189).

Inevitably, this conversation and exchange became important to Jamison. Mogens encouraged her to use her experiences in her research, writing, and teaching. This narrative episode represents an epiphany that evolved for me over the past several years of work on my dissertation research. The influence of my family and my history has lurked around every corner. Often, I have pushed it into the shadows of my soul and at times, I’ve run away from it. Even now, it seems difficult to share, but it must be shared. It is welling up inside of me.

I've been rehearsing and preparing for this research my whole life. I'm an insider. No one else could tell my story. The research is about me and my younger brother, Christopher, a sibling who struggled to learn and still learns differently. It is not only about us; it is also a parallel study about another family and another child who has struggled to learn and continues to learn differently. The dual nature of the research project makes it particularly unique. It is about two families, our teachers, our social worlds, and the institutions of schooling and society that structure the terrain incorporating both students labeled "at-risk" and those who find success in the system. Learning to navigate these shifting social spheres has been challenging for both families in my study.

I live a story that only now am I beginning to acknowledge and narrate in a public way, the story of growing up with a younger brother who struggles to learn and learns differently. It is this intimate relationship that served as the catalyst for research. The research is a personal project, one that I have mustered up the courage to pursue. Tracing the academic origins of this project propelled me through flashbacks of decisions made about course work. The turning point for making my life a dimension of my research came in Dr. Patricia Bell-Scott's "Race, Class, and Gender in Individual and Family Narrative" course. It was in that course that I found support for using narratives, my own and those of others, as a viable means of knowing the world. I developed the desire to engage in narrative research explorations. Alongside this pivotal course, every time I met with Dr. JoBeth Allen, she pulled out my folder and made notations on the front side, keeping a record of my evolving research interests. Every time, she gently nudged me with questions like, "What are you really interested in? What is this really about?" Soon,

an obvious pattern developed as I connected my academic wanderings. My research interests pointed toward children who struggled to learn. My academic tenure had come full circle, for I began my higher education with an undergraduate degree in special education. JoBeth and Pat were incredibly patient as I took small steps and gained courage in revealing the contents of my closet of intentions. My research is encased in memories, and many of those memories are encased in more memories. Sifting through those memories systematically was a goal of my research. With this project, I climb the ladder of my internal attic and invite you along as I unpack the boxes called remember. These boxes I carry with me always, airtight and secure. Concurring with Michael Dorris (1994), I believe that

the past is redemptive . . . The past exists in its own continuum, valuable, if not to its creators, at least to its appreciative audience—distinct from its sequela. I keep the box because its contents mattered, and therefore matter. I keep it for perspective and because, when it doesn't make me sad, it makes me smile. I keep it because I can't leave it behind. (p. 4-5)

Now, take glimpse inside my box of intentions. I'll unpack a few things to help you understand the origination of the problem that has troubled me through the years.

Introducing Christopher

My younger brother, Christopher, had a fairly typical childhood until he started formal academic training, also known as school. Questions about his development began to swarm about him—questions about being different, delayed. He was mischievous, creative, and above all, an individual. He marched to his own drum. He rarely conformed to the behavior of the children around him. Instead, he crafted his own way into the social

worlds of others. To me and my family, he seemed marvelous. Very soon after his entrance into schooling, teachers and specialists questioned his understandings and potentials and then began delineating his limitations. So began a long haul of multiple narratives on and about Christopher.

Early on, I became more than Christopher's sibling; I became a confidant, friend, and teacher. I like to think that I was his "more capable peer." From my position now, I clearly see that many times before, but especially now, he has become my "more-capable peer." Children who struggle to learn and learn differently can teach us much if only we learn to listen differently, to view them from different perspectives. Christopher and I spent many hours at the kitchen table after school working on homework together. How we experienced homework was significantly different and starkly contrastive.

During those times together, we experienced demands, tears, laughs, frustrations, and successes. I desperately tried to think of strategies that would help Christopher become successful in school. After studying together at the round, oak table, Christopher often grabbed his big, white overstuffed bear and headed for the trampoline in the backyard. From the window or the edge of the deck, day after day, I gazed at a little boy with so much joy and love for anybody, anyone. I prayed the world would understand that he was much like them. Yes, perhaps he did learn differently and maybe he hadn't memorized his addition facts. But he had an unending, unfailing love for his friends. Couldn't they see it? Couldn't they value his differences?

The research story is but one, only one version of the stories told on and about children who struggle to learn; I suspect there are many others just beneath the surface. And I argue that this story, this life, is but one version of the epic of many other people,

for we are actors in each others' stories. You will read in the subsequent pages multiple stories shared side by side from two families. The parallel nature of two families engaged in a similar experience and the autoethnographic dimension made this research distinctive from other studies. Our stories are important to how we live and how we interpret our worlds. In essence, we become who we are through language—through the stories of our lives.

Stories: An Introductory Argument

Stories have been told around campfires, on front porches, in bedrooms, on church lawns, at family reunions – wherever people gather. Within the walls of schools and beyond them, storytelling and the crafting of children's stories abound. Narratives are multilayered, densely constructed phenomena that occur in the textures of everyday life. We live them, we tell them, and they live beyond us. Children bring stories to school and create stories about school; children bring stories home and create stories about home. Children create stories with peers and learn to manage their lives with more stories. Intersecting stories of home and school can inform us as educators and perhaps can challenge us to resee not only educational pedagogy and curriculum but also the essential humanness that lies within invisible differences.

All narratives are blurred genres in the sense that many of them vacillate among facts, fictions, folklore, and myths. They are told and enacted every day. No matter what genres are adopted by their narrators, these stories have powerful implications for schooling. Stories echo within the walls of school and beyond those walls. Norman Denzin (1989), citing Sartre, claimed that

if an author thinks something existed and believes in its existence, its effects are real. Since all writing [or telling] is fictional, made-up out of things that could have happened or did happen, it is necessary to do away with the distinction between fact and fiction. (p. 25)

Therefore, “to argue for a factual correct picture of a ‘real’ person is to ignore how persons are created in texts and other systems of discourse” (Denzin, 1989, p. 23). So, it is given that stories, however *real* they are important to human development and the understandings of social worlds of learning. My study became a focus on stories both from within and from outside schools. The best resources for understanding children’s stories outside of schools are families. Each family member brings additional layers of narrative that warrant our attention.

As I conducted my research, I opened spaces for the stories of children and families from their points of view (Taylor, 1993) and listened in on “the ordinary, nonprecocious moments” in their lives (Newkirk, 1992, p. 5). I explicitly accounted for my story-in-progress. It is easy to dismiss talk that seems insignificant or irrelevant, and in fact, I argue in the current effort that it is just such talk that mattered most. “We can begin by observing children [and families], learning with them and from them as they learn with us and from us. . . . In this way we can create philosophical and theoretical frames for our observations of the learning environments we make for one another” (Taylor, 1989, p. 191). My research is about two boys growing up and learning differently and the families of those boys. It is about revealing the emotions of learning differently. Words can fail to convey our meaningful intent. Certainly all children learn in different ways. I am using the term, however, to describe intellectual and processing differences that often are

demonstrative in academic settings and escape our vision in other social worlds. In other words there visibility differs given different contexts. There are no rules for learning differently and certainly no maps; instead, there are lots and lots of narratives.

The professional and personal writing in this project coincide and merge; they appear seamless and complementary. My teaching life has always been a part of my life, a part of how I define myself. My researching life has also been an ongoing part of my life. I've always wondered and wandered as researchers do. My many hats of teacher, researcher, husband, father, brother, and son coincide and it is my hope that within the pages of this research project, you will see each of them expressed. Connecting stories and theories, I weave together my voice with the voices of scholars and researchers, of former students and their families, of friends and colleagues, and even the imaginary voices that race through my head. I write to tell my story and to offer spaces for the stories of others just as their stories provide spaces for my own.

The Problem with Labeling

Labeling children enables schools and teachers to overlook the child beneath the label. Categorizing and shuffling children based on criteria outside of understanding who they are as a person is problematic. When a child fails to read or write within a certain period of time, it is assumed there must be something wrong with the child. Tests are administered, referrals are made, and labels are given. Labels shackle a child's creativity, learning, potentials, gifts, and talents. Specialists often use obtuse, opaque medical language to describe the problem: diagnosis and remediation, treatments and prescriptions, literacy clinics, reading and learning disabilities. "Because of who or what schools imagine some students to be, they may limit who they can become" (Rhodes &

Dudley-Marling, 1996). The labels and the subsequent “fixer-up” programs, including many special education and remedial programs, have failed and continue to fail as documented by a plethora of research initiatives (many notably included in Allington & Walmsley, 1995).

As if the act of labeling is not problematic enough, too often, blame accompanies the labels. Blame is placed on children’s diets, home life, neglectful parents, and so on. It is time to redefine and level the playing ground for children who become labeled. Roller (1996) suggested that we consider struggling readers as exhibiting “variability not disability” (p. 7). According to Kenneth Goodman (1986), “If these pupils are to become literate, they must lose the loser mentality. They must find the strength and confidence to take the necessary risks...” (p. 56). I argue that we can learn more from them by considering their evolving stories rather than affixing labels. By doing so, we reposition how we come to know a child, not through testing alone but through the stories they share. Through narrative, children and families and become positioned by others in and out of schools (Gallas, 1994). The epiphanal experiences of children and families are made visible through social interactions in various contexts. By considering these social interactions and the narratives that swarm about them, I explore new ways of understanding variability and begin “subverting the language of childhood of disability” (Lightfoot & Gustafson, 2000, p. 71).

Educator Vivian Paley (1990) argued that “every child enters a classroom in a vehicle propelled by that child alone at a particular pace and for a particular purpose” (p. xii). The classroom terrain where these children and families meet must be crossed carefully. Writing about Jason, a child who learned differently, Paley (1990) stated,

There are labels that might be attached to Jason, but we'll neither define nor categorize him. None of us are to be found in sets of tasks or lists of attributes; we can be known only in the unfolding of our unique stories within the context of everyday events. We will listen to Jason's helicopter stories and offer our own in exchange. In this evolving classroom drama every relation is necessary and equally important, for our goal is more than fantasy. It is fairness. (p. xii)

The classroom represents but one of many social worlds that children and families navigate. Human development theorist Urie Bronfenbrenner (1979) reminded us of the importance of children's perception and interpretation of social worlds and the critical point of transition from one world such as home to another world such as school. If these transitions do not occur smoothly, alienation and isolation can occur. By learning from children and families, we explore the social worlds wherein meaning becomes coconstructed.

Learning in School - Learning at Home: Zones of Possibility

First years of school are important rites of passage. Parents go to great lengths to make sure that their child is prepared for the first day of school. The question of what it means to be ready for school continues to be debated in literacy and child development circles. Entry into school is perceived as a beginning of learning and growing, and much debate surrounds children's readiness for school. On that first day, children suddenly become "big boys and girls." Then, it is expected that children's academic growth will follow a linear path. "They'll learn to read in first grade. Right?" What narratives are constructed about children who fail to march along the same line with other children? Schooling expectations, like when a child should learn to read, place some students at

risk for being labeled different. Gordon Wells (1986) challenged the narrow notion of learning and insisted that this conception of schooling be enlarged:

[E]ntry into school should not be thought of as a beginning, but as a transition to a more broadly based community and to a wider range of opportunities for meaning making and masteries. Every child has competencies, and these provide a positive base from which to start. The teacher's responsibility is to discover what they are and to help each child extend and develop them. (pp. 68-69)

By reinventing current notions of the social worlds of schooling and expanding the possible spheres of learning, we challenge beliefs derived from deficit models and offer ones that offer a range of possibility. Teachers can begin the process of reinvention by engaging with the experiences of children and families as they are objectified through narratives, and as John Dewey (1916) suggested “the educational process [can become] one of continual reorganizing, reconstructing, [and] transforming” (p. 50).

Acknowledging family stories is a beginning to understanding.

Students' “funds of knowledge” (Moll & Greenberg, 1990) actively influence children's social understandings of schooling and of life outside of school. Students learn what is allowed in school and what is not, who is a “good” student and who is not, what a “competent” reader looks like and what one does not. They bring to school other notions of what is normal and what is not. The affective dimensions of their stories and the spaces for such stories are in constant flux, creating a constant need for accommodation—change in language and change in meaning making—what Moll and Greenberg called “zones of possibility” in curriculum. For students who learn differently, capitalizing on these zones of possibility can create spaces for a more responsive

education, one that weaves together the ethical, emotional, and cognitive threads of learning. Some of the spaces children encounter in schools are open for sharing and constructing lives, spaces where dialogue is apparent and where many discourses are welcomed. While some students find success within these rigid spaces, there are others who are marginalized by such spaces—spaces that seem restrictive and cramped, only allowing for a few, “success” narratives to be lived, thus, casting doubt upon other lived experiences.

From an ecological perspective, Urie Bronfenbrenner (1979) argued that the transitions between school and home and home and school are critical to growth and development or the lack thereof. How students journey through social systems affects their personal development, academic growth, identity, and agency. What happens in one social system affects others; thus, what occurs outside of school and the perceptions of events in school by families and children have direct effects on the motivations of children.

Stories of schooling and stories of families along with stories of the interaction between the two will provide a springboard for understanding the dynamics involved in a developing child. Karen Gallas (1994) conveyed, in an exemplary study of children’s exploratory use of language in student-directed learning opportunities, “[t]eaching and learning are embedded in the world outside school” (p. 158). Anthony Pellegrini (1996) noted that “we still know very little about children outside of school settings” and challenged researchers “to generate such descriptions” (p. 2). This research responds to that challenge. I illuminate and describe narratives told from students who struggle and families struggling to carve out places in the social worlds of learning for themselves and

their children. “[T]he practices of human communication—the negotiation and performance of acts of meaning—should become our model for how we tell about the empirical world” (Ellis & Bochner, 2000, p. 748). Below I outline my intentions, my wonderings, and my expectations for this research. First, I explore the purpose of my research and then state the guiding questions.

Purpose and Goals of this Research

In her memoir, A Slant of Sun, Beth Kephart (1998) alluded to the notion of invisible differences as she searched for responsive schooling for her son,

“We have a bias toward those with the kind of physical handicaps that the other children can readily see,” the headmistress tells me point blank. “Those sorts of handicaps are easier both to remember and to be kind to, and what we focus on here is empathy. Your son, his difficulties, are—to the young eye—invisible. He wouldn’t be much use to us here.” (p. 112)

This research endeavor, to understand and explore the experience of invisible difference, is multidisciplinary and embraces narrative as a central tool for objectifying and understanding experience (Vygotsky, 1934/1986, 1978; Dewey, 1934). In particular, it drew on theories from the humanities, social sciences, and psychology specifically including language theories of Lev Vygotsky (1934/1986, 1978), James Gee (1996), and Mikhail Bahktin (1981, 1986), narrative theories of Jerome Bruner (1986, 1990), James Britton (1970/1993), Robert Coles (1989), and Barbara Hardy (1977), child and family development theory of Urie Bronfenbrenner (1979), and educational theory of John Dewey (1916, 1934, 1938/1963) and Maxine Greene (1995).

As I alluded in my opening statements, narrative theory and narrative inquiry frame my research (i.e., Bruner, 1986, 1990; Coles, 1989; Connelly & Clandinin, 1988; Denzin, 1989; Lieblich, Tuval-Mashiach, & Zilber, 1998; McAdams, 1993; Polkinghorne, 1988) and I situate myself within a sociocultural perspective (Vygotsky, 1934/1986, 1978). I use narrative as both process and product in my research. By adopting an autoethnographic stance (Ellis, 1995a; Ellis & Bochner, 2000), I unleash many possibilities. I draw upon and make explicit connections to fields outside of education, broadening the potential audience of the research. The focus of this research is on familial narratives of two boys who learn differently, boys who appear quite “normal” on the outside, but have difficulty learning. In essence, their intellectual differences often appear to be invisible differences.

The purpose of my research was to explore how two families use narratives as tools for defining and understanding themselves as they attempt to construct, participate, and navigate worlds of schooling and worlds beyond school. Labeling was not a goal of this research. Rather, understanding, experiencing, and describing were central goals of this research. In A Slant of Sun: One Child’s Courage, Beth Kephart (1998), wrote about her son,

I will not, no matter what, confuse my child with a label. I will not be taken down by false constructions, empty forecasts. I will not lose sight of the gift that my son is, will not let go of my expectation—my surety—that Jeremy will find his way into this world (p. 85).

The intent of this research is to offer spaces and zones of possibility for narrating about a particular lived experience. In particular, I explore how children with invisible

differences and their respective families define themselves as they “learn to do school” (Dyson, 1984) differently. In a study of the relationship between learning to write and learning to perform school writing tasks, Anne Haas Dyson carefully observed and constructed case studies of three kindergarten children. These students came to school with some notions of how to do school. “While educators may conceive of the school’s function in narrow terms, such as to teach specific skills, young children playing school illustrate their sensitivity to school as a social affair...” (Dyson, 1984, p.233). By way of extending Dyson’s ideas of “learning to do school,” I elaborated upon her notion of learning to do school “differently” by suggesting we consider how children with invisible differences and their families learned to do multiple social worlds of learning. As two families shared their narratives, they inevitably shared the texts of their lives. I documented the understandings of two families and their various social worlds with particular attention given to the subsequent connections that reverberated beyond the walls of school. I focused on the meanings two families attached to the social objects and experiences that were important in their lives.

As Carolyn Ellis and Art Bochner (2000) noted,

[I]t’s important to get exposed to local stories that bring us into worlds of experience that are unknown to us, show us the concrete daily details of people whose lives have been underrepresented or not represented at all, help us reduce their marginalization, show us how partial and situated our understanding of the world is (p. 748).

I invite you to join a journey in which you will develop an experiential sense of what it is like to learn differently and live differently from the perspective two families. Readers

will gain an experiential sense of learning differently rather than a prescription or diagnosis. Furthermore, I explore not only the cognitive and linguistic processes of learning, but give particular emphasis to affective, emotional details. In addition, I craft meaningful and evocative narratives about the topic of learning differences from an ethic of care and concern, and in doing so, I hope to provoke stories and dialogue about learning differences within educational communities. Finally and perhaps, most importantly, my goal is to reduce the stigma and marginalization of persons with learning differences. Before I review theoretical and literature connections to this study, I reveal the guiding questions of this study.

Research Questions

According to Jean Clandinin and Michael Connelly (2000), inquiry, driven by narrative, “carries more of a sense of a search, a ‘re-search,’ a searching again . . . a continual reformulation” (p. 124). Above and in the pages that follow, I provided evolutionary details and directions for this research telling you the story of the research and of my developing interest in the phenomena of learning differences and learning differently. It remains deeply personal for me; readers will experience the telling of the researcher and the research. In some research, questions can be clearly defined and solutions can be given at the consummation of the research. However, as in most qualitative inquiries, I began with questions that represented wonderings and continually revisited those questions. Since the phenomena of learning differently seemed somewhat elusive and rested on shifting ground, as a researcher, I returned often to the ever-evolving influence of these questions.

Below are the guiding questions:

1. How do I construct and make use of my narrative and others' narratives in shaping an experience of difference for others?
2. How do two families describe and assign meaning to their social experiences with learning differences? What are their perceptions of experiences in school and beyond school? What are the recurrent themes and metaphors inherent in the social construction of learning differences?

In this exploration, I attempt to deconstruct the language of childhood disability by sharing a vicarious experience of an experience through narrative. Through the exploration of connections of the focal families, I share an understanding of narratives of and about children who struggle to learn and their families. I show the interplay of social forces and ideological pressures that inhibit and/or foster growth and development. By adopting a narrative stance that honors the process and product, I identify both the shifting positions and stances that such children and families inhabit as they navigate among safe and not-so-safe places to learn and live. I also reveal changes over time as well as the goals and aspirations of children who learn differently. Now, onto the work ahead.

Reader's Overview

While I resist providing an exact roadmap for you, I believe it important to give you a general overview of what to expect in the coming pages. This is a dissertation concerned as much with the heart as with the head, as much with ethic as intellect. The first chapter stands to provide a history and rationale for the research. While the second chapter presents a review of the literature, the third chapter offers the hows of this research. The methodology chapter provides in greater detail how the narrative chapter

was written and created. You may elect to read these chapters prior to reading The Narrative Work, or you may elect to read The Narrative Work and the final chapters first. Chapter Four offers the crux of this research, that is The Narrative Work. You will find multilayered narratives that are woven together along a shifting timeline. There will be flashbacks and flashforwards. Chapters five and six work congruently to provide both the elaboration of themes and the implications of this research. Chapter seven provides two letters, one for educational professionals and the other for families. As a reader, you must decide how you will read the work. In whatever order you read, I implore you to make yourself vulnerable, for I suspect somewhere between the lines of this narrative, you may find yourself or someone you know.

CHAPTER TWO:

THEORETICAL/RESEARCH CONNECTIONS

In this section, my intent is to draw upon theoretical and research literature in making connections to this research. I begin with a discussion of the merits of learning about social worlds with children. Before moving to a discussion of language theory, I explore a definition of how experience will be treated in this study and make narrative connections to how experience is conceptualized. Finally, I note possibilities of this research and conclude with summative statements and significance of this research as warranted by the selected literature. It was not my intent to provide an exhaustive or comprehensive review of family development theory, language theory, narrative theory, or educational research relating to families. Instead, my purpose was to illuminate literature pertinent to the current effort, make a case for researching lived experiences, and convey to readers the implicit and explicit connections to the field of language education. Additionally, this chapter sets up the theoretical framework by which the narrative work was crafted. Drawing explicitly upon Urie Bronfenbrenner's ecological theory of development, I first consider the merit of learning about children's social worlds and the theoretical dimensions that directly apply to this study.

Learning about Children's Social Worlds: Opening the Possibilities

Studying with families can change our perceptions of . . . those students [who learn differently]. . . . Societal pejoratives no longer have meaning. New sensitivities replace old stereotypes. And eventually the socially constructed

accounts of the research can be used as the basis for more humane, family centered policies that provide opportunities for all parents and children to become active members of the society to which they belong (Taylor & Dorsey-Gaines, 1988, p. 196).

The intent of the following section is to argue for the primacy of children's social worlds, especially those outside of school, as sources of knowledge for understanding literacy development and possibilities for realms of meaningful activity outside of school. In focusing on children in an endeavor to understanding their social worlds, it becomes necessary to consider the social worlds in which they are central characters. Along with their families, children move about many nested social worlds; thus, I considered the full cast of characters in this study. Denny Taylor's work (1983) focusing on literacy at work within family contexts and her joint study with Catherine Dorsey-Gaines (1988) of literate practices among inner-city families illustrates the importance of understanding family contexts. JoBeth Allen, Betty Shockley, and Barbara Michalove (1993, 1995) also contributed significantly to the argument that we need to know and understand children and families in order to build partnerships between homes and schools. Anne Haas Dyson's (1989, 1993, 1997) explorations of children's social worlds provided further understanding of the ways that children construct their own literacies from influences of both peers and families.

If we are to understand personal development, encompassing cognitive and affective development, consideration of the social worlds of children and families becomes paramount. According to Bronfenbrenner's (1979) ecological theory of development, development occurs as children move among various social spheres or what he calls

systems. He proposed four levels of systems. The first level, the microsystem, is characterized as a child's immediate setting (e.g., playground, school, home, peer group); it consists of the activities, roles, and the network of interpersonal relationships of the participants (e.g., parent and child, teacher and student) and the contextual dimensions of those settings. The three additional levels influence the immediate setting of the child. The second level, known as the mesosystem, consists of the interrelations of two or more of the primary social settings wherein the child participates as a member of that setting; how each setting affects the child's perceptions is central. The exosystem represents the third level and refers to settings that the child is not an active participant but where events in that setting affect the other systems that the child participates; effects of the exosystem are more indirect but still may affect the development of the child. Finally, the cultural milieu, representing the final level, encompasses the microsystem, mesosystem, and exosystems of the child's environment. This level includes the political, cultural, ideological, and social history of a period of time. Bronfenbrenner (1986) added the chronosystem to the above model explicitly recognizing the temporal nature of changes in the above systems. Bronfenbrenner argued that these settings must be considered from the child's perception or interpretation of events; mere observation would not suffice. A child's development and behavior guided by the child's meaning making of each setting. The child's imagination and idiosyncratic interpretations reveal the activities, roles, and interpersonal relations of the systems.

Given the figure provided in Appendix A, we can conceive of this approach to development as nested concentric circles. In the center of the whole system is the child. As one moves outward from the center, the child's relationship with various spheres

becomes more and more detached. The activity among each system is complex and interdependent to some degree. Each realm can be opened or closed and fluctuates across time. Activity occurs bidirectionally. How one navigates about these social worlds and how successful one becomes in this journey inevitably affects personal development. My interest in this model is to consider the potential for development that arises as children and families move back and forth among social systems. It is during these critical moves that Bronfenbrenner (1979) believed the greatest potential for growth and development resides. Thus, adopting such a model requires attention to not only the influential events and actors in each system but also to the ways they interact across systems. I used this ecological model as both a guiding metaphor for this study and a development theory for considering social worlds of development for families and children.

Along a similar vein of theorizing, James Gee (1996) argued and theorized a powerfully compelling notion of language communities that revolves around the idea of Discourses. He argued that in treating language as a socially influenced construct, we need to focus on “Discourses (with a capital D).” Words alone cannot capture the complexity of the contextual dimensions of coming to know oneself and one’s community. Discourse includes more than mere words. Rather, it includes actors “behaving, interacting, valuing, thinking, believing, speaking” in a variety of ways that define “particular roles” due to membership in specific groups (p. viii). “Discourses are ways of being. ... They are, thus, always and everywhere *social* and products of social histories (Gee, 1996, p. viii). We are members of invariably different and dynamic Discourses. The same story in different contexts can be very different stories. Contexts are shifting and constantly in the process of being negotiated and resisted by members of

various Discourses. Discourses condition its members to act in certain ways to be *normal*. “A Discourse is a sort of identity kit which comes complete with the appropriate costume and instructions on how to act [and] talk” (Gee, 1996, p. 127). Being part of a club could serve as a metaphor for what Gee calls Discourse. In a club, you have to meet certain qualifications and take a pledge of allegiance. A member must pay their dues and act in appropriate ways that live up to the creed of the group. And there are many, many tacit rules on behavior. If we want to be part of the club, then we participate and act within the dimensions set by the Discourse. We learn the discourse of the Discourse by participating in them.

Understanding life outside of classrooms and how learning and living become enacted became central to this study. What counts as knowledge and what it means to be a contributing and acting member of various social spheres becomes determined by the local social history across time and events (Bloome, 1985; Bloome & Egan-Robertson, 1993). In order to construct a more inclusive and responsive curriculum, knowledge must come from children and families. We can invite them to become co-researchers with us (Dixon, Frank, & Green, 1999; Green & Bloome, 1997; McCaleb, 1994).

Funds of Knowledge

Contrary to notions that teachers and textbooks are ultimate authorities over what counts as knowledge and how it is understood, the production and utilization of knowledge does not only happen in schools. The “funds of knowledge” work of Luis Moll and colleagues (Moll, Amanti, Neff, & Gonzales, 1992; Moll & Greenberg, 1990) suggested that we look outside of schools for “historically accumulated and culturally developed bodies of knowledge and skills essential for household or individual

functioning and well-being” (Moll et al., 1992, p. 133). This foundational work set out to draw upon family and community knowledge and skills as teachers developed instructional modules for teaching students. Understanding the sociopolitical and economic contexts of households along with the social history of families revealed “thick and multistranded” social networks across a local community. Key to the successful acquisition of family knowledge were notions of reciprocity, trust, and social relationships/interdependence. Adopting a positive view of the cultural and cognitive resources of families, the teachers of the students began to develop more complete and sophisticated portraits of the whole child making use of this newly gained knowledge to transform their instruction. The “funds of knowledge” work serves as the primary impetus for my interest in researching the stories of children struggling to learn and their families.

Narrowing in: Learning About Childhood and Families Through Narrative

We all need stories to nourish ourselves, to feed the mind and heart. Today, children and families are eagerly trying to figure out and fit into a socially complex world, especially students who struggle to learn. Narrating stories can allow us to see ourselves in relation to others, appreciating difference within ourselves and evaluating ourselves, others, and overlapping experiences. Classrooms and communities are places where children and families meet, bringing their pasts, their differences, their hopes, their distinctive strengths and weaknesses. Since schooling discourse can be rigid, it is often outside of classrooms that children talk more openly about the way they learn, how they perceive other classmates, and what is important to them about learning. Weaving these “life stories and storied lives” (Ochberg, 1994) into the curriculum is one responsive

means of reaching and teaching *all* children, but only if we heed the call of stories (Coles, 1989) and learn to listen carefully. Understanding children and families multiple social worlds may help us broaden our understanding of intellectual diversity and can perhaps help us develop empathy for such diversity.

Too often, mainstream definitions of family permeate the educational field and constrain the kinds of conversations that are desirable or even possible (Pipher, 1996). Although there have been attempts at getting to know families through parent education and family intervention programs, too many of them continue to offer formulas or recipes. In addition, they seem to reestablish past mythologies and perpetuate what Beth Swadener and Sally Lubeck (1995) called “children and families at risk” (p. 2). Lubeck and Garrett (1990) challenged the at-risk labeling movement of the 1980s and 1990s arguing it positioned problems in families and communities rather than in institutional structures.

Effectively researching families requires educational researchers to shift the role of expert as Betty Shockley, Barbara Michalove, and JoBeth Allen (1995) demonstrated in a study of families. By placing ourselves as researchers in a position of learner, we forego being the expert. Educational researchers can learn from families, recognizing them as “more capable peers” (Vygotsky, 1978). In an exemplary teacher research study, Cristina Igoa (1995) intertwined her own immigrant story with the voices of the immigrant children she studied; she pursued not a “formula” but a reflective telling of the cultural, academic, and psychological dimensions of learning to do school. In the process of developing learning opportunities from familial narratives, she began the challenging work of creating new pedagogical practices and reforming old practices. Working from

such viewpoints will not only position parents as important participants and informants, but will expand our definition of families to include extended family as we invite aunts, uncles, grandparents and children to play instrumental roles in our research. Moreover, this myriad of participants and informants allows us to consider the multiplicity of meanings and the multiple levels of experiencing various social worlds. The “local knowledge” (Geertz, 1983) that is gained from varying our perspective and lenses can help us adjust the focus upon families. Understanding family knowledge can help us identify discourse communities and the impact of that language on the movement among system.

In an endeavor to understand and learn from children’s social worlds, it is important to clearly articulate how experience is defined and how narrative is employed.

Experience is an often confusing and contested notion in research. I have included theoretical discussion of experience in order to set before you the way in which it was conceptualized for the project and further the way that it guided my thinking. Below, I begin with a discussion of how experience was conceptualized for this study.

What Counts? Theorizing and Conceptualizing Experience

John Dewey’s theory of art is key to understanding his entire philosophy. Dewey’s ideas and theories have gained greater attention recently as his philosophy has reemerged throughout educational and aesthetic discourse. Researchers are beginning to insist on redefining the essence of learning, experiencing, and being from a Deweyan perspective (i.e., Alexander, 1987; Berleant, 1991; Clandinin & Connelly, 1994; Fishman & McCarthy, 1998). For Dewey (1934), ordinary, everyday experience has the aesthetic potential for art. We live through many experiences, and albeit unconsciously perhaps,

we are constructing experiences. This unconsciousness of experience is perhaps due to a disconnected society and an educational field that at times seems limited and constrained in teaching children. Despite a plethora of scholars who have called for hands-on active learning, including Dewey's (1938) classical *Experience and Education*, many schools continue to focus upon the products of such teaching rather than on the complex processes of learning and experiencing. Schools instead teach content and curriculum and pay less attention to the processes and activity of constructing a work of art. Palmer (1983/1993) feared that our society is disconnected despite our need to connect with others through experiences. Too often, we simply overlook the significance of the accumulating experiences within our lives and their implications upon our transaction with the social world around us. When we embed ourselves in habit, we miss the inherent connections of our experiences with the experiences of others. By consciously bringing lived experience to the fore of our reflections, we reposition how we act upon the world and how the world attempts to act upon ourselves. We are better prepared to actualize a more attuned relationship with our social worlds.

All narratives are steeped in experience. Experience emerges from the ordinary, everydayness of our lives. We go here and there, meet this person and that person, answer calls and hails, and all the while, albeit unconsciously perhaps, we are learning and constructing experiences as we move about and through various referential spheres. Dewey suggested that everyday experiences – what Maxine Greene (1978) called “the cotton wool of daily life” – have the potential to be not merely recognized but rather, they have the potential to become aesthetically acute. By paying attention to the quality of the moment and dimensions of experience-in-action, we can move beyond merely selecting

what seems practical for existence. Instead, we can consider the emotional and intellectual qualities of experience. Further, this awareness and consciousness of narrating experience becomes a newly, reexamined experience, one with aesthetic potential. It provides possibilities for reshaping our experiences and reforming the meaningful activity that we create in settings with others. Education and experience are inextricably connected and interwoven (Dewey, 1934, 1938).

As Dewey (1934) noted, there is often a “chasm between ordinary and esthetic experience” (p. 10). This artificial division requires a separation of ordinary living experiences from the more revered artistic expression of art. Dewey proposed a philosophy of aesthetics which creates the possibility for the ordinary to be embraced; further, his philosophy suggested the ability to cultivate perceptual abilities and recognize the developmental processes of a journey toward *an experience*. In essence we become active perceivers of life. Attending to lived experiences in more systematic ways can provide fresh perspectives. And by opening up such possibilities, we create a space for new realities, fresh visions, and “unsuspected experiential possibilities” (Greene, 1978) rather than probabilities or guarantees. Active perceivers of lived experiences use various tools as they craft experiences.

Mikhail Bakhtin posited that “there is no such thing as experience outside of embodiment in signs. ... It is not experience that organizes expression, but the other way around – expression organizes experience. Expression is what first gives experience its form and specificity of direction” (Voloshinov, 1973). We use words as psychological tools for not only organizing (Vygotsky, 1934/1986, 1978; Britton, 1970/1993) and representing our worlds but creating and transforming the potential possibilities of our

realities. The words, one of many sign systems we use to create our being and our communities, become increasingly important for us to consider as we seek a sense of harmony and equilibrium within each experience. While Dewey emphasizes the individuality of ordering our lives, he also notes the influences of the social transactions occurring within a sociocultural-historical context. In Deweyan thought, the individual is critical and central in understanding how a transactional experience develops but standing alone, the individual remains an artificial construct unless she is understood within the framework of the social. “What counts is what we *do*, not what we receive” (Dewey, 1934, p. 102). It is both the “doing and undergoing” that are important, the rhythm of our experience. As we enter experience through the realm of meaning, Polkinghorne (1988) emphasized that it is “not a thing or substance, but an activity” (p. 4). It cannot be objectified outside of the actual doing. Novelist Bernhard Schlink (1997) conveyed a similar image in *The Reader*, “The tectonic layers of our lives rest so tightly one on top of the other that we always come up against earlier events in later ones, not as matter that has been fully formed and pushed aside, but absolutely present and alive” (p. 217). While language is an important, often privileged, means for rendering a reality, Dewey reminded us that it falls “infinitely short of paralleling the variegated surface of nature” (p. 215).

We can extend our understandings of experience by considering narrative constructions. Perhaps our evolving understanding of social worlds is incomplete without considering other sign systems and the actions of lived experience. Our stories may be objectified, displayed, and interpreted through words but often these stories come from interaction with art, music, nature, or other ethereal experiences. In any case, the

narratives are very alive and are influenced by the social forces around us. However, as Rosenblatt (1938) indicated, these social conditions are “shifting and uncertain” (p. 84). The tensions and rhythm of experience lead researchers to consider the impact of not only current conditions but to situate these historically within the individual and the social worlds in which the individual interacts.

Our past informs the present and moves us to rewrite, rework, reconstruct our current experience which in turn becomes our past. It is important that we consider the intellectual and emotional dimensions of an experience (Greene, 1978). We deepen our understanding of the present and future possibilities by drawing upon the past and expanding upon it. This shuttling back and forth between the old and new creates a certain rhythm by which the old is no longer seen as old but as a new old, understood differently in space and time. The change that occurs is a defining feature of the act of expression. Change requires tension and resistance. It is not merely the activity itself; rather, we become an active part of the transaction. We never fully reach a consummation; although, we have been conditioned from Western philosophy to believe that experience has an actual ending. Rather, we reach a sense of closure which in turn becomes an awakening for a new experience. In short, the process is continuous, cumulative, and recurring.

Recreating experiences is a “construction in time, not an instantaneous emission” (Dewey, 1934, p. 65) . Our experiences and the language we use to create a reality need time to develop, time to ripen. Experience is temporal (Ricoeur, 1984). It is not a linear process nor is it in any way uniform. Our movement across social worlds and through various activities never looks the same for two people. Instead, it is phenomenologically

experienced and interpreted based on the interrelationships of previous experiences. What occurs is an accumulation of experiences; and from these experiences, we learn to create expectations about the future, “expectations which, as moment by moment the future becomes the present, enable us to interpret the present” (Britton, 1970/1993, p. 12). We use language as the medium by which we not only act but reflect upon our world. We strive to understand the world through narrative. How we theorize narrative and use language in learning and researching become critical issues as we constantly reinvent knowledge and make knowledge of our experiences.

Narrative

Jerome Bruner (1986) explicated two modes of thinking, each with particular ways of ordering and construing reality. Neither is reducible to the other and they function in radically different ways. Paradigmatic thought is the form of cognitive function that is primarily concerned with forming a logical argument through induction. The narrative mode differs fundamentally—its concern is on establishing verisimilitude through a good story, employing the particulars of experience. It is this narrative mode that I will emphasize in this theoretical review.

Narrative, one’s story of one’s experiences, is an important dimension in understanding ourselves and others, anticipating and reflecting on life in action, and transforming ourselves and our social worlds. Through narrative as a process and product, we begin to shape our worldview and upon that talk we invent and reinvent who we are and who we are becoming (Britton, 1970/1993). Norman Denzin (1989) claimed that “[o]ne becomes the story one tells ... In fact, we create the persons we write about, just as they create themselves when they engage in storytelling practices” (pp. 81-82). It

is through narrative that we build relationships among ourselves and others and open spaces for transcending the “obviousnesses” of our lives (Althusser, 1971, p. 172). It is through narrative that we “preserve the texture of truth, not to let its fibers slip beneath the web of silence and collusion which people—often with the best of intentions—spun to sustain and protect one another” (Hegi, 1994, p. 28). According to first grade teacher and scholar Karen Hankins (1998b), “carefully synchronized and interpreted journaling of individual stories of the present and the past” (p. 24) enables us to create “unsuspected experiential possibilities” (Greene, 1978).

We give meaning to our lives through a narrative mode of thinking, and through this narrative mode we embody everyday human experience (Langer, 1995). In a biographical study of five women, Mary Catherine Bateson (1989) claimed that we are, in effect, “composing a life” (p. 8). The decisions we make, the processes we undergo, the rhythms of our lives – all improvisations – take on new importance as we rethink the “texts” of our lives. Bateson (1989) and Dewey (1934) suggested that our efforts at “composing a life” are never static. Rather the composition is dynamic, fluid, improvisatory, in constant flux, providing spaces for tensions and resistances. Further, this dynamicism is critical if our goal is to construct aesthetically acute lives. While Bateson (1989) considered women and their unique experiences specifically, she extended the call for such explorations to include the lives of men and children. She claimed that children need to be able to “reinvent themselves again and again in response to a changing environment” (p. 17). Knowing about the lives of children through stories told by them and those told about them can give us important information for educating future generations.

Children in “official” school worlds and “unofficial” school worlds (Dyson, 1993) are constantly negotiating roles in society, choosing stances by which to appropriate other roles and by doing so, ultimately create “possible worlds” (Bruner, 1986, p. 45) and “imaginative universe[s]” (Geertz, 1973, p. 13). These social worlds are formed and informed through story. How one journeys through multiple social worlds is made known through the narratives created about such experiences. As Guy Widdershoven (1993) suggests, “the implicit meaning of life is made explicit in stories” (p. 2) and as we experience life we narrate it and interpret it narratively. Narrative is more than a genre; it is a way of inhabiting the world. According to Barbara Hardy (1977), “we dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, count, revise, criticize, construct, gossip, learn, hate, and love by narrative” (p. 13).

Some researchers (i.e., Heath, 1983; Miller & Mehler, 1994; Dyson, 1993, 1997; Gallas, 1994, 1998; Paley, 1997; Connelly & Clandinin, 1988; McGinley & Kamberelis, 1996) have suggested that by considering the stories of young children and the impact of such stories on educational understanding of children and families, teachers can inform and reconstruct current educational practices and paradigms of thought, creating what Anne Haas Dyson (1993) called “permeable” curricula. Unfortunately, experiences of children who learn differently are often marginalized and misunderstood. Literary theorist Perry Nodelman (1996) listed common assumptions of childhood that treat children as being more alike than different and that “define childhood almost exclusively in terms of its limitations” (p. 74). These assumptions are generalizations and cannot apply to all children. “In this world, each child is his or her own person, an individual being whose values and abilities are influenced both by heredity and environment. When

we make assumptions about the similarity of all six year olds, we lose sight of the immense significance of individual differences” (Nodelman, 1996, p. 76) in the process of learning and their life experiences. Nodelman (1996) suggested that we transcend the “idea that children are limited and even empty” (p. 83). Rather, as Bronwyn Davies (1993) wrote, teachers and researchers alike must create zones of possibility for children to “invent, invert, and break old structures and patterns and discourses and thus speak/write into existence other ways of being” (p. xviii). Perhaps “narrative arrangement[s] of reality” (Denzin, 1989, p. 24) can provide a unique lens from which to consider both individuals within socially complex and multifaceted worlds and the overlapping, relationships of students, parents, and siblings.

Echoing the words of Shakespeare in As You Like It (Lathem, 1999), Peter Smagorinsky (1999) offered an image of the world as a stage. Drawing upon Vygotsky’s works, he argued that art can be a vehicle for understanding the world around us and the world within us. “Life itself is a drama, one that is played without the benefit of a director, script, or second takes” (Smagorinsky, p. 17). If we as researchers can view students’ experiences and their families’ experiences, conceptualized narratively, as possible works of art that are pregnant with meaning and aesthetic possibility then, the study of narrative expressions seems essential to the study of our lives. Smagorinsky’s argument and illustrative data serve as a powerful challenge to change how we typically think about lived experiences and texts, how we understand language and respond to language, and how we conceptualize experience and experience narratives.

Narrative inquiry helps us build bridges between our experiences and life experience in general (Clandinin & Connelly, 1994). It helps us assess the interrelationships of the

social worlds we inhabit. Our life experiences become the social catalyst for researching social worlds. We use language as the medium by which we not only act but reflect upon our world. We strive to understand the world through words. How we use language in learning becomes critical as we constantly reinvent knowledge and make knowledge our own. Understanding how one constructs these narratives and interprets experience becomes imperative to consider. Words are central to the development of stories and to the objectification of experience. In the next section, I will delineate the notions of language theory; I will draw upon sociocultural theory as a paradigm from which we can consider the storied landscapes in which children and families construct themselves. This research study provides a forum in which we can look within ourselves for meaning, and understanding can substantially change how we perceive and respond to the stories told.

Language

Learning language, learning to use language, and learning through language involves words – words that are inherently slippery and imbued with various meanings and ideologies, words that have social consequences. This complex and endless act of learning language involves social interaction and relationships with others; it involves both public and private spheres of thought. It is dialogic and intertextual. It is the manner in which people mediate ideas, define themselves, and establish relationships. Language learning and language use are intellectual, affective, and practical operations. In understanding experience and narrative construction, we can draw upon Vygotsky's and Bakhtin's contributions to a sociocultural theory of human consciousness. From these perspectives I critically consider the role language plays in the creation and transformation of experiential narratives.

Social Context of Language: Building a Foundation for Experiential Narratives

Speech and thought are inextricably connected. Vygotsky warned that as we consider the concepts of language and consciousness, we cannot solely research the cognitive domain but must consider the social factors too. “Thought is not begotten by thought; it is engendered by motivation. . . . Behind every thought there is an affective-volitional tendency, which holds the answer to the last ‘why’ in the analysis of thinking” (Vygotsky, 1986, p. 252) Instead, we should unite the affective and intellectual domains. This is a difficult challenge and while some researchers have considered the influence of social interaction, fewer researchers have paid particular attention to the affective dimensions of learning language, particularly as they are manifested in the construction of stories.

Narratives are constructed socially and temporally and through these dimensions of understanding reality, Vygotsky’s work is helpful in explicating the social forces upon language. The social context of thought and language is a cornerstone of Vygotsky’s works (1978, 1986). As we engage in social acts, these acts become the origins for higher mental functions. Vygotsky posited that language and cultural development occur on two levels. As we use symbols and other sign systems to construct meaning in a particular social milieu, we move from an interpsychological plane of meaning to an intrapsychological plane. Higher mental functioning in an individual first is played out in social activity among others. As we move between these two planes, we construct newly formed information, appropriated knowledge. Since even our private speech, “inner speech,” is originally shaped through our interactions with others, the social milieu in

which interaction occurs becomes critically important as we consider intellectual development (Wertsch, 1985).

Our words and their meanings are dynamic and change as individuals change. Words and thoughts are so closely interrelated and serve to condition each other. The relationship between thought and word is always shifting, moving back and forth between thought and word and back again (Vygotsky, 1986). The way we approach our experiences and encounter obstacles is influenced by our social context and our experiential history. Over time, the structures of these mental functions change not only in interaction with others but also in communication with oneself. Just as thought and speech undergo changes so does our intellectual and affective development; they are closely intertwined. Given the often emotional dimensions of being different and the uneven social pathways, children and families reinvent themselves through bidirectional movement between the interpsychological and intrapsychological planes.

Echoes in Language: Dialogic Nature of Language

The related theory of Bakhtin's conceptions of dialogism, utterances, and voice can be helpful as we consider their impact on a narrative inquiry of stories. Bakhtin (1981) suggested that no utterance, thus no thought, belongs solely to the individual. Rather, the utterance has a history. Bakhtin (1986) posited that the meanings of words and thoughts are subject to the dialogic nature of discourse. Speech and thought are both shaped by previous utterances and anticipated utterances. What came before always influences what may come beyond. Thus, I speak not as one but as a chorus of many who have come before me. In my voice, the voices of others echo. This tension, the relationship of self and other, is centered at the sociocognitive, sociolinguistic event of sharing life stories.

Whether we are adopting the roles of teacher, parent, peers or other such roles, we fling ourselves into the construction of “zones of possibilities” (Moll & Greenberg, 1990) for meaning-making and various discourses for storying within specified communities. This is the nature of socially organized activity, specifically the activity of talking about one’s life experiences and making sense of them narratively as described in this research venture. Since words are negotiated and carefully selected when constructing a life, it is important to consider the theoretical dimensions of those words. It is by such words, words loaded with cultural, political, and social meanings, that we create a life. Through dialogue with others, speech and thought undergo shifts and changes that in effect influence our psychological planes of understanding and experiencing. The meanings and connected associations with such words are appropriated, negotiated, and situated temporally and socially.

As children and families tell their stories, either implicitly or explicitly, teachers and researchers respond to these textual lives. It is often the contextual dimensions of such constructions that bear upon understanding and meaning making. Teaching and meaning-making are complex notions; both are always in flux and change. We use words to make visible the stories of our lives and thus how we come to understand the meanings and essence of such words becomes a critical matter in narrative inquiry. In effect, Vygotsky (1986) argued that word meaning develops, that it is not dormant. Rather the development of meaning and understanding is a process of spiraling through many layers of thought as experienced in socialization just as we move about different social spheres. I contend that it is conscious attention to this process, embedded in social interaction, that warrants and informs this research proposal.

As I strove to construct a theoretical frame that informs my thinking in regards to narrative inquiry and stories of children, I borrowed Dyson's (1997) applications of Bakhtinian theory to her investigation into the writing worlds of children. Dyson (1997) suggested that "our texts are formed at the intersection of a social relationship between ourselves as composers and our addressees and an ideological one between our own psyches (or inner meanings) and the words, the cultural signs, available to us" (p. 4). She posited that composing as a process has both horizontal and vertical dimensions. Along the horizontal axis, we consider the construction of text for oneself or for others and this decision further influences the text product. An additional tension is created along the vertical axis as writers attempt to construct a text that reveals inner meanings to a public or private arena; this text is somewhat limited due to the availability of words or signs for expression. "Composers, then, are not so much meaning makers as meaning negotiators, who adopt, resist, or stretch available words" (Dyson, 1997, p. 4). It is in this manner that this study focused upon the perception and consciousnesses of social worlds as objectified through children's narratives.

Intersection of Children's Narratives and Children's Consciousnesses

Children's consciousnesses are revealed through language and through social interactions and enactments of reality; they create spaces for negotiation and appropriation. Vygotsky (1986) stated, "Thought is not merely expressed in words; it comes into existence through them" (p. 218). Dewey (1934) contended that experience is cultivated through, conceptualized in, and derived from expression. Narrative, then, becomes critically important to consider as a central organizing phenomena for research. Vygotsky (1986) wrote, "Thought and speech turn out to be the key to the nature of

human consciousness” (p. 256). We can only begin to understand the development of consciousness and subsequent behavior by considering the tools that individuals use in mediating human transaction with the world. Considering the tools that individuals use requires attention to not only technical tools but also psychological tools or signs.

Thus far, I have argued that experience is a unique construct that meaning is created through language and other sign systems. Moreover, having an experience is active and ongoing and reaches beyond the artificial objectification of such an experience. I also have suggested that narrating our stories is a fundamental means by which we make meaning; it inevitably pervades all systems our social worlds. In this section, I argued that language as theorized by Vygotsky and Bahktin can inform how we understand the development of life narratives. How language defines us and how we respond to such lives as texts becomes critically important in exploring the social worlds of children, understanding the stories of families, and inventing new ways of knowing. Below, I elaborate on language theory by offering a series of connective possibilities for explicating dimensions that should be considered as teachers, researchers, and students respond to each other’s lives—lived experiences, texts in action.

Concluding Thoughts

In the above discussion, I argued for a renewed conception of experience, narrative, and language, families and children often considered “at-risk.” Furthermore, learning about children and families can be fostered through a narrative lens. As argued above, we reveal our experiences through narrating. It is important then for us to consider how we define experience, how we can become more acutely sensitive to the everyday occurrences in our lives, how we understand the social dimensions of language, and how

language and thought shapes one another. Teachers, students, parents, and researchers use words as tools (Vyogtsky 1934/1986) to tell stories. While language involves more than the mere words that we choose to objectify an experience, it is often the place at which we start when we seek to understand the meaning of our lives. The telling of the narrative organizes experience in particular ways and moreover influences our perceptions. Both the form and substance of the telling can be considered as a whole, constantly influencing one another. Therefore, as responsive teachers and sensitive researchers, we consider not only the experience but how that experience is objectified through words and how it is socially and historically embedded. Experience begets stories and stories beget experiences. Thus, the trajectory for this research lies within the stories to be told, shared, and coconstructed. In the next section, I explicate the methodological frame adopted for this research.

CHAPTER THREE:

THE WRITING STORY

But I talk about my life anyway because if, on the one hand, hardly anything could be less important, on the other hand, hardly anything could be more important. My story is important not because it is mine, God knows, but because if I tell it anything like right, the chances are you will recognize that in many ways it is also yours. Maybe nothing is more important than that we keep track, you and I, of these stories of who we are and where we have come from and the people we have met along the way because it is precisely through these stories in all their particularity, as I have long believed and often said, that God makes himself known to each of us most powerfully and personally. If this is true, it means that to lose track of our stories is to be profoundly impoverished not only humanly but also spiritually (Buechner, 1991, p.30).

In this chapter, I offer you a writing story, a story of how this research evolved and why it became what it is. I describe the methodological frame of this study: a parallel study of two families at different points in time and yet timelessly bound by a similar experience. I tackle the usual methodological sections in a narrative format that I hope will engage you in my personal struggle with writing this story. This research is uniquely different from others in that the emphasis was on two families, my family and another family. Both families experienced social worlds of learning and navigated those social worlds with a child who struggled to learn and continues that struggle today. Some might

describe the study as a “now and then” look at the phenomena of learning differently, for I look back upon my experiences with a younger brother who has now graduated from high school. From that flashback, I also fall forward into the life of a third grader and his family as they reside in the midst of the political, social, and cultural realms of learning to journey through various social worlds. There are past, present, and future temporal dimensions to this study that make it unique.

In the Field

I suppose the first question methodologically that readers wonder may be, “Where did you go and what did you find?”—questions that focus on the nitty-gritty of the work. I’ve been “in the field” all my life. I’ve been rehearsing for years, seeking ways to understand the struggles of my younger brother and other students like him. The stories told as a part of this project are ultimately life stories; my researching story is told in the following pages.

Before I move to a discussion of some of the particulars of how this research was shaped, I delve back into my journal to determine how autoethnography became the central methodological focus for this inquiry. It was during my preprospectus meeting, a meeting wherein I had proposed studying students’ stories on schooling and incorporating portraiture (Lawrence-Lightfoot & Davis, 1997), that the notion of autoethnography was first raised. From the corner of the conference room table, Dr. Patricia Bell-Scott peered at me, raised her brows and suggested that I investigate autoethnography as methodology. She paused just long enough for the air to thicken. It seemed to her, after all, that “this research is really about you, right Shane?” Portraiture seemed to distance me; it allowed me to escape the spotlight. I liked it; it was

comfortable. However, Pat had ushered in a new notion for me to consider and noted that autoethnography differed from Lawrence-Lightfoot's (Lawrence-Lightfoot & Davis, 1997) portraiture methodology in that the researcher became a central part of the portrait being constructed and created rather than serving merely as a frame for the portrait. I had not heard the term, autoethnography, in my qualitative research classes. But her gentle nudging sent me swirling through a search of literature and ultimately served to convince and persuade me that laying my life out as data could turn my world upside down and perhaps offer an alternative telling of families of children who struggle to learn. And it gave me a chance to revise my own story in progress. I have a passion for storying and for stories that are untold like Carolyn Ellis and Art Bochner's (1998) story of abortion, stories that become silenced like Christine Kiesinger's (1995) narrative of an anorexic life, and stories that are lived along the margins of life like Carol Ronai's (1996) story of growing up with a mentally retarded mother. These stories and others like them re-center discussions on issues that are often hushed and "the act of telling a personal story is a way of giving voice to experiences that are shrouded in secrecy" (Ellis & Bochner, 1992, p. 79).

Getting Acquainted with Autoethnography

I left the preprospectus meeting with more questions about what I wanted to research. I looked toward new pathways with a renewed, yet hesitant interest in this new notion. Would I be willing to make my life and my younger brother's life and my family's life a topic for academic debate? I wasn't so sure. I engaged in searches of journals and methodology texts looking for a lineage of the term. Certainly, as with other words describing qualitative inquiry, autoethnography held multiple meanings for multiple

people in multiple contexts. The two primary strands that seemed to hold the methodology together were ethnography and life history, both of which I had encountered in my qualitative research coursework. Putting them together seemed certainly an interesting albeit impossible task. And while many methodologists suggested the importance of the researcher as instrument, none suggested that one's life history could become the data of a project. From Hayano's (1979) very narrow use of the term, describing "insider status" as the marker for determining a project "autoethnographic" to the Reed-Danahay's (1997) suggestion that the practice of autoethnography "involves rewriting the self and the social" (p. 4), it was clear that many people had something to say on this topic of using autobiography as part of research.

The one person who intrigued me the most and whose writing kept me awake at night was Carolyn Ellis (1995). She made explicit the turning of the ethnographic eye inward on the self while looking at the broader context wherein the self resides. She argued that autoethnographies were "stories that focus[ed] on the self in a social context" (Ellis, 1997, p. 117) and "concentrate[ed] on telling a personal evocative story to provoke others' stories and adds blood and tissue to the abstract bones of theoretical discourse" (Ellis, 1997, p. 117). As I was preparing the prospectus and rethinking my research on and about children who struggle to learn, it became clear to me that this research was about my younger brother, Christopher and our family and even more significantly, it was about me.

Meeting the Research Face to Face

In January 2000, at the 13th Annual Conference on Interdisciplinary Qualitative Studies conference on qualitative research, Carolyn Ellis was a keynote speaker. This

conference solidified my growing interests and commitment to engaging in autoethnography as a methodology. I arrived at the Georgia Conference Center and stepped out of my car, not knowing that I would step back into my car with more fears and more worries about the days ahead. The day would also be the beginning of a journey of researching, healing, and knowing myself more intimately. I jotted notes during Ellis' talk. Below is the poetic form that I later gave to my interpretation of her most important words that day.

Doing Autoethnography

Back and forth movement

Deep inside

Personal Experience

Connect to others

Connect to academic self

Connect emotional and cognitive

Fractures the art and science wars

Rejects the reader as passive

Evocative stories

Compel emotional response

Long to be USED

Become told and retold

For healing, transformation, and social change

A private register of thoughts

Co-Constructed narratives

Why can't our own experience be a part of our research?

Why must it be hidden?

Teaching and researching with

Love

And

Compassion

Ethical responsibilities

Vulnerability

Emotional turmoil

You can't call it back

You are what you wrote

Pain

And

Discomfort

LIFE AS LIVED—WORTH IT!

I'm ice cold as Carolyn Ellis talks about autoethnography. Her words and challenges resonate with what I really want to do with this dissertation. I want to share my life and yet all this is really scary—putting myself and more importantly my family right out there in the front for everyone to see. Autoethnography would be a fragile, intimate attempt to open spaces for other such stories. I had been running away from this dissertation for quite awhile. There was a time that I didn't understand why but that day I had a better idea about why. It was too close. It seemed too intimate, self-absorbed. And besides, those worries in the form of self-writing could never be accepted in the academy,

especially from a mere doctoral student. I mean, yes, I had read some of the scholars in the field that had written about challenging the canons of conventional social science. It just seemed impossible. How would I ever convince anyone that this story was an important one?

Like Carolyn Ellis (1997), I am “pushed to follow my ‘wonderlust’ and try to connect social science to literature, academic interests to personal ones, emotions to cognition, and social life to the concrete of living it” (p. 117). I have a passion for story. I understand myself and others through relationships and story. I view stories as a way of living (Hankins, 2000; Coles, 1989). I set out to tell a story, share a life, and provide an experience of an experience (Ellis & Bochner, 1992). Specifically, I acknowledge the huge influence that my younger brother’s schooling struggles has on my life and career as a nurturer—as a teacher and as a researcher. It was his story and its influence on my story that served as the catalyst for my life trajectory.

Carolyn sent me a methodological chapter from the *Handbook of Qualitative Research* that she and Art Bochner had written on autoethnography, a first of its kind to be included in the volume. From it I adopted Ellis and Bochner’s (2000) definition of autoethnography as

an autobiographical genre of writing and research that displays multiple layers of consciousness, connecting the personal to the cultural. Back and forth autoethnographers gaze, first through an ethnographic wide-angle lens, focusing outward on social and cultural aspects of their personal experience; then they look inward exposing a vulnerable self that is moved

by and may move through, refract, and resist cultural interpretations
(p. 739).

Autoethnography became both form (see i.e., Angrosino, 1998; Ellis, 1993, 1995b, 1995c, 1996; Ellis & Bochner, 1992; Frank, 1991, 1995; Kiesinger, 1995; Ronai, 1992, 1995, 1996) and a method of inquiry (Bochner, Ellis, & Tillmann-Healy, 1997, 1998; Ellis, 1991a, 1991b, Ellis, Kiesinger, & Tillmann-Healy, 1997; Tillmann-Healy, 1998; Polkinghorne, 1988; Richardson, 1997, 2000; Rosenwald & Ochberg, 1992) in which the personal and cultural become blurred and multivocal, dialogic text created.

From There to Here

Having decided to follow the lead of Ellis and standing on the shoulders of other scholars who have adopted similar understandings of autoethnography (Tillmann-Healy, 1996, 1998; Ronai, 1996, Richardson, 1997; Kreiger, 1991), I became part of the phenomenon under the scope of the inquiry. I traced my academic and personal life by writing personal evocative narratives of families of children who learn differently (Ellis & Bochner, 2000; Bochner, Ellis, & Tillmann-Healy, 1997, 1998). I could not disengage myself from this project. Instead, I wanted to understand the nature of my participation and its effects on what I learned and to interrogate how I went about making sense as I sludged around in real lives looking for truths.

My coparticipants included my immediate family members along with another family and their children; as coparticipants, they “participate[d] in a personal relationship” with me, were “treated as coresearchers,” “share[d] authority,” and “author[ed] their own lives in their own voices” (Ellis & Bochner, 2000, p. 742). My goal, again echoing Carolyn Ellis and Art Bochner (2000), was “to write meaningfully and evocatively about topics

that matter and may make a difference . . . and to write from an ethic of care and concern” (p. 742). I wanted to encourage compassion and promote dialogue. Let me offer you a set of vignettes, a snap shot of the participants in this project, before moving to the burning question: “How’d you convince them?” I suspect you will find these somewhat incomplete and you will want to know more; I implore you to be patient, for I believe you will come to know them better within the pages that follow this discussion of methodology.

My Family and I

My upper middle class, European American, immediate family included myself, my wife, Jennifer, and our son, Trent. Jennifer and I both hold professional careers; Jennifer is a dentist and before working fulltime on my doctorate, I was an elementary educator, working in both special education and general education assignments. What is important methodologically about my family is situating some of the life-changing events that impacted my perception as an autoethnographer. At the time I made the proposal for this research, Jennifer and I had been married 7 years and were beginning to think about starting a family. In June 2000, we learned that Jennifer was pregnant with our son, Trent. As I entered the field to collect data, fathering and the experiences of parenthood consumed much of my thinking. I began transcribing data and analyzing narrative sets and Trent was born. He was here and impacted me more than I ever realized. He consumed my every thought. My world began to revolve around him. During the writing of the narrative, he was diagnosed with plagiocephaly, an environmental condition where the formation of the skull is affected creating a flattened area. I was intensely concerned about its effects on Trent and these concerns impacted my ability to

write. Certainly, my role as a father impacted my perception of the events that took place during this project and my interpretation of the data. During the latter part of the writing of this dissertation, Jennifer became pregnant and miscarried, representing one of the most emotional experiences we have endured. She soon was pregnant again, and we now await our new little one.

Christopher and his family

Christopher is my younger brother. Middle-class, European American markers fit our family. Our parents worked in semiprofessional careers and both had some college education. I am Christopher's only sibling. He loves Nascar Racing and follows sports closely. He is active in his local church and assists in a boys' program on Wednesday evenings. Christopher is quite a computer wiz, enjoying games, surfing the net, and memorizing odd tidbits of information. He and I grew up being best friends and continue to spend time together when possible. I looked out for him. He likes routine and is always on time; he's obsessed with not being late. Christopher is now 25 years old and graduated from high school five years ago. He was employed with an automobile sales lot and contemplated attending a technical school. Currently, he lives with both parents. During the data collection of this research, Christopher and my parents lived in a northwest Georgia town, near a metropolitan area and some of the data collection occurred in that area. They now live in Gainesville. Still other data collection from my family occurred at different locations including my home in Gainesville. Access with my family was a given; I was an insider and shared memories of events and interpretations of our lived experience. I discussed this project with them often over the past years.

It was a difficult and long process convincing my family that this kind of exposure would be a helpful and healing process for me and ultimately, I hoped, for them as well. After many emails and conversations in person and by phone, they hesitantly boarded this research journey with me. I'm not sure that they were convinced but they trusted me. My mother begged me to do something different but honored my commitment to finding my way through the haunting of growing up with a sibling for whom learning was difficult.

Due to the fragile and intimate nature of this research, I remained sensitive to my family's response and participation and constantly negotiated issues of representation. I noted these in my researcher journal. I initiated discussion of the other family and their experiences; this practice enabled me to open pathways of discussion with my family, shedding light on their perceptions of learning differently and living differently in the world. The intent of this research was not to compare, contrast, or evaluate. Instead, it was to set the stories of two families side by side and consider the overlapping experiences. The goal was to share what it might be like and feel like to be a member of such a family.

Jacob and His Family

Jacob's family can be described as middle-class, European American. His parents hold professional careers and both hold college degrees. Jacob has two siblings, an older brother and an older sister. During the inception of the data collection of this project, Jacob was nine years old, a third grader attending a private school for students who find learning difficult. Jacob loves sports, especially baseball. He is very adept at sensing the feelings of persons around him, and especially sensitive to his mother's feelings. Jacob

remains very close to his older brother, Michael. Prior to this year, he was enrolled in a public school. The parallel family lives in midtown Atlanta and thus much of the research occurred in the Atlanta area. Jacob lives with his parents and two siblings, an older brother and an older sister. I gained access to the family through informal and formal conversations about the project. They provided verbal and written approval and support of this project. We engaged in communication about this project via telephone and email in early March 2000.

I first met Jacob's family in 1998 when Jacob was a first grader in a friend's classroom. I observed in his classroom and was enthralled by him. In many ways, he reminded me of Christopher. I phoned my friend and she introduced me to this family. I met Jacob's family and my friend at a coffee shop in March 2000 to discuss the possibilities of this research. While Jacob's parents were initially apprehensive about "research" and "researchers," I conveyed my genuine interest in learning about Jacob and the family. I also shared part of my story growing up with Christopher, making myself vulnerable in the beginning. I offered to hear their side of the story and ultimately persuaded them to open their lives and home to me. They hoped to gain some insight from me, an outsider who happened to be an insider.

Politics and Ethics: Some Concerns

I had a general awareness of the politics and ethics of engaging in this personal research and tried to address these concerns when I elicited participation from my family and Jacob's family. Ethical matters in an autoethnographic project shift and change as the inquiry develops. Negotiations are continually being made and revised as the project is undertaken. According to Jean Clandinin and Michael Connelly (2000),

researchers must be “wakeful” throughout an inquiry. By the very nature of this study, I cocreated and shaped personal relationships with the coparticipants. I made myself vulnerable; they in turn willingly shared their lives.

Confidentiality was guaranteed throughout the research project, as I employed pseudonyms and created composites within the narrative. In particular, I crafted a third family, Travis’ family, for purposes of ethics and confidentiality. Travis is a composite character created to merge the narrative data of the two families and events and conversations buried in my journals about other families and students whom I taught during my teaching career. By crafting Travis and his family, I was able to liberate my writing and write without constant hesitation.

I used pseudonyms and abbreviations for identifying information in transcripts, journals, and any preliminary write-ups and in labeling transcripts and audiotapes. I transcribed all audiotapes of interviews and only I had access to audiotapes, journals, transcripts, familial artifacts, pertinent documents, and so on. All data were stored in a locked file cabinet to which only I had a key. I acquired written informed consent from all participants. I used no deception in the consent form nor in the project.

Since much of this research was personally lived and was emotionally charged, I remained sensitive to the emotional well-being of participants. I considered myself a “guest in the private spaces” (Stake, 1994, p. 244) of the participants’ worlds. While I kept risks at a minimum, the risk that could not be completely eradicated during the project was the possible emotional discomfort of recalling personal experiences that are charged with emotions. At no time did I insist on pursuing topics that might jeopardize the participants and the relationships of this project. If at any time during data collection,

participants showed signs of discomfort, I intervened and reassured the participant until he/she was ready to continue. Since some of the narratives were potentially unsettling for participants, I adopted the stance of an advocate and recommended referrals to resources (i.e., clinical therapists and reading materials) for assistance in dealing with emotions that were out of the realm of my professional ability.

It is my hope that each participant benefited from his/her interaction with me and the opportunities to talk about their experiences. Family members benefited from having an empathetic, nonjudgmental listener, being able to talk about and tell about their experiences. Further, they better understood how each narrative contributed to an evolving portrait of learning differently and how they employed narrative to make sense of their lives.

Revised Expectations

As I began the project, I expected to capture Jacob's perception of his learning difficulty and I expected that my younger brother would openly revisit the past with me. I was surprised by their lack of outright disagreement. For Jason, every time I raised the issue of schooling, he shifted the talk quickly to other matters such as who the Braves would be playing Friday night; in several cases, he simply tried to thwart my attempts at reasonable discussion. He had learned the answers that teachers wanted to hear. He had better things to do. I remember the day that he became increasingly frustrated with my attempts to make my visits about school. I had asked him to read. He would not. He asked me to leave. I clearly had to shift my researcher intentions.

And each time I talked to Christopher about memories of school, he said it was fine and became ever-so quiet. I never got much more than that. He'd rather talk about

Nascar Racing or football, anything other than school. I've come to believe that neither Christopher nor Jacob wanted to relive the past, a past fraught with struggling. After reliving my own participation in Christopher's struggles and after interacting intimately with Jacob's parents and my own parents, I understand why perhaps Christopher and Jacob resisted. It was emotionally draining for me; it certainly was more magnified for them. In addition both young men have language processing difficulties that impact their communication with others. Therefore, I abandoned my original intent to fully include the perceptions of Christopher and Jacob. They are indirectly related here by third parties, primarily by their parents. I turned my focus to the perceptions and understandings of the other family members, most specifically my own and those of both sets of parents.

About Data and Theoretical Positioning

Through storying, we construct a life that Paul Ricoeur (1981) suggested can be considered as a text, a human text to be interpreted. Conceptualizing our lived experiences as texts-in-action suggests that I consider not only words but the emotions of circumstances surrounding those words including actions, reactions, doings, and happenings, which Jean Clandinin and Michael Connelly (2000) called "narrative expressions" (p. 79). Before moving to the next section where I describe ways I obtained these expressions, I discuss the theoretical paradigm guiding the data collection and analysis.

Phenomenological Hermeneutics

"[T]he phenomenological inquiry is not unlike an artistic endeavor, a creative attempt to somehow capture a certain phenomenon of life in a linguistic description that is both holistic and analytical, evocative and precise, unique and universal, powerful and

sensitive” (Van Manen, 1990, p. 39). Artistic researchers become imagineers, seeking to interact with experiences of others. My intent has not been to “capture” the experience of my participants; I do not think we actually can. Instead, I attempted to coconstruct a realm wherein endless possibilities for meaning-making exist and readers draw upon limitless histories to transact with the ever-evolving narrative. Educational philosopher Maxine Greene (1995) has posited that it is imagination that “makes empathy possible. It is what enables us to cross the empty spaces between ourselves and those we teachers have called ‘other’ over the years. If those others are willing to give us clues, we can look in some manner through strangers’ eyes and hear through their ears” (Greene, 1995, p. 3). Educators often package children. We label at-risk students, students performing below average, L.D. students, B.D. students, and honor roll students. William Ayers (1998) in writing about biography worried that “the children become invisible, lost in the blizzard of names they never call themselves” (p. 241). Just as Charlotte spun webs of significance for Wilbur (White, 1952), we, too, must accept the challenge to spin webs of significance with children and their families.

The nature of the lived experience pulls us into the realm of hermeneutics. Margaret LeCompte and Jude Preissle (1993) stated, “Contemporarily, hermeneutics is concerned with ways to explain, translate, and interpret perceived reality” (p. 31). Hermeneutics is the study of the interpretation of texts, and hermeneutists are careful in making it clear that much of the meaning-making occurs from one’s interpretive position. “Hermeneutics asks, ‘What are the conditions under which a human act took place or a product was produced that makes it possible to interpret its meanings?’” (Patton, 1990, p. 84). For Dilthey (cited in Van Manen, 1990), a major proponent of hermeneutic philosophy,

A lived experience does not confront me as something perceived or represented; it is not given to me, but the reality of lived experience is there-for-me because I have a reflexive awareness of it, because I possess it immediately as belonging to me in some sense. Only in thought does it become objective (p. 35).

Ricoeur (1981) extended the applicability of hermeneutic interpretation to lived texts, cultural activity, meaningful action. Heidegger (cited in Van Manen, 1990) claimed that language, thinking, and being are one. Language shapes thought and thought in turn shapes language and our beings come into existence through this transaction. We might think of the relationship of thought, language, and lived experience as trinitarian. In past decades, much research has emphasized one at the expense of the others. Still other research has considered these elements without considering the sociohistorical and sociopolitical context in which it arises. Such research neglects the humanness and social consequences of our interactions and transactions with the world around us and within us. In navigating among various discourses, we construct the multidimensional texts of our lives. According to Ricoeur (1981), all human interactions can be considered texts to be interpreted. By considering our lived experiences as texts, we entertain questions of readers, multiple interpretations, and notions of response.

While I have not, thus far, made an explicit postmodernist claim, clearly my work reverberates the notions of Michael Foucault (1977), Roland Barthes (1975), and Jacques Derrida (1978) in so much as their writings serve to support my preoccupation with the dialogism of texts, contested truths, reflexivity, responsive representations, and ever-shifting subjectivities. More specifically, my intimate researching relationships with data and representation of that data have been influenced significantly by Carolyn Ellis & Art

Bochner (2000), Laurel Richardson (1993, 1997), and Sara Lawrence-Lightfoot & Jessica Hoffman Davis (1997). The significance of this research for my study resides in what it says about the in-between, among the texts that readers bring to the research text and the transaction that occurs. Thus, data of lived texts is open to a multiplicity of meanings in various contexts. This dialogic shift, adopted by postmodernists fits within this discussion as it explores ways in which language, power, and history shape our view of reality, truth, and knowledge. According to Derrida (1978), all writing amounts to interpreting interpretation so that it becomes impossible to determine either the absolute origin or the end point of a process that is theoretically limitless. Therefore, the present discussion of hermeneutics is set alongside the idea that there are multiple, cyclical, and varied readings of the narrative text. Ultimately, you and I become interpreters of interpretations that are furthermore based on interpretations.

The interpretations of lived experiences can be characterized by a hermeneutic circle. The continuous fluctuation back and forth from the parts of a text to an interpretation of the whole may produce useful insights without resulting in any definitive understanding. Rather than a complete and static meaning, a postmodern hermeneut seeks more understanding and a stretching of perception. I started with intuitive hunches, vague understandings of the text as a whole. I began to look at the particulars and the contextual influences of parts and then moved again to the whole—which became a new whole, different from the one before. The parts were determined by the global and evolving meaning of the whole. This spiraling metaphor of interpreting experience served to deepen the meaning (Kvale, 1996). “Like artists, hermeneuts construct a detailed picture beginning with rudimentary shapes and adding further refinement and detail with

continued rendering” (Michrina & Richards, 1996). Although life is “soaked through with language” (Van Manen, 1990, p. 38), language alone will continue to fall short of “capturing” the full essence of a life. Thus, in analytic procedures, I used multigenres of literature, seeking to have a conversation with the evolving texts

Based upon the above claims, I considered the data of lived texts from a phenomenological hermeneutic perspective (Van Manen, 1990) saturated in dialogical intent. For Max Van Manen (1990) hermeneutic phenomenology is both a descriptive and an interpretive methodology. “The implied contradiction may be resolved if one acknowledges that the (phenomenological) ‘facts’ of lived experience are always already meaningfully (hermeneutically) experienced” (Van Manen, 1990, p. 180) and that meaning is always shifting given new histories and new contexts. Furthermore, a phenomenological philosophy is interested in lived experience, experience that is not replaceable or reproducible. Finally, Van Manen (1990) emphasized that “hermeneutic phenomenological research is fundamentally a writing activity” (p. 7). The interpretation of texts became a dialogical effort when the tellers were involved in ongoing dialogue with the interpreter. Below, I delineate the analytic strategies used in my study.

How did I collect the data?

In this research exploration, I employed the method of *interactive interviewing* as described by Carolyn Ellis, Christine Kiesinger, & Lisa Tillmann-Healy (1997). In this method of talking about experience, the role of researcher is shared participant, and the distinction often made between researcher and participant becomes fuzzy. My interviewing experience was a collaborative, open-ended communication process. Researchers “need to listen critically to interviews, to our responses as well as to our

questions” (Anderson & Jack, 1991, p. 17). My emotions and stories were as important as the participants in this study.

I scheduled three interview sessions with each family member. While I started interview sessions with a list of anticipated topics and themes to be explored (see Appendix B), I rarely used them. Instead, questions occurred naturally and emerged from observations and conversations. I made adjustments in interviews according to participants’ reactions to a probe or a story and the attitudes, feelings, and thoughts that affected the conversation. For example, when the topic of Jacob’s hospitalization was raised at the end of a session and was accompanied with a tearful sigh, I decided to shift the topic and revisit it at a later date. The interviewing was soon storytelling and not interviewing at all which made me feel as if I was in an endless state of interactive interviewing even during moments of informal discussion.

As a method for eliciting stories and talk, discussion of candid *photographs* produced greater comfort levels in sharing about personal issues. During one data collection event, Jacob’s family and I gathered around for spaghetti; our discussion turned toward family events that were connected to particular photographs. On another occasion, family members used disposable cameras to photograph things/events/people from their environments that were important to them. I used these photographs to elicit conversation about each family members’ contribution to the family narrative. I contributed photographs of my own to the discussion, making myself vulnerable and sharing my story to encourage dialogue, explicitly shifting my position as researcher. My stance was more of an ongoing relationship, one that was highlighted by “dialogue rather than

interrogation” (Ellis, Kiesinger, & Tillmann-Healy, 1997, p. 123). My process reminded me of what Steiner Kvale (1996) referred to as “interview[ing] as conversation” (p. 19)

As our relationships and friendships developed, both families offered more and more data, opening up further possibilities. I created a researcher’s box wherein my reflections and reactions were stored along with other sources of reflection on the project, for example, quotes from a reading or a newspaper article on learning disabilities. This data archive was a collection of the abstract, serendipitous, and random artifacts. The families shared *pertinent documents*, such as correspondence with teachers, psychological testing results, and report cards that elucidated the narratives about learning differently. In addition, I often recorded my immediate reactions via cassette recorder on my drive home from spending time with my family and Jacob and his family.

I encouraged the coparticipants to engage in similar activities by forging regular *email conversations* and reflections. I maintained a *double-entry journal* throughout this research experience, noting my experiences, observations, and emotional reactions. The journal served as a place for both “headnotes” (Emerson, Fretz, & Shaw, 1995, p. 18) and “heartnotes” (Hankins, 1998b, p. 83), temporal, interactional, emotional, and spatial information about interactions and observations. I recorded fieldnotes and intuitive hunches. While my intent in using a double-format was to adhere to the tradition of separating the data from the interpretation, the journal soon evolved into a blurred mix of genres. I reflected on my experiences as a sibling to a brother who learned differently, as a researcher experimenting with new forms of representation, and as an intuitive learner of the social worlds around these families.

Since I wanted to forge relationships with Jacob, his parents and his siblings, I became like another member of the family, participating in and initiating 2-3 *excursions* per week with Jacob during June, July, and August of 2000. These sessions included exploratory educational experiences (i.e., touring CNN, SciTrek visit, Fernbank) and getting to know you events with different members of the family (i.e., swimming, playing at the park, ice cream talks). Such sessions allowed Jacob to talk about his learning, how he learns, what he likes/dislike, etc. Through these weekly excursions, I provided natural opportunities for exploratory talk. I maintained a *detailed calendar* alongside the journal for noting decisions about learning excursions. I also accompanied Jacob to a week-long day camp in June.

I engaged in similar activities with my family including interactive interviewing, photograph discussions, email conversations, and informal phone calls. Since it is often easier to talk about yourself by talking about someone else, I used Jacob's experience as a means for eliciting data from my family members. And in turn, I used Christopher's experience to open possibilities for Jacob's family. I informally interviewed my family members about their experiences and how they have learned to live beyond the expectations of society. Opportunities with my family included camping trips, weekend visitations, weekends taking care of my bed-ridden grandfather, and so on. At all times, I strove for natural opportunities for discussing our experiences.

Preparing to Write—Data Summary and Analysis

I spent over 100 hours with Jacob and his family over the course of 20 weeks from May through September 2000 (See Appendices C, D, E for data source descriptions). In addition, I engaged in open-ended email conversations with both families logging more

than 150 email discussions of varying lengths. The family members, most often Jacob's mother and my mother, and I initiated email conversations for arranging visits but more importantly for storying. Both mothers at different times emailed me with present concerns; they needed to be heard and they needed to articulate a current crisis. I also emailed with both of Jacob's siblings; Jacob's older sister, in fact, wanted to be interviewed via email. She was hesitant to orally articulate her anger over her parents' "babying Jacob." Email became an important way of documenting the unfolding of the research narrative. I had over 400 pages of transcript data, 329 pages of pertinent data documents from official school documentation, report cards from each grade, along with other artifacts in my researcher box. I also depended immensely on my personal, research, teacher, and quote journals. I used a research calendar to document planned events and daily summaries.

Since I have been preparing for this research most of my life, much of the data collection escaped temporal dimensions as the feelings and emotions persists beyond time. For example, the data collection with my own family occurred more often in serendipitous moments as they became more willing and more knowledgeable about the project. I had discussions by phone, email, and in person as much as possible and documented them by reconstruction in my journals. I confirmed my wonderings of events and results of systematic introspection with them. It was time to begin systematically sifting through those memories, journal entries, photographs, and other items in my researcher box.

During conversation with Carolyn Ellis (personal communication, 2000), I expressed my desire for an analytic frame; she indicated that the analysis in autoethnographic

projects comes in the writing, that much of the back and forth movement of the researcher is the struggle with analysis—with the writing. This struggle became evident in my data analysis. As I prepared to search for the story within the data, I surrounded myself with my friends—books. Like Anna Quindlen (1998), I find myself most at home in a book and so I decided that I needed to wander among books. I stared at the mounds of data to the right of my desk and realized that it was time to make sense of what I have become through this process. In *One Writer's Beginnings*, Eudora Welty (1983) suggested, “It is our inward journey that leads us through time. . . . As we discover, we remember; remembering, we discover” (p. 102). She was right; as I began to dip into the data, I realized that the data collection, data analysis, and data representation were certainly colliding. Rather than separate events or periods, they occur in tandem, reflect a cyclical nature, and are multi-dimensional and multi-layered. Much of the preliminary analysis occurred through reflection and writing research memos, memos that note both the head (Emerson, Fretz, & Shaw, 1995) and the heart (Hankins, 1998b).

The analytic challenge became determining procedures for analyzing a variety of narrative forms including transcriptions, written artifacts, field notes, conversations with participants, reflective journal entries, photographs, and other data. Adopting a modified version of “constant comparison” (Glaser & Straus, 1967) with my data collection and using strategic suggestions made by Alexander (1988) for data analysis, I established thematic categories from the data for threading the collected narratives together as a portrait. Such emergent themes guided subsequent data collection; established a set of themes to refine, discard, and modify during the final stages of the project; and provided a scaffold for completing the evocative narrative.

I applied Irving Alexander's (1988) method of analyzing personal data as the primary method of analysis. He challenged researchers to focus on "discovering who the [participant] is in a dynamic sense rather than what the person is in a categorical sense" (p. 268). Claiming researchers of personal data are "personologists" (p. 265), his method required meaningful units of data to be analyzed along nine principle identifiers of saliency: primacy, frequency, uniqueness, negation, emphasis, omission, error or distortion, isolation, incompleteness. I used these nine identifiers as guides for letting the data speak; however, in the spirit of constant comparative methodology, I remained open to other possibilities as well: recency, conflict, inconsistency, incongruity, and so on (p. 278). Lawrence-Lightfoot and Davis (1997) clearly suggested that researchers consider data sources beyond words alone, aspects that are often overlooked or avoided in traditional research: attitudes, feelings, colors, pace, ambiance, smells, environment, and time all play important roles in the construction of portraits. In her study of students' exploratory talk, Bettie St. Pierre (1997) challenged readers to rethink notions of data and consider other possibilities including emotional data, dream data, sensual data, and response data; she further asserted that once researchers trouble current conceptions of data and widen possibilities for data, we can begin to reinvent education in a postmodern world.

I also consulted Catherine Reissman's (1993) suggestions of identifying poetic structures and metaphorical statements to reduce and interpret the data which parallels a similar procedure, "the selective or highlighting approach," advocated by Max Van Manen (1990). These metaphors became helpful in organizing the final representation. Ultimately, I returned to the full narrative in rearranging and retelling the story. Through

the analytic procedures I explored resonant themes and overall thematic concepts (Lawrence-Lightfoot & Davis, 1997). Once this analytic process occurred, I transformed the data into a multilayer, shifting time narrative.

I printed out all my fieldnotes and transcript data. I read and reread the fieldnotes, interview transcripts, email data, researcher journal, and personal journal. I sifted through pertinent documents including report cards, testing results, and photographs. I also relistened to approximately eighteen hours of conversations with Jacob and Christopher in my car as I traveled; by listening, I was able to emotionally return to the past. I reviewed my descriptions of events and conversations and poured over my emotional and analytic responses. As I relived the data, I began making a list of emerging themes and key events. This list of key episodes became the impetus for getting started; I kept this list with me, making notes whenever ideas surfaced. I remember night after sleepless night of turning on the soft white light on my nightstand to record an idea or an image that was keeping this project at the forefront of my mind.

I relied heavily on fieldnotes, transcriptions, and my personal journal. I began crafting the narrative as a series of connected narratives. Each narrative was composed and revised multiple times. I wanted the reader to emotionally experience the data and so I used emplotment, tension, characterization, reconstructed dialogue, and other literary devices to accomplish that goal. I wanted readers to experience the experience unencumbered by research literature and so I addressed those matters in the final chapters. I also wanted the reader to experience the imbalance and chaos that often results when a family finds a mismatch between a child and school. Thus, I crafted a multi-layered story that transcends shifts in time. I am reminded of Norman Denzin's (1992)

suggestion that life is “lived through the subject’s eye, and that eye, like a camera’s, is always reflexive, nonlinear, subjective, filled with flashbacks, after-images, dream sequences, faces merging into one another, masks dropping, and new masks being put on” (p. 27). I used systematic introspection (Ellis, 1991a) to recall childhood memories and other events that were triggered as a result of immersing myself in the data. There were times that I could better elicit such memory by locating myself in places and spaces that encouraged such recall (i.e., a playground). Those writings of recall, in turn, became more field data.

I began writing but became increasingly blocked by my hesitation to write about myself and to expose my family secrets. I shut down at times and felt defeated by the data. I knew I had to write and I had to consider a way through the narrative. I began to write about Travis, a composite character created to merge the narrative data of the two families and events and conversations buried in my journals about other families and students whom I taught during my teaching career. By crafting Travis and his family, I was able to liberate my writing from constant hesitation.

The first draft of the narrative took nearly six months to complete. I began sharing portions of it with my writing group. I would be elated at their favorable comments and thoughtfully considered criticisms and suggestions. And then, I would become numb. I would not be able to engage or write about the project for weeks. The emotions and pain were simply too much at times. I buried myself in other projects, and then I would remember an interaction that I had with a friend, Bernadine, during a writing retreat at the beginning of my data collection phase when she insisted that I was avoiding the important work of writing. Still, I insisted that I had to be the best caretaker possible for

our son, Trent, and that meant avoiding the dissertation. At the same time, I feared that if I did not finish, he would one day question if my failure were somehow his fault. So I persisted.

I wanted to be done. I wanted relief. I remember handing JoBeth an incomplete draft of what I had done and saying, “I can’t do anymore. I don’t want to do more. I am finished.” My recall of this event is unsettling at first, but certainly part of my travels in writing about this intensely personal and familial narrative. I am sure that JoBeth was more than disappointed in my decision; however, she gave me the space and urged me to take a break and return to the work when I was ready. It would be nearly six more months before I would begin again. Perhaps I was afraid, what would happen if I actually finished this?

Finally, I returned to the draft and began tightening the narrative, adding and deleting, modifying and reshaping. Even decisions about tense became problematic as I sought to keep the dissertation unfolding by keeping much of the writing in present tense. I made decisions about the use of past tense to indicate writings that I relied on and events that clearly occurred in the past. My co-chairs read portions and urged me to consider how to interweave the related research and literature. At first, I was taken aback and resisted their attempts at changing the narrative. Then, I began to see spaces where it seemed appropriate to pause for discussion with the reader. I tried developing pauses for discussion but remained dissatisfied with how these pauses obstructed the narrative as it was lived. Again, I shared more drafts with my writing group. I eventually made the decision to include an additional chapter that discussed the thematic development of the narrative and new theoretical discussions. I highlighted the pertinent literature that I drew

upon in my analysis to elucidate the narrative. I prepared a full draft of the project and offered it to my co-chairs and the committee for their suggestions and for revision. In addition to the readers already mentioned, I offered my narrative to a colleague whose daughter has struggled with traditional schooling practices and whose interest in my dissertation provided a fresh reader; she read all chapters through the lens of mother and scholar.

Since this project was also an investigative endeavor, I detailed my thinking and decision making. The representation is not a mirror image of any one participant as language makes such an effort impossible; every story is partial and situated. It was not a chronological telling; instead it defied temporal order. It provided concrete action, dialogue, emotion, embodiment, spirituality, strong imagery, dynamic characters, flashbacks, flashforwards, monologue, and self-consciousness among others.

Research or Therapy?

When someone finds out that I am working on a dissertation, they often ask, “What’s it about?” or “What did you find out?” Rarely, is the question of merit, action, and use raised. A prominent psychologist and story advocate Robert Coles (1989) wrote, “the beauty of a good story is its openness—the way you or I or anyone reading it can take it in, and use it for ourselves” (p. 47). I hope that I have created a story that you can take in and use in some positive way. I know that I have changed. Given the benefit of time and reflection along with the intentional documentation of the emotional terrain that I covered in this project, I am convinced that what you hold in your hands stands as both research and therapy. Many autoethnographers and writers of personal narratives have noted the personal understanding and therapeutic value of sharing their stories (Frank, 1995; Ellis,

1995, Krieger, 1991; Richardson, 1997). Shifting our focus on the results of research can reveal “personal understanding,” “hope,” and “helping each other live useful lives” (Bochner & Ellis, 1996) as sensible criteria in resolving how and which stories we decide to tell in our research. Carolyn Ellis, Christine Kiesinger, and Lisa Tillmann-Healy (1997) concluded, “To the extent that research makes a difference in people’s lives, it always has a therapeutic dimension” (p. 145). While therapeutic value is rarely the primary goal or objective of research, often it is a result of engaging in and writing autoethnography—what Ellis and Bochner (2000) call “action research for the individual” (p. 754). Just because research happens to be helpful and therapeutic does not negate its intellectual substance. As Ellis (1995a) contends, “Neither the therapeutic and scholarly nor the particular and universal are mutually exclusive” (p. 308). And John Dewey provides (1934) support for the cognitive, emotive, and practical dimensions of experience. The next challenge often aimed at autoethnography and other narrative methodologies becomes one of the search for *the truth*.

Narrative Truth?

‘It’s all connected, Dominick,’ she said. ‘Life is not a series of isolated ponds and puddles; life is this river you see below, before you. It flows from the past through the present on its way to the future. That is not something I have always understood; it is something I have come to a gradual understanding of...’

(Lamb, 1998, p. 610).

I did not want to offer definitive answers or to judge the answers given; I knew that I could not anyway for I had never found any. Rather, the truth of the narratives came in the telling of the past in the present. The meanings constituted from any narratives are

always partial, situated, incomplete, and tentative. They may be revised and reshaped by future experiences for every present soon becomes a past (Britton, 1970/1993).

According to Carolyn Ellis and Art Bochner (2000), meaning becomes constituted in the expression of narrative; “narrative is both about living and part of it” (p. 746). Life and narrative are inextricably interwoven and interrelated, influencing one another. By narrating our lives and our experiences, we give shape to the event’s of our lives. Perhaps the primary question becomes, “does the story enable you to understand and feel the experience it seeks to convey” (Ellis & Bochner, 2000, p. 749)? Does the narrative resonate with memory, imagination, and strong emotion—what Judith Ortiz Cofer (1990) calls “poetic truth” (p. 11)? Additional questions adapted from Carolyn Ellis (1995a) include:

Did my story engender conversational response toward the text as you read? Did the story illustrate particular patterns and connections between events? Did you want to give the story to others to read because you think it speaks to their situation? How useful would this story be as a guide if you encountered a similar experience in your life? What text did you, the reader, create of my story? Did this narrative make you think about or shed light on events in your own life? Would you have acted differently than we did? Would you have told this story the way I told it? Did the words I wrote elicit from you an emotional response to examine? What did you learn about yourself and your relationships through your responses to my text? (p. 319)

By understanding narrative truth differently, discussions of reliability, validity, and generalizability shift to more productive possibilities. Instead of using our traditional sense of these words, I offer some other considerations.

Reliability, Validity, and Generalizability?

I like to believe that the poem or story contains the ‘truth’ of art rather than the factual, historical truth that the journalist, sociologist, scientist—most of the rest of the world—must adhere to (Cofer, 1990, p. 12)

“Language is slippery when wet.” It is imbued with ideological forces. It is opaque rather than transparent, and no single truth exists. In addressing concerns about reliability, validity, and generalizability in this research endeavor, it was necessary to understand these terms differently. Research relying on narrative inquiry from an autoethnographic perspective depended on criteria other than reliability, validity, and generalizability to argue its worth in academe. Seeking verisimilitude and apparency (Van Maanen, 1988) was the goal of this research rather than the establishment of absolutes. The question became, “Is this research believable, possible, lifelike?”

According to Carolyn Ellis and Art Bochner (2000), “there’s no such thing as orthodox reliability in autoethnographic research” (p. 751). Human behavior is never static and project relationships and events cannot be replicated. Achieving reliability in the traditional sense of the word is impossible (Merriam, 1998). Yvonne Lincoln and Egon Guba (1985) offered other explanations for considering reliability including “dependability” and “consistency” (p. 288). Offering a detailed audit trail of how I arrived at my interpretations enhanced the reliability of this study.

Given the final narrative, I hope peers and colleagues will concur that the interpretation is consistent and dependable, that it echoes a reality, a truth—not the reality, the truth. Elliot Eisner (1998) labeled such a request “consensual validation” (p. 112). He challenged that qualitative research should be referentially adequate; he argued that a work is “referentially adequate when readers are able to see what they would have missed without the critic’s observations” (p. 114). I included verbal member checks along the way to assure myself and my coparticipants that indeed I was getting the particular experience as close to “right” as possible (Lecompte & Preissle, 1993; Merriam, 1998). The participatory nature of this project enhanced validity. Furthermore, I made my assumptions and biases known throughout the project. Steinar Kvale (1996) argued for understanding validity as validation through craftsmanship; this conception broadens the notions of truth. The focus was on the process, the craft of representing the experience.

Ideally, the quality of the craftsmanship results in products with knowledge claims that are so powerful and convincing in their own right that they, so to say, carry the validation with them, like a strong piece of art. In such cases, the research procedures would be transparent and the results evident, and the conclusions of a study intrinsically convincing as true, beautiful, and good. Appeals to external certification, or official validity stamps of approval, then become secondary. Valid research would in this sense be research that makes questions of validity superfluous (Kvale, 1996, p. 252).

While this research was certainly individualistic, it was situated in the structures of society’s cultures and institutions; I explored the social and personal and revealed the influence of culture on our lives. Just as folktales and proverbs provide guidelines for life

through story, I generalized the particulars of the narratives to other families and children. I trust the generalizations will provide hope for families with children learning to navigate social worlds and school worlds differently. Readers may sense that the narrative is both particularistic and generalizable. In the latter, readers may confirm the experience as like their own or others that they have known (Lincoln & Guba, 1985). And this last assertion is made along with the contention that the reader is a part of the transaction of considering research (Dewey, 1934). So not only am I, as the primary researcher, asked questions about what I made of the data but in turn, I ask what do readers make of this interpretive text?

Proposed Evaluation Standards

I offer the following questions as standards to consider in evaluating the product of this study. Laurel Richardson (2000) recently identified 5 standards for alternative works of research and I list them here as possibilities for judging this project:

- (1) Substantive contribution: Does this piece contribute to our understanding of social life? Does the writer demonstrate a deeply grounded (if embedded) social scientific perspective? How has this perspective informed the construction of the text?
- (2) Aesthetic merit: Rather than reducing standards, [Creative analytic practices] ethnography adds another standard. Does this piece succeed aesthetically? Does the use of creative analytic practices open up the text, invite interpretive response? Is the text artistically shaped, satisfying, complex, and not boring?
- (3) Reflexivity: Is the author cognizant of the epistemology of postmodernism? How did the author come to write this text? How was the information

gathered? Are there ethical issues? How has the author's subjectivity been both a producer and a product of this text? Is there adequate self-awareness and self-exposure for the reader to make judgments about the point of view? Does the author hold him-or herself accountable to the standards of knowing and telling of the people he or she has studied?

(4) Impact: Does this affect me? Emotionally? Intellectually? Does it generate new questions? Move me to write? Move me to try new research practices? Move me to action?

(5) Expressions of a reality: Does this text embody a fleshed out, embodied sense of lived experience? Does it seem "true"—a credible account of a cultural, social, individual, or communal sense of the real? (p. 937)

With these criteria in mind, Richardson challenged critics of alternative versions of research to use both social science lens and creative lens in judging the worthiness of a project.

A Reader's Guide

As The Byrds adapted the Psalmist David's thoughts on time from Ecclesiastes, I also borrow these words to invite you to enter in and consider the temporal and emotional nature of this research endeavor through the metaphor of seasons. I want you to realize that at some level, each decision made within this project was limited by my own interpretation of lived experience as it was situated in time. While one moment may create hope, another day brings pure despair. The experiences are understood through events and relationships, not in linear succession. Rather the narrative is episodic. And while as a writer, I wanted things to be tidy and to clean up well, I too faced the truth that

this experience, the experience of living with a sibling that struggled to learn was in no way tidy, nor could I fix it in the end. I still struggle with the latter. Instead, I respectfully learned that struggling to learn also involved learning to struggle. It meant recognizing that all family members struggle on some level. It meant recognizing that the journey never ends, but opportunities for growth and renewal existed at every turn.

I can not tell you how to read or what you should gain from the reading of *The Narrative Work*; however, I can give you some insight into what you will encounter in the pages ahead. The multilayered narrative that has been crafted invites you to partake in shifting narratives of three families. You will meet Jacob and his family, Travis and his family, and Christopher and my family. You will hear stories told within the walls of school and others that moved beyond those school walls. I move through various roles of researcher, teacher, husband, father, brother, and son. You will encounter shifts in time as I pause in one story and begin another. Intertextuality is evident as one narrative text begets another narrative text. I decided to intersperse both present tense episodes with past tense commentary as is the case throughout this dissertation. This research is continuously unfolding and so in the remaining chapters, you should sense an urgency and recency to the events that I share.

CHAPTER FOUR:
THE NARRATIVE WORK

Protecting Travis

I entered the library conference room waiting for the others to arrive. Dr. Fillimore had finished the psychological testing battery of Travis over two weeks ago and of course, as his teacher, I was interested in how Travis performed in the testing situation. Now a third grader, Travis had been served via a resource model of special education since first grade. He had received speech services since kindergarten. Increasingly, he posed challenges to his learning environment and at least historically, he required additional resource assistance each year. The gap between his academic ability and his age-appropriate grade level continued to widen. He arrived in my classroom right before the winter break. I won't ever forget that morning.

Interrupting our graphing activity, Dr. McDonald tapped the P.A. system microphone with a pencil and it echoed in my classroom. Third graders snickered and pointed to the ceiling. I waited patiently and then the voice resounded,

“Mr. Rayburn, could you please come to the office?”

“Yes,” I responded with some hesitation. After all, I hated interruptions, “it will be a few minutes. Will that be okay?”

“Oh, of course! We'll see you in a few minutes.”

“We'll!” I'm thinking. Who else may want to see me? Perhaps Dr. McDonald wants to review the draft of the SACS report that the committee turned in Friday.

I turned to my teaching assistant, Ms. Nolan, who had just arrived. I whispered, “I have to go to the office for a few minutes.”

I directed, “Ok, students, as you know, I need to go to the office for a few minutes. Please find a partner and complete the graphing activity. Once you are done, you may select a book and begin your silent reading time before lunch.”

As I took the shortcut through the teachers’ lounge, I overheard Ms. Smith and Ms. Young from the kindergarten department discussing a child that evidently they had already deemed “at-risk.”

“He can’t sit still and coloring inside the lines is impossible.”

“Maybe you should refer him.”

I wanted to respond to their pigeon-holing efforts but I restrained myself knowing I needed to press-on. I didn’t have time to save every child in the school today.

“Good morning y’all!”

I made my way past the copier and through the side door of the main office. Darlene, the office manager stayed in her seat, smiled and with a sweeping motion directed me to Dr. McDonald’s office door.

“You’re up, Shane!” Ruth, the attendance clerk waved from her desk in the corner.

I mouthed, “For what?”

“A new student!” she mouthed back.

WHAT! My mind went berserk as I realized that just a week and a half ago, I had received a new student. How could this be? There are six of us on the third

grade team, and we agreed to a rotation schedule for new students. Surely, we haven't had five new students in 7 days. And besides, I already had 28 students. I walked to the principal's door that appeared to be cracked open slightly. I tapped softly. I heard Dr. McDonald stand from her desk, walk four paces and open the door.

"Come in, come in."

As I stepped into the principal's office, it occurred to me that this was not the typical procedure for meeting new students. Usually, Ruth would handle the introductions and ask a student to show the student around the building and so on. Nevertheless, there sat Travis and his parents. Travis was tall and slender, a bit tall for his age it seemed. I winked at Travis, noticing his curling blonde hair and said "hello." And then I shifted my body toward Dr. McDonald who had nervously made her way back around the desk and started talking.

"Well, Mr. and Mrs. Michaels. This is Mr. Rayburn. He will be Travis' teacher. He has a background in special education and will work well with Travis."

Both Travis and his parents looked at me and smiled hesitantly, but Travis' eyes diverted quickly back and forth and then settled on mine, begging for response yet fearfully wondering what that response might be. The hesitation and the squirming young boy seemed to signal that he may be just as nervous as I seemed to be. I did not know what to say at first and so I just smiled. His eyes again looked away toward the window and he remained motionless for the remainder of the discussion about him.

All of a sudden, it made total sense. This is another special education child and Dr. McDonald is using me. I felt all used up. Just because I had taught special education and just because my younger brother had also struggled with academic tasks and just because I was the only male in the building was never enough of a rationale to dump every sensitive case into my classroom. My mind raced as Dr. McDonald's words became garbled nonsense.

Finally, I snapped back, as Dr. McDonald suggested, "Mr. Rayburn, why don't you show the Michaels down to your classroom. And good luck to you all."

Hhhmmm, I wondered internally. What did that mean? Good luck?!? At times, I felt my cynical side seep into my passion for teaching and I hated it. I hated that pure cynicism could persuade my usual optimism, but I knew first hand how difficult this could be. It seemed that every new student that struggled to learn and entered my classroom begged for my help. And beneath their every breath resides a familiar voice, the voice of my brother, whispering, "Help me!" That incessant plea and the frequent connections I made to my brother made my very existence unbearable at times. I faced his many years of struggling everyday in the faces of my students. If only we as teachers could hear the crying.

"Think for a moment about the boy who cried wolf. His false cries did not mean that there were in reality no wolves. If you recall, there were—and there still are. That fable would have had a much happier ending if only the people had paid attention to what really mattered: the boy was crying" (West, 1999, p. 319)

Pure exhaustion from trying to reach those "special" students made me question my career intentions. I had long grown weary of being deemed special

since I worked with special kids. I did not want to be special. I wanted to be ordinary. I wanted Christopher to be ordinary. The echoes of stereotypes surrounded me, making it difficult to concentrate, I kept hearing the incessant words:

“How do you do it?”

“You must be special and have the patience of Job to be able to withstand the frustrations of teaching children to whom learning is not natural. I could never do your job!”

“Oh, you teach the children who ride on the short bus?”

“That child will never be able to learn. I mean won’t you be proud if he learns to function independently. I don’t have time to help him. I have 25 other children that warrant my attention too, you know?”

They always wanted me to relieve their anxiety with reassuring words, but rarely did I. It was more effective to absorb their insensitive words and let them squirm in the reality that these “special” students were everyone’s students. At times, I stood firm and resoundingly assured those same teachers that yes, such students could learn and while I am not happy about it, there seemed to be almost as many times that I remained too quiet, allowing such accusations and stereotypes to linger while the person behind the words walked away. I was too weak to argue, too weak to take a stand, and yet I was so haunted by the memories that I had to take a stand. I had to argue. If for no other reason, I had to do it for my brother. It became a passionate goal, a way perhaps to forgive myself for failing him. Now, if I could just help another kid.

Hesitantly but confidently, I turned, shook hands with the parents and suggested that we walk down to the classroom.

As I turned to exit after Mr. Michaels, Travis, and Mrs. Michaels, Mrs. Michaels turned 180 degrees, clinched her purse, made direct and commanding eye contact and solemnly stated, “This little boy is the most precious human in my life. He is just the neatest person I know. He has endured so much already. Be nice to him please. Can you help him?”

The office walls seemed to be closing in on me as I stared back at this quiet, gentle mother who was entrusting her child to my care. Somehow, after years of similar introductions with children with special needs and after flashbacks of growing up with a sibling for whom school was often a terrifying place, I somehow felt words escaping me, none would suffice for the situation.

There was an awkward pause and then I simply responded, “Oh yes, of course, yeah, he’ll be fine. Trust me.”

Her doubt-filled eyes pierced inside me. I felt naked as she wondered whether I would be able to keep my word to her and I feared that I might fail her. Meanwhile, I searched for some way to alleviate her fear and worry. And as she worried, I worried even more, “Would I be able to help him?”

“Would he like me?”

“What learning challenges did he have?”

“What had his previous schooling experiences been?”

“What strategies might I use to increase his learning potential and achievement?”

“What had I learned in college to prepare me for such a situation?”

More importantly and perhaps most frightening of all, “What had I lived that would inform this current situation? How could I keep him from wanting to erase the developing memories of schooling? How could I help him learn to succeed in school?”

I’m 12 years old, a sixth grade boy, engaged in schooling and the academic life. School is the place where I am confident, where I succeed, where teachers smile and ask me to take notes to other teachers and to deliver material to the principal’s office. Why? Perhaps I could be trusted in the hallways during class. Perhaps because I inevitably followed directions explicitly. Perhaps because I wanted to please. No matter the reason, I found favor with school and the people within the walls of school.

I soaked in everything school had to offer—teachers, books, rules and consequences of breaking those rules. School worked for me. I knew how to play the game. After all, I would be a teacher one day. I would! I was often kidnapped by my own imagination about school and I would rehearse for that teacherly life. Whether I was riding on the lawn mower in the back yard or riding my bike, I would engage in pretend conversations with myself and my students and echo the language of my teachers. I was sure that I would need to write up pink slips on students, assign detention, and grade with a strict red pen. Playing out possible school scenarios had

long been a practice when I was alone. One afternoon in those blurry middle school years, when my younger brother and I had accompanied Dad to the church, I wandered down the Sunday School hallway with homework in hand. In the security of a quiet place, I studied.

To prepare for the test, I thought it made sense to role play the information taught to us by my social studies teacher, Mrs. Holder. Just the day before, she had chalked our study guide onto the board and we had spent that day and the next day copying that study guide into our neatly organized folders. I opened my notebook and filled the chalk board with questions and began to orally rehearse, taking on the character of my teacher and drilling the empty chairs of that Sunday School classroom. I internally answered my questions and responded audibly with the voice of approval or redirection. If Mrs. Holder had been two decades younger or I had been older, I am certain that I could have competed for her job. In my elaborate drama, Christopher entered the room with a loud, “Boo!” “What are you doing?” he insisted.

Playing it cool, embarrassed, I responded, “Get out here, I’m studying.”

I wasn’t sure I wanted to be caught pretending to teach. Christopher, of course, could not be easily shaken. He came over, “what’s that?” He pointed to the chalkboard.

“It’s hard stuff. It’s for my test tomorrow.”

In his aggravating-little-brother sort of way, he took the eraser sitting on the edge of the chalkboard, reached for the board and began to erase the words. I was livid and went to grab him and the eraser, yelling “Stop.”

He dropped the eraser and took off down the hall, yelling “na-na-na-boo-boo.”

I huffed, ran after him, and tackled him to the floor, tickling him and teasing, “Don’t do that again.”

It is not until now that I have thought about this recurring event that happened often—it didn’t matter what subject I was studying — social studies or math, science or English...it didn’t matter if I was drilling Christopher on math facts or helping him finish his homework, he insisted and often succeeded at disturbing the “pretend school” I was developing and rehearsing in my mind—the school where there was for me, structure, pattern, predictability, expectations to be mastered. Unfortunately, Christopher did not experience the same success with school as I had. I think at first, this surprised me. I couldn’t understand fully why he didn’t like school as much as I did. Perhaps the rules were inflexible. I wonder now if he had wanted to erase the board at school, if he had wanted someone to chase him down the hall and tickle him. I wonder too if he was seeking my attention over my intense relationship with academic matters, trying to erase the difference between our disparate worlds. This frustrating and endearing image of dissonance between our schooling experiences thrust me back and forth now, considering how the intersections of our schooling lives frustrated me then and angers me now. The schooling I had experienced was more or less “one size fits all.” Where schooling patterns and structures fit for me, Christopher erased the regularities!

We walked down the overwhelmingly long hallway. I pointed out the computer lab and the library. I wiped my brow. I had begun to sweat and my stomach rolled, feeling empty and hollow. We made a turn at the third hall on the right.

“Four doors down on the right,” I broke the silence again.

We stopped and I turned to Travis.

“This is your classroom. I hope you like it here. There are some wonderful children behind this door that will be your friends. Ok?”

He only had one statement, “I hope you don’t read in this class. Because I hate reading. It’s too hard.”

He took his backpack off without waiting for a response. I watched as he walked slowly into the room, paused and gazed back toward his parents. I had encountered similar comments from many students before but this time it seemed to ring continually in my ears. What would this mean I wondered? What did reading mean for Travis? I opened the door and Travis and I walked into the doorway of our classroom.

Jacob yelled, “A new student! Cool! A Boy!”

And other boys cheered while the girls giggled.

Mrs. Michaels tugged at the elbow of my shirt and whispered, “Can we talk to you for a minute?” as she sank back into the hallway.

I nodded and said, “I’ll be right back.”

“Class, please come to the carpet, I’d like for you to introduce yourselves to a new friend, Travis, and then we’ll find out about Travis. Travis, you can put your backpack by my desk. We’ll get you a desk during lunch. Ms. Nolan, would you please coordinate the introductions?”

While students began to share everything from favorite colors to favorite pets, I meandered through the islands of desks and back to the door. I felt the beads of sweat on my forehead. While I walked toward the doorway, both Mr. and Mrs. Michaels waved to Travis. Peering back over my shoulder, I saw he was sitting next to the big rocking chair, next to Ms. Nolan, and he too was rocking nervously in perfect rhythm with the chair. I prayed he would be okay.

“Mr. Rayburn, we want,” Mrs. Michaels began.

“Please call me Shane.” I insisted.

“Ok, Shane, Travis has had some difficult years.”

She paused, glanced at her husband and continued hesitantly, “Travis is like every other child. He likes to play and loves sports. He just has a hard time learning.”

Mr. Michaels added, “He’s all boy, you know?”

I responded, “I understand,” a statement that I have come to believe is a bit over-used and often misused. Maybe I didn’t understand, maybe I couldn’t understand. Nevertheless, it was all I could come up with to soothe their worries.

Mr. Michaels interrupted, “Just know we are here to help you, Mr. Rayburn, I mean Shane. I guess what I’m saying is, please let us know if you have any problems with Travis and whether we can do anything to help at home. I mean we

have bought copies of the reading texts and workbooks adopted by the school system. We'll do anything to help him. We pray that he will learn better and better every day. We pray for you too."

I nodded and could sense an urgency to really try and understand this family and the pain that resided just barely beneath the surface of their words for I had lived such troubling emotions. I remembered my family purchasing extra workbooks and making every effort to go beyond expectations. I remembered similar worries as I accompanied my parents and brother to open houses through his school years.

Mr. Michaels had used the word "problems." Was that a self-selected word or one that they had been given to describe the learning challenges awaiting me on the other side of the classroom door?

"I tell you what, I know I have a lot to learn from you and Travis. Let's plan to have coffee soon. Then, we could talk about Travis and your experiences and all that may have occurred before now. Maybe that would help you and me and in turn, Travis. How's that sound?"

They exchanged a glance and responded, "Well, okay."

Mrs. Michaels turned with a folder, "Here's a bunch of papers, school reports and testing results. You might want to look at them. We have learned to, well, just keep it all in perspective. We know a different Travis than the one portrayed between those pages."

I reached to take the material, but knew exactly what I would do with it. I would file it in the cabinet and wait. I'd wait to make my own decision and assessment of Travis. I agreed with Mrs. Michaels assessment and suspected that the Travis I

needed to get to know did not exist between the pages of the folder. I knew that the Christopher I knew then was not the one reflected in the testing he had endured. I had long adopted the procedure of avoiding permanent folders on new students as I wanted the opportunity to get to know the child outside of the labels and historical myths that often are enclosed in the brief narrative descriptions found inside such folders.

We each said goodbye and agreed to have coffee soon.

The door to the library conference room opened. It was Dr. Fillimore followed by the speech-language pathologist, the resource teacher, and Dr. McDonald. Each took a seat around the table.

“Where are the Michaels?” I asked.

“They’ll be here, they’ll be here” Dr. Fillimore grumbled as he began pulling papers from his black leather briefcase, “We need to get started on time today, I have four more re-evaluations today.”

No one said a word. Everyone around the table appeared to be engrossed in one form of paperwork or another.

I sat down at the end of the table. The conference room seemed exceptionally cold and uncomfortable. I had skipped breakfast and almost always felt uneasy about these staffings. It too often seemed that teachers’ voices and families’ voices were missing or ever-so quietened. I was certain that the Michaels would not miss this meeting; although, I was afraid that Dr. Fillimore may go right ahead and begin momentarily. I looked down at my watch and realized that we had a few minutes before it was officially time to start

and so I made it known to Dr. Fillimore and told the group that I would be back. I walked briskly down the hallway, through the lounge, and into the office.

“Have you seen the Michaels?” I asked Darlene.

She stopped typing and said, “I thought they may have driven up a little bit ago, but no one has checked in.”

“Thanks.”

I walked toward the row of glass doors at the front of the building, blocked the sun from my eyes, and spotted their minivan at the end of the row of cars. I opened the door and walked out toward the van. The van door opened and Mr. Michaels emerged.

He spotted me, waved hello, and said, “Hi Shane, Grace is pulling herself together. This part is always hard. It never seems to get any easier. She was up all night with worry. I keep telling her, honey, it’s okay, don’t worry about it, God’s gonna take care of everything. I mean Travis just needs extra time, he’ll catch up.”

From the other side of the vehicle, Grace appeared, her face a bit flushed and her eyes seemingly swollen.

“Hi Shane, I’m so sorry. I’m sorry I get emotional about this sort of thing. It’s still hard, it’s still hard to have to hear the test results. It’s like I’ve already told you, we have never put a lot of stock in those tests but boy, everybody else seems to. Nobody ever wanted to take the responsibility of delivering the news that our son was different from his classmates, even in preschool, no one wanted to identify a problem. It leaves us in such limbo. And now every three years, we do it again with a reevaluation. It never gets easier.”

Ability Questioned

Grace and Raymond arrived at Lucy's Creative Learning Center early for the 1:20 end-of-year conference appointment. To their thinking, Travis had had a successful preschool year at a reputable learning center known for its creative approach. It was known as the Harvard of all playschools. Travis had accomplished the goal of coloring inside the lines; although, it remained rare that he ever wanted to color, especially within the lines. And when made to do so, World War III broke out at home—tears, sweat, and exhausted family warriors. But he could do it if he had to do it! And Grace decided that if coloring came up as an issue again, she'd whip out some of the pages that he had accomplished during the year as evidence. He simply wasn't interested in conforming to boundaries of the coloring book. For that matter, he did not conform to much of anything. While waiting outside the classroom door, scanning the art displayed on the wall, searching for Travis' masterpiece, Raymond chuckled when he thought about Travis' rash attitude toward coloring.

"Grace, just last night, I tried to get Travis to color his clown picture and you know what he said. He looked right at me and said, 'Well, okay, but I'm gonna scribble.' And he picked up a red crayon and that whole page was red in two minutes flat."

Raymond laughed again and shook his head, "Grace, he just doesn't want to be still, I mean, it's too consuming. He wants to be outside, active and playing. Anyway, I didn't like to color either. And what's so bad about coloring outside the lines anyway."

At 1:15, twenty-five children marched single file out of the classroom, down the hall, toward the playground. Grace and Raymond got a friendly wave from Travis and his teacher, Ms. Frank, motioned for them to come into the classroom. They both settled into the four-year-old plastic blue chairs and breathed the aromas of preschool—the infamous mixture of crayons and kid-sweat. Ms. Frank gathered some things from her desk and met them at the table.

“Well, how are you both?”

Almost in unison, they responded, “Fine.”

Raymond continued, chuckling, “How about you? It seems the kids are ready for playtime.”

“Oh, fine, only three more weeks and then we’ll take summer vacation. They’ll get a break, and I’ll get a break.”

Without making eye contact she continued, “Ok, now onto the important stuff. I have really been thinking about Travis and what will be best for him next year. I would recommend that you consider keeping Travis here another year rather than sending him to kindergarten.”

Their faces must have expressed their surprise because she persisted,

“Well, I just think he would really thrive if he were here another year.”

Grace sighed and internally could feel the confusion swarming about her. What kind of reason was that? He would thrive?!? Was there a problem that she wasn’t telling them? And so they pleaded, “What do you mean? I don’t understand.”

“Travis is a sweet boy and tries very hard. I just think he would really blossom with another year of preschool. He can develop his fine motor and gross motor skills more fully through play. I mean we have noticed that he hesitates when he walks down the hill to the playground despite his new glasses. He just needs more practice. I mean like coloring. Take coloring for instance . . .”

Meanwhile, Grace and Raymond were having internal conversations with themselves while Ms. Frank continued on to other objectives such as all preschoolers needing to know and recognize all the letters of the alphabet before beginning kindergarten along with coloring and counting to 20. The exchanges of the remainder of the conference were jumbled and Grace and Raymond left more confused than encouraged. They looked at each other, shrugged their shoulders and said, “What just happened?”

False Reassurance

A week later, Grace called the director of the preschool, “Nancy, I was just calling about Travis. Ms. Frank suggested that he stay at the center for another year so that he will “thrive” more. I guess I’m just confused. I mean she wasn’t able to give Raymond and myself a convincing reason. Can you give me one? ‘Cause we want to know if there is a reason.”

Nancy sighed and said, “Oh no, no, I see no reason why Travis can’t go on to kindergarten.”

That settled it. They would send him to kindergarten.

As we approached the glass doors, I patted Grace and Raymond on the back and said, “It’s okay, really! We’re going to protect him. We’re going to make good decisions on his behalf today.”

Grace stopped before getting to the school doors and looked at Raymond and back at me. Raymond was first to put words to my timely expression, “That’s how we have felt for so long. We have been his protectors! But why? Why do we feel like we have to protect him?”

“That’s a great question Raymond.”

I am silent for the remainder of our walk to the library. I’m ashamed. I’ve reinforced their greatest worry—the need to protect. But that’s how I felt every morning when I walked Christopher to his classroom door and continued through the breezeway to the middle school. Every step I took toward the middle school put more distance between me and my brother. How could I possibly protect him when I was in a completely different building? How could I keep him from being ridiculed when I seemed to be walking away from him? I wanted to run back to him but forced each foot in front of the other toward homeroom. I felt powerless.

Raymond continues, “I mean school should be a safe place and yet it has felt very unstable for Travis in the past. We listened to well-meaning teachers and allowed him to repeat the same frustrating experiences. I mean, he has been retained twice already. We thought that was the right thing to do, that maybe he would catch up. And you try really hard, Mr. Rayburn, you do. I know all you want to do is break through for him. You have been an advocate for him, but even you—just now, used the word—protect—to describe the meeting that lay before us this morning. Is it really about protection?”

Protecting Jacob

Dr. McDonald left a folded, stapled note in my box. It was always important and private when it was folded and stapled. The note asked me to stop by her office at my convenience. I was expecting that she wanted to talk about Travis and I wasn't sure I was ready to talk about Travis. He was adjusting fine and trying very hard, but I knew the limitations of my influence. I only hoped that perhaps the success he could find with the academic support I offered could carry him through other years of schooling. I recall a colleague chastising my attempt to help another student. Shauna was the student and she had an extraordinarily difficult time remaining in one place very long. Her previous teachers had over and over recommended that her parents consider medical alternatives such as Ritalin. I simply wanted to give Shauna the opportunity to move and learn at the same time. Shauna would often be found under her desk or spread over a beanbag during writing workshop just like her classmates. She thrived with a little confidence and my adoption of a flexible instructional style. Other teaches ridiculed my efforts suggesting that Shauna was still in for a rude awakening in the years to come. I worried about that same rude awakening awaiting Travis and other students like Travis.

After a bag of popcorn during lunch, I finished collecting mapping materials for introducing the geography theme in the afternoon. I had ten minutes to spare before lunch was over and Ms. Nolan would take the kids out to recess. Entering the office, I slipped through the line of students waiting to get their medication and knocked lightly on Dr. McDonald's door. I could hear that she was just getting off the phone. She came to the door momentarily as I asked Darlene about the fresh flowers on her desk.

“Hey Mr. Rayburn, come in.”

I walked in and took a seat while Dr. McDonald closed the door.

She continued, “Shane, I’m concerned about a little fellow in 2nd grade, Jacob Higgins. He’s in Ms. Hayes’ room, do you know him?”

Searching my memory, I responded, “Is that Michael Higgins’ younger brother?”

She nodded.

“Ah, yes, then I guess I do. Michael was in my class last year. Very nice family. Michael, such a sensitive kid. What’s going on?”

“Well, I’d just like for you to talk to his parents. Actually, I don’t know much except that they are considering a private school for him. I just know they are concerned about Jacob. Jacob seems to be having difficulty with learning. He appears to have some short-term and long-term memory problems perhaps and is easily distractible. He tries to enter classroom discussions but often enters the conversation with inappropriate contributions. And we’ve tried Student Support Team with he and his parents. Ms. Hayes has made some changes in her academic programming for him, but he still struggles. I just thought you might help us in this situation. Oh and by the way, he’ll be a third grader next year.” She winked and concluded, “Just keep that in mind.”

My eyes rolled behind my eyelids and the hairs on my neck stood straight up.

Bewildered, I respond, “Sure, I’ll be glad to do it. But why me?”

“Well, Shane, you seem to empathize and connect with these families that face children who are struggling to learn. You have experience, after all. I thought you might be able to give them a fresh perspective since you are a specialist.”

I was beginning to feel less and less like a teacher with specialty. Instead, nearly on a daily basis, I became more and more bewildered by the children that struggled in my

classroom. I struggled daily trying to understand my relationship with my younger brother and his disability. I seemed motivated and terrorized by such experience. Some days I was filled with passion and energy and other days I was paralyzed by the reality. I wanted to develop a classroom that fostered creative alternatives and yet it seemed to be getting harder and harder to maintain such a vision in the atmosphere of standards and accountability mandates.

“Okay, I’ll contact the Higgins and arrange something. And maybe I’ll talk with Ms. Hayes as well.”

Dr. McDonald nodded and stood up from her desk, the signal for “Okay, We’re done.”

She hadn’t asked about Travis but I offered anyway, “Oh and by the way, Travis is settling in just fine.”

“Good, good, I’m glad,” she responded and led me out to the front office.

I wondered whether she had heard my comment about Travis.

Walking back to my classroom, I began wondering about Jacob. Last year, I had seen him many times since my third graders were reading buddies with his first grade class. When we passed his class in the hall, Jacob always waved at Michael and me, politely saying ‘hello.’ Still waves to me now. I also recall Michael journaling about Jacob having some problems learning to read in first grade. Last year, Michael had befriended a student in our class who had been in an automobile accident, incurred some brain damage, and was fighting to regain academic ground. Michael had written that Jacob had problems learning like Charlie except that Jacob didn’t have brain damage like Charlie.

As I turned the corner, I spotted my class entering the side door from recess, huffing with beet red faces from running on the playground. I waved, knowing that I'd have a few minutes to myself as Ms. Nolan would stop by the restrooms and water fountain before bringing them back to class. I dug through my file cabinet to find a copy of Michael's journal from last year. I had made copies of several writing portfolios to share with other classes. Michael's had been one of them. The students filed in and began their silent reading time while I scanned through Michael's entries looking for clues about Jacob. I found the entry where Michael had written about Jacob.

The rest of the afternoon went well. Students worked in pairs with maps and grease pencils, marking lines of longitude and finding landforms. I was thinking about Travis during the activity. He kept watching his peers, following their lead. It seemed to me that Travis responded very well to cooperative learning and made me question the competition so evident in our society. If he had a more capable peer, he could perform tasks every time. Sometimes it took him longer. Other times he needed a lot of reminders, but nevertheless, he just needed a model, a friend.

After our geography exploration, I read aloud a chapter from *The Bridge to Terabithia*. And then, the children went home.

The room was quiet and Ms. Nolan had just left. I could hear the floor buffer in the distance and an occasional click-clack of shoes in the hallway. I was tired but still plagued by a part of the read aloud chapter that I couldn't shake. So I opened the pages and read again. It was the part where Leslie suggests that Jess draw a picture of Terabithia, their co-constructed fantasyland. He responded, "'I can't.' How could he

explain it in a way Leslie would understand, how he yearned to reach out and capture the quivering life about him and how when he tried, it slipped past his fingertips, leaving a dry fossil upon the page? ‘I just can’t get the poetry of the trees,’ he said. She nodded. ‘Don’t worry,’ she said. ‘You will someday’.

I was thinking about Travis and my younger brother Christopher and now I was thinking about Jacob. I realized that I felt like Jesse had felt at times—when I worked with children, especially children who struggled to learn and learned so differently from those around them. I had encountered many students as a teacher, both a general education and special education teacher, and I had lived with a younger brother who struggled to learn within the confines of traditional schooling.

It was difficult to put into words the poetry of their lives—both the good and the not so good parts. It was difficult to fully comprehend their seasons of emotions. It was, at times, difficult even to acknowledge since no easy answers existed and no quick answers would suffice. It was difficult to know how to respond. Instead, I worried and worried, oftentimes ignoring what stared me right in the face—a history of struggling to reach the student that seemed to be slipping through the cracks of an imperfect system. For me, every student was more than a student. Each student embodied my younger brother and his struggles and difficulties. When I looked into the eyes of my students, no matter their eye color, I always saw Christopher’s dark blue eyes staring back at me. I became determined to find a way to get to know, to fully embody my own experience of growing up as a sibling to a brother who struggled to learn and the experience of other students who learn differently. So in a way, the stories that are written herein are more than individual stories, they are blended stories. I had to help such students. I had to learn

about them on a level that transcended academics and that was the beginning of helping them—getting to know the social spheres of their lives and it was the beginning of a therapeutic adventure for myself.

At home, I picked up the phone three times before I finally called the Higgins. I wanted to help, but I did not want to interfere. I knew that some educator had probably already suggested tutoring and scores of other suggestions dashed through my mind.

It's a week or so after school has ended and I have figured out that Christopher's teachers have recommended tutoring for the summer. He's a first grader. I'm an upcoming seventh grader. I've overheard mom and dad make arrangements with Mrs. Murray, a used-to-be teacher that stays home now and tutors children. Christopher had been riding his bike with Jimmy from around the corner and the Brady Bunch episode ends as I overhear mom confirming Christopher's tutoring time with Mrs. Murray.

"We'll be there. Thank you," she says and hangs up the phone.

My mom takes in a deep breath and walks through the kitchen. I follow her as I have learned to do. Not only did I want to take care of Christopher, I wanted to take care of my mom too.

"Mom, what is Christopher going to do at Mrs. Murray's?" I ask.

"She's going to help him with his reading and math skills. His teachers recommended that he work with someone this summer to 'catch up.'"

I was angry that I had not done well enough helping him with his homework after school. I wanted him to do good. I wanted to help him. I would try harder. I had to try harder.

My parents had done all the right things to help Christopher ‘catch up,’ giving him every advantage to excel each subsequent school year. The metaphor of catching up suggests that if you just work hard enough, if you just expend more effort, that with extra help, one can catch up educationally. After all, there are summer enrichment programs, summer remedial programs, summer school programs, all claiming much can be gained by spending more time trying to learn. What happens to the children and parents who are swept away with such promises? Any parent would arrange for help in moments of uncertainty and definitive ambiguity. My parents had and so would the Higgins I suspected. I wanted to reassure the Higgins and have answers for them, but I was worried that they may ask a question that I undoubtedly would fail to be able to answer. I felt like I had spent years avoiding these issues although I faced them everyday in my students’ lives. But I had avoided them, I knew I had. I continued to deliberate all the way home, debated with myself while I ate dinner, rehearsed my phone call with Jennifer, and finally decided to let the Higgins do most of the talking.

I dialed the number; no one answered. I took a deep breath and hung up the phone.

I grabbed Wally Lamb’s (1998). *I Know This Much Is True*, found the marked passage and read, ‘The point is this: that the stream of memory may lead you to the river of forgiveness.’ (p. 397). Hhhmmm, I think to myself. Talking, remembering, and acknowledging our lives as stories intertwined with one another may have the potential for changing how we approach differences. How could my learned experience help me

understand Jacob and how could I use my storied life to reflect back some hope to the Higgins? I decide that I should allow the Higgins to talk, but I mustn't stop there, I must talk as well. For in short, our sharing with one another becomes the story that our existence rests upon. It becomes the place for connections to be made. Despite my greatest fear, exposing myself and making myself vulnerable, I commit to sharing my story, how I experienced Christopher's struggle to learn, for it is obvious to me that I too was deeply and forever affected by Christopher's disability. I still am. I realized that I could only share my version of the story but decided that that version was an important one to be told.

I pick up the phone and dial their number again. The phone rings and adrenalin races through my veins, emptying into my stomach. I feel light-headed.

"Hello," a young voice answered.

"Hi, this is Shane Rayburn from school, is your mom or dad home?"

"Well, hey Mr. Rayburn, it's me Michael. How are you doing?"

"Fine, Michael. How do you like fourth grade?"

"I love 4th grade, but I miss you."

I knew why I loved this kid. He always knew exactly what to say. I can't suppress the smile stretching across my face. He continued, "Have y'all built simple machines this year?"

But before I could answer, he says, "Hang on, please, and I'll get my mom for you." Michael yelled for his mom and tried to mask the yelling by placing his hand over the receiver. I smile as I reflect on the previous year and Michael's tender politeness. "She'll be right here, Mr. Rayburn."

“Thanks, Michael.”

Another voice: “Hello”

It was Carol.

“Hi Ms. Higgins, It’s Shane Rayburn from school. I just wanted to call and chat with you for a moment. Dr. McDonald,”

Carol interrupted, “Oh, so she talked to you. She said she might. That’s fine.”

Silence.

I could hear Michael and Jacob in the background whispering.

There was another pause.

I wasn’t sure if she wanted to talk and couldn’t or didn’t want to talk at all. It appeared that I would need to talk first and so I began,

“I know that Jacob has been having some problems at school and thought you might want to talk to someone about it other than his primary teacher. It might be helpful to you and your husband just to talk.”

“I’m glad you called. Now is not the best time though, could I call you back or come by during your lunch time tomorrow?”

“Sure, that’ll be fine.”

I hung up the receiver and worried. I worried about whether I had said the right thing, the right words. I knew how piercing words could be at times. I knew the tension that could potentially exist after a teacher called. I cuddled under the fleece throw and returned to my book, thinking I’d escape. However, the struggle with difference resounded in the words of Wally Lamb and I again was thrust into the back and forth pull of the past and the narrative words of Wally Lamb. I flung myself back into the book,

trying to escape, only finding reflective images staring at me through the words of a book. I finally put down Lamb's book and reached for one of Frederick Buechner's books where he once said, "Listen to your life. See it for the fathomless mystery that it is. In the boredom and pain of it no less than in the excitement and gladness: touch, taste, smell your way to the holy and hidden heart of it because in the last analysis all moments are key moments, and life itself is grace."

Tears seep from my eyes and I pray.

I pray for Christopher.

I pray for my parents.

I pray for my students.

I pray for the baby growing inside of Jennifer.

And mostly, I pray for me.

We Love This School But . . .

Right before lunch, Darlene called over the intercom, "Mr. Rayburn, you have a guest. She said you were expecting them."

For a moment I was puzzled but remembered the phone call the night before with Carol Higgins.

"Ah yes, send them down. Thanks."

I finished stacking the art projects and cleared a space for us to sit at the round table in the center of the room. Moments later, they appeared at the door, both Carol and Jim, her husband. I motioned them in, greeted them, and we all settled around the table.

"It's good to see you again, Mr. Rayburn." Jim extended his hand for a shake.

"Now, please, y'all call me Shane."

“Well, Shane,” Carol began, “We’ve decided to send Jacob to a private school next year” She stopped and looked at Jim. They both stared at me and waited.

I allow the silence to persist. I’ve learned to wait.

Jim continued, “We just, well, we are very concerned about his self-esteem and everything that has happened over the last few years. I mean we love this school, but you all are not prepared for children that learn differently.”

I was cornered by this accusation because I realized that in many ways he was right. I had been frustrated as I watched student after student being staffed into special education classrooms without much question or challenge. It happened here and it happened in the two previous schools where I had taught. It had become easier and easier for teachers to shift the responsibility to parents and other teachers.

How many times had I heard, ‘Well, it’s not my responsibility. I’m not the special teacher. I have 28 other kids that need me too. And besides we have to make the student responsible for his learning. Shouldn’t we expect him to keep up with his homework assignments. I don’t have time for a homework folder.’

The words were nauseatingly familiar.

I wanted to make this conversation as comfortable as possible as I remembered coffee with Travis’ mom and dad, when Grace said, “Shane, I hate the whole atmosphere of conferences, especially support team meetings. I feel hurried and the goal seems to be ‘let’s do this and get through.’ Then they ask, ‘Any questions? Great! Okay, call if you have any questions. Let me show you to the door.’”

How could I respond to Travis’ parents who had obviously experienced the muddle of uncertainty? And now, how could I respond to Jim and Carol?

Carol fidgeted with a pencil laying on the table and started again, “We know Dr. McDonald is concerned about the whys, but it’s just too much to explain. I’ve had it. I’m tired and even I don’t understand all the whys, but I do know that I love my child and want only the very best for him. School seems to be failing him, but we simply will not. We will not fail him, Shane.”

I nodded and then began, “You know, I concur with some of your worries. I have worried about students, and I, too, have wondered whether a private school with smaller classes could make a difference or whether changes in how teachers work with these students affects their learning potential and how so. I realize how little time parents and teachers have to talk and get to know one another. I guess my biggest disappointment is not that you are taking Jacob to a private school, but instead, that our teachers will not have the opportunity to get to know him.”

“That may be part of the difficulty that we have had, Shane. Teachers have the best intentions but often overlook the child. They are bombarded with standards, testing, and paperwork. The child gets covered up in the midst of educational reform. Anyway, we know you have many students to attend to and don’t want to bother you with our problems.”

“Don’t be silly.”

As I utter the words, I realize that with those words I may have dismissed their experience with previous teachers. How often have their perceptions been simply—dismissed. So I backtrack, “I mean, sure, yeah. I do have many students. In fact, I got a new student with learning difficulties a couple of months ago. He’s unique, different. I have recently come to realize that all the training I received in college has failed to

adequately prepare me for the emotional aspects of teaching children who struggle to learn. I just would like the opportunity to learn from you and from Jacob. I think by getting to know students who struggle to learn that I will become a better teacher to all of my students. I want to understand the experience.” I think about mentioning my brother but hesitate.

Carol responds with passion, “Shane, that’s what I want for teachers too. I want them to understand, but I’m telling you I just don’t think they possibly can until they have a son or daughter like Jacob.” Or brother, I think to myself.

“I don’t know if they can ever fully understand unless they experience the experience. Shane, if Jacob had not had learning difficulties, I would never have even been aware or even marginally aware that these children even exist. And therefore, I would know nothing about what it meant.”

“Carol, Jim, you should know that my younger brother struggled in school much as Jacob has and I have often wondered the same thing. Perhaps you have a point. How could we experience your experience? I mean how could I really experience how you experience this?”

Jim offers, “Well, you could come live with us.”

We all laugh but there is some merit in his suggestion because I now realize that no one could fully embody the phenomenon of living in a family with a child who struggles in school unless you lived in such family and maneuvered about the overlapping social spheres of learning.

He continues, “I mean the reality of growing up with a learning problem is that it affects families. It affects more than just school and somehow schools get caught up with

all the academic stuff which certainly is important but teachers and specialists seem to fail to really understand this endless journey.”

“I think I understand.” I nod. I do understand. I know that the difficulty exists because few opportunities exist in school for teachers to experience emotionally what it must be like for a child who struggles to learn to read or to write a paragraph or to follow directions. I know of no report that makes a family’s experiential knowledge accessible to educators.

Carol responds again, “It’s just easier to get out there and advocate for your own kid. But it seems quite lonely at times also.”

I realize that lunch is nearly over and so I offer a plan, “You know, Carol and Jim, I am motivated by our discussion today. You have raised some important issues, but I still want to know what this feels like for you and your family and for Jacob and his siblings. Let’s plan on dinner in a couple of weeks if you would like. Think about it and talk to each other. I’d like to hear your story. It might just turn out to be therapeutic for all of us. And good luck with your decision about a private school.”

Carol and Jim nod and agree to let me know soon about getting together. As they leave, fear creeps from the four corners of the room. Am I ready for this? Am I ready to face my own raw emotions? I again think back to a coffee meeting with Travis’s parents. Grace and Ray had responded to my queries about Travis in similar ways.

“We’ll have a latte and two cappuccinos.” Ray orders as Grace and I find a table in the corner.

“What a treat,” Grace responds. “Our meetings with you are so different than the meetings at school. I don’t feel rushed and hurried to finish the deal, sign the papers, and move on.”

“Maybe we should put a coffee/tea suggestion in the principal’s advice box, huh?”

We chuckle as Ray arrives with the hot drinks.

Grace asks in a hesitant voice, “Well, what do you want to know? I gave you the psychological testing and you have all of his previous conference reports and certainly his permanent record has been filled. And well, we’ll cooperate with you, and.” She fills the silent space with words but I interrupt, patting her hand, “It’s okay with me if we just talk about him, about Travis. What’s he like?”

Grace smiles and begins, “Well, he loves to jump on the trampoline. He loves his big white burly bear. He would rather wrestle on the trampoline with his white bear or ride his bike than think about school.”

As tears form in the corners of her eyes, she continues, “He loves peanut butter and grape jelly sandwiches and loves to be tickled. And he can tell you all about the stats of any Braves baseball player.”

Special Words

That night, after my meeting with Carol and Jim, I sent them an email thanking them for getting together with me, restating my interest and concern for Jacob, reminding them to let me know about dinner, and finally suggesting that perhaps they could write a letter to me about Jacob, a way to facilitate our next discussion. I suggested that they might think about it as “a letter to a teacher.”

A week passes with no responses. Then another.

After thinking about Jacob more and about Travis and his family, I decided to send Carol and Jim another email. This time, I wrote, “If you are having trouble telling me about Jacob, here are some prompts and questions to get you started, ‘what does Jacob like to do in his free time? What are his favorite activities? What are his strengths? Who are his friends and what does he like to do in his free time? What are his favorite activities? And by the way, don’t worry about the particular format. Oh yeah, let me know about dinner.’”

The next day I received a prompt response from Carol, expressing gratitude. Her response, “Thanks for releasing me to write about my son,” surprised me. What did she mean? Hadn’t I already done that? Isn’t that what I wanted from them in the first place. She said she felt she had writer’s block upon my first request because I had asked for a “letter to a teacher.” She had felt constrained about what to include, but after I elaborated my suggestion, she felt she could write about Jacob. Jim had told her she was “being too intense” before and worrying about what to write.

Here is a brief section of her attempt to write about Jacob when I framed my request as a “letter to a teacher”:

Jacob is a child who has “difficulty understanding and processing language,” according to the neuropsychological evaluation performed in July 1998. Jacob is a good-natured, bright child with good social skills. He gets along well with other children and also adults. He really seems to enjoy being around adults. He has difficulty hearing some phonological sounds and therefore has trouble with reading and writing.

To me, it was evident from this initial attempt that Carol indeed knew what “teachers” might want. She had learned the language of school and had tried to appropriate that language in her attempt. Knowing the language of the discourse community is important for communication. But for her, she felt constricted by the language of my request. I had paralyzed her effort by making my request in the form of academic language.

She could certainly write an IEP or describe a child in a support team meeting, for the very language she used to first describe her child was stilted, unrevealing, allusive, and allowed for easy substitution of another child’s name. In my teaching career as a special educator, I had known many children like the Jacob described above. Indeed, I had encountered many psychological testing results that read similarly. Sadly, in the hustle and bustle of schooling worlds, I had even contributed to some of the descriptions in a likewise manner, unfortunately, masking the child’s story. What mattered to the professional specialists in these meetings were the “academic” insights I had to offer, the objective-behavioral observations I could submit, and the behavioral and academic modifications I could recommend—not the presumed “tangential” stories of the child. The psychologists offered the often meaningless numbers to parents while they awaited the interpretation. They depended on the interpretation of the expert. In such a setting, few parents could compete with the loaded language used to describe their children. Such “school language” hides the humanity and complexity of children who struggle and their families and works to “protect” teachers from “becoming too involved.” This fragmented and limited discourse makes children who struggle to learn, “the ones we worry about most,” invisible, and yet the very words serve to heighten their visibility. However, the heightened visibility manages to distort the child, reducing him/her to a label. The labels

redefine and limit what can be seen. What an insight! I was already learning from this family. I'm so glad I sent the second email, unleashing her to write about her child, her love, her world.

In her subsequent writing, she wrote:

Jacob loves sports—especially baseball. Up until this spring, he played with a little league team at Holcombe Park. I think he decided not to play this season because the game has become more complicated and competitive as he has gotten older and he finds it harder to remember all the rules and process all the instructions given by the coaches. But he hasn't actually voiced this—he just said he didn't want to do it.

She obviously felt a release from finding the right label that would capture him for me. She was weaving a story, a story rounded with her own wonderings, worries, and speculations about Jacob. I realized that Grace and Ray too were doing this if I would only listen. While certainly the stories they shared are selective and partial, they can also be characterized as exploratory—serving to help us discover what it is we think and know and how we come know it.

Being a Good Friend

My students bound through the door after lunch. They settle on the carpet and wait for instructions. I look at them, making direct eye contact with some of them. A few giggle. Others smile. There are a few frowns and huffs. Perhaps the game of tag had not gone so well for all of them. Then, I spot Travis squirming at the edge of the carpet near the back of the group. His fingers delicately fiddling with the ragged edge of the carpet. He catches my eye and I motion for him to join us. He wiggles his way to my side and I

begin reading. Half way through the chapter, I realize that I have indeed been reading but subconsciously have been thinking about Travis. I finish the chapter and do a minilesson on characterization. Students then collect their writing folders and disperse in the room for writing workshop. I watch Travis. He goes to his desk, reaches in for a piece of paper and pencil. He soon becomes frustrated and borrows some from a neighboring student. He lays his head on his left hand and grips the pencil with the other. His knuckles become white, exposing the genuine effort at getting it down and getting it right. From his behavior, Travis had “learned to do school.”

He shifted about in his seat and entered the realm of contemplation. What to write about! He smiled and began the tedious task of putting the print on the paper. Almost immediately, he had created a tear in the paper and knew there was no way to assure that the paper was perfect after all. Everyone knows that perfect papers do not have holes in them. Just as the frustration was reaching a peak, Cameron was at my conference table asking for help with spelling a word. I asked Cameron if he had asked a friend. Travis, overhearing the exchange, quickly volunteered to help. He wanted to be a friend, and I believe he wanted to avoid writing. Travis was up and at Cameron’s seat helping him along. He did not accomplish much writing of his own but he clearly offered moral support to his peers.

After school that day, I wondered what his previous schooling experiences had been and what other teachers might have done. At the same time, I worried about my response. After all, I had not intervened. I hadn’t kept him “on task” as teachers would challenge. Exhausted, I gathered my things and made myself a note of a bright yellow Post-It note to call Travis’ parents about our next coffee. Before leaving, I noticed my desk calendar and

gladly turned it. It was May. Only 22 days and school would be out. The summer would be ahead for all of us.

Good Friend Expert

After talking with Jacob's parent and Ms. Hayes, I arrange to observe Jacob Higgins during his reading session with the teaching assistant. My students leave for art and I grab a legal pad for notes and walk down to Jacob's classroom. Immediately, I sense that there is something about Jacob, something that transcends the visible struggles with learning he encounters every day.

According to the label across the top of Jacob's desk, he is "the good friend expert." Other students in the classroom claim expertise in other areas. There was a "math expert", "spelling expert", "music expert", "game expert", and so on. Labels, as I have argued, can be misleading, may be inaccurate and often simplify the complexity of a person. However, I decide to consider what this label might mean for Jacob. I'm not especially surprised by this label. His mother and brother have described him in similar ways. Given this title, Jacob is given a role and responsibility for helping his peers foster friendships. It seems that this ability comes almost naturally to Jacob for his peers do not simply consider him "friend" but rather, a good friend. I wonder, What does "good friend" look like?

What does it mean to acquire and maintain this label in this setting?

Jacob and three other peers gather at a table in the corner of the classroom. The teaching assistant, Ms. Moore, reaches on top of a bookcase and pulls down four books for this reading group. While reading, Jacob seemed distracted at first, scraping the lead

of his pencil back and forth in the ridge of the wooden platform. Ms. Moore overlooked Jacob's behavior and asked Peter to begin reading.

Peter stalled and tried to put off the inevitable, "I don't want to start, make Jacob."

This comment jolted Jacob.

He stopped scraping, looked up, and encouraged, "Peter, you can do it. Just try it."

Jacob returns to following the groove of the wood plank, seemingly not paying attention.

Frustrated, Peter begins and Jacob certainly should be following along more closely in his book, but doesn't until he recognizes that this is not going to be easy for Peter after all.

Peter stumbles over some of the words and tries to "tap them out" (a drilled strategy of phonetically segmenting each sound, apparently the only strategy he has for decoding the word). Peter grows more frustrated with each word that challenges his ability.

Finally, the tension is released and he emphatically yells, "I hate reading! I hate it!"

This interruption caused Jacob to contort his face and raise his eyebrows. As Peter began again and struggled, Jacob, perhaps in an effort to make this easier and as a way to alleviate the next accumulating tense moment, interjects with the word. Peter continued reading and Jacob intuitively responded before Peter explodes from the tension.

Ms. Moore stopped Jacob and stated, "You should let Peter do it. Be a good friend, Jacob and let him do it."

In an attempt to define what it means to be a good friend, she stressed, "He has to do it, Jacob." Jacob seems disappointed in her chastisement and her redefinition of how he understands friendship.

He is not easily shaken and as Peter begins again, Jacob stated, "Ok, well how about this . . . What if I just wait, say, uh, like 10 seconds and then help him. How about that?"

Jacob raised his eyebrows, offered a charming smile, and looked hopeful that this will work. “Thank you, Jacob,” Ms. Moore responds.

Having experienced the stress of reading allowed in front of his “abled” peers in second grade, Jacob responded appropriately, I believe, to a friend in stress, a stress he has certainly experienced before, and perhaps in this very setting also. Ms. Moore had attempted to redefine being a good friend. While no one can know for sure what was happening in Jacob’s head, it seems to me that he constructed a solution that would meet both the demands of his teacher’s definition and his own understandings and demands of friendship. He allowed his friend an opportunity to “tap out the word” by waiting and withholding, but he could not and would not allow him to drown in the frustrations. During the remainder of Peter’s reading, Peter did try and was successful in some attempts.

Learning to read can seem to be an independent and isolating activity. Peter was not alone, however, as Jacob sat nearby and listened attentively to the cues that his friend needed help. These cues manifested themselves as intonations of Peter’s voice, deep sighs, and reattempts at verbalizing a word. In each case, Jacob was ready to acknowledge his friend in need, offering encouragement in a moment of despair.

Facing the Inevitable Question—Why

The phone rang. It was Carol.

“Hi Shane, Only a few weeks of school left. I can’t believe it. Listen, Jim and I don’t want to send Jacob to summer school. What do you think?”

Silence is troublesome and I try to respond quickly, but behind my vocalization is the worry that again she is trusting me for guidance.

“Well, I think it’s your call. You know him after all.”

“It’s just that he has worked so hard, but I thought I’d ask you your opinion. Oh and we also wanted to get together for dinner.”

“Well, dinner, of course. I’d like that very much. Maybe we can talk about your email and more about the summer then. How about a week from Friday about 7 o’clock at Rudolph’s?”

”Perfect, we’ll see you then.”

“Deal.”

Several days passed and Carol had emailed me asking whether I had seen a recent issue of U.S. News and World Report. Evidently, it included an article on the relationship between Learning Disabilities and Environmental Toxins. The evening that I received the message, I ran out to the local bookstore and sure enough there was a section devoted to environmental toxins and its relationship to the growing and increasing number of students with learning problems. The cover page child was a young boy from Atlanta. That evening after reading the article, I wondered if Carol and Jim were seeking answers to the inevitable why. Why does their child have learning problems? I decided that I would raise the issue during our dinner engagement. I knew that my own parents had struggled with such questions.

Losing Ground

Friday arrived, and I met Carol and Jim in the parking lot. We exchanged greetings and wait to be seated.

“This is nice,” Jim says, “We don’t get to get out much without the kids.”

We all laugh and I begin, “I’ve been thinking a lot about Jacob and the issues you raised at the school. I really want to hear your story. I have been wondering about your summer school aversion. Tell me what you’re thinking.”

Jim responds, “Well, Jacob works so hard all year long and well, I’m just not going to make him sweat bullets over homework every night from summer school.”

The hostess seats us in a cozy corner next to a window and Carol continues the conversation, “See our frustration is that during the end-of-year conference, Jacob’s teacher remarked that he had to work every day this summer to keep up, that he didn’t need to lose any ground. She suggested “an hour a day” of tutoring.”

“Sort of like, ‘an apple a day will keep the doctor away’ huh?” I chuckle but realize the eerily close comparison to the metaphorical prescription that I have spoken.

Jim interjects, “I just can’t make him do it. He works so hard every day of the school year. He has little time for fun.”

“What if I work with you all this summer?” I’ve said it before I completely consider what that means.

Carol reacts, “Really, well, that would be, uh, what do you think, Jim?”

“That would be great but how we present this to Jacob will make a world of difference. It’s got to be fun or he’s not going to want to do it.”

As he talks, I wonder . . . so it has to be different than school. It cannot be loaded with the same expectations and cognitive processing load that Jacob encounters everyday.

Jim continues, “I mean I think he deserves a break too. Summer should be a time that he can have some fun.”

“Luckily we agree,” I smile, “I too believe he deserves some fun and I am actually thinking that we might all learn something significant about Jacob and the way he reveals himself outside of schooling and tutorials. Maybe Jacob and I could spend some time socially each week, and the three of us can spend some time talking more about how Jacob’s learning difficulties affects you and your family, and we’ll make it up as we go along.”

Carol and Jim decide to consider it.

From the Beginning: The Village Ogre

I continue, “So tell me, tell me how all this begins.”

“I hope you have more than just tonight,” laughs Carol.

“Of course, sure!”

Carol begins, “Well, I guess it was kindergarten when we began to become concerned about Jacob’s learning environment. He was assigned to Mr. Hickman’s classroom.”

“And nobody messes with Mr. Hickman,” Jim interjects.

“We would have requested a teacher change had our daughter been assigned to him. He was just so strict and domineering and Carla was a shy child and well, we felt like she would have been scared to death. He would not have been our first choice for Jacob either, but we expected that perhaps Mr. Hickman would be good for Jacob. I mean we knew he had very structured classes and we thought, you know, maybe Jacob could handle it. I guess we were in the dark until after Christmas. We assumed that everything was going okay, at least, academically.”

Carol continues, “Like I said we thought things were going fairly well. We knew he was having some trouble with some beginning reading stuff, like visual patterns and

recognition of some patterns and letters and stuff like that. Then, after Christmas, we requested a conference and had worried about some of the skills that he was still struggling with. So we met with him and asked, ‘Is there any reason why Jacob can’t go on to first grade?’ I guess we already had our worries and looked to Mr. Hickman for answers. He looked at us somewhat surprised, I guess, and said, ‘Oh no, he’ll go on.’ And we’re like ‘okay, fine, great, if you say so.’

I silently recall Grace and Ray’s similar story about Travis and preschool.

Time Out—Punished or Misunderstood?

Jim interjects, “Somewhere in the midst of all of this, we discover that Jacob is being put in time out a lot. Mr. Hickman is the kind of teacher that says, ‘I’m going to give these directions one time and one time only and you better get it.’ Well, evidently, Jacob wasn’t getting it. Jacob wasn’t comprehending and so he was asking kids next to him, ‘hey what are we suppose to be doing?’ Boom, he was in trouble, just like that.”

“He would get home and I would say, ‘Jacob, did you have timeout today?’ and often he would respond yes. To which, I countered, ‘Do you know why?’ He never knew, and that just broke my heart” Carol adds.

“I’m struck by what you describe. I mean Jacob gets in trouble for trying to figure out what to do. And if you think about it, he was being pretty smart about it, “if I shouldn’t bother the teacher, how can I figure this out?” It’s kind of smart if you think about it. Yet he ends up being punished for adopting a social solution to a sticky problem.”

Carol takes a deep breath and continues, “I feel all kinds of guilt now—that I wasn’t, well, I didn’t know what was going on. And I can’t, I mean I try not to beat myself up about it. I hate that he went through that.”

Another Village Ogre

My own mind races to the many times that my mother has responded with the same intensity of guilt and I recall a similar conversation with Grace about Travis.

Grace came by my classroom early one morning, said she had been haunted by an earlier experience from Travis' kindergarten year. I encouraged her to go on. She pulled up a chair to the corner of my desk. "Well, it was in another school system, his teacher was just horrible. Ray and I already suspected some problems and were willing to help Travis with every possible challenge, but this teacher simply didn't have a heart." Her face flushing red, she went on, "I still have nightmares when I think about her attitude." She shakes her head and swallows hard. "She just did not appear to be a happy person. I could be wrong, and I hate to be dogmatic about someone you don't know very well, but Travis had been in her classroom for nearly four months when this occurred. It was January and Travis still had not mastered the art of buttoning his clothes and tying his shoes. We were working with him. One cold winter day, Mrs. West told the teaching assistant that she could not help Travis put on his coat anymore. 'He'll have to do it by himself,' she said, 'He's just being lazy.' Some days, the teaching assistant would sneak and help him. To this day, I still thank God for her. She told me about the incident and I suppose I should have talked to the principal. I mean, that was a difficult task for Travis in kindergarten. I really think that she thought he just didn't try hard enough. Well, how hard do you have to try? I think it was a very difficult task for him to master. But he did eventually, and I am so proud he did. No thanks to his kindergarten teacher. I wonder how much more Travis could have learned from this teacher if she had only tried to help him. Instead, she created a wall between the two of them. And that was just the beginning

of a terrible start to schooling. I try to give people the benefit of the doubt, but sometimes it's hard. I do have a problem with saying negative things about people, but sometimes there just isn't a way to avoid, no other way to describe the experience."

And even now, I am covered up in my own guilt-laden consciousness, what could I have done to ease the pain for my family and now how can I respond to Carol's revelation without belittling this real and intense emotion. I decide to stay quiet for now.

Surprises, More Revelations

Carol continues, "Anyway, six weeks before school is out, we suddenly get this standby notice reading, 'your child should repeat kindergarten.' So we immediately schedule another conference. We sat down with him again."

"And I'm saying 'Tell us what's going on here. Is there something wrong?'

Carol continues, "And he says, 'No, it is too soon, I can't really say that there is any real learning problem.' And then he says Jacob can go on to first grade, no problem. I mean he totally switched and back pedaled at the conference. He turned it all around. We couldn't believe it. We shook our heads and thought it was weird but now thinking about it, perhaps our it let us move on without confronting the issue head-on. And so I guess that was the beginning of actually realizing how difficult school was going to be for Jacob."

"Well," I sigh, "I'm exhausted from you just telling me about that difficult and exasperating first year. We can talk more next time. Talk to Jacob about this summer and let me know what you all want to do. Oh and by the way, I picked up the U.S. News and World Report about learning disabilities. I've got it in the car if you would like it."

We pay the bill and start out to the parking lot. ‘Thanks, Shane,’ Jim says. I reach into my car for the news magazine, turn and hand it to Carol.

“Thanks Shane for the news article. After I read it maybe we can talk about it. Oh by the way,” Carol adds, “Jacob was a c-section baby too. He was always a handful.”

Suspicious

Had I mentioned my mother’s own difficult pregnancy and incurred c-section? I couldn’t recall. Odd I think.

The day came that my parents told me that I would have a new brother or sister, that he or she would arrive in nine months, that I would be a big brother. Big Brother! What a responsibility then.

And still, what a responsibility now.

With endless days of cuddling next to Mama on the couch and watching her tummy grow, I waited and anticipated. I remember the special times that Mama would call to me, “The baby’s moving. Come feel.” I would gently put my small hand on Mama’s belly and feel a rumble, like her stomach growling. A grin stretched across my face each time. I would be the best Big Brother. I would take care of that baby, rock that baby, read to that baby, protect that baby, and call that baby, “mine.”

The day soon arrived when Mama was overwhelmingly large. I remember her expressing her discomfort, eventually calling my Nannie to come and help. Simple every day tasks became exceedingly difficult as her feet began to swell and she required help to get off the couch. I was beginning to worry. I hoped that she would be okay and that the baby was

okay inside. Of course, I knew it would be. Every night as I said my prayers, I prayed, “Dear God, Help my mama and daddy and the baby and Nannie and Papa and Granny Rayburn and all my aunts and uncles and cousins and my teachers and my friends. Give me a good night’s rest and don’t let me have bad dreams, let me have good dreams.” They were all covered—the people I cared about the most. And already the baby to come had captured my heart.

Mama’s due date came and went and I knew from the adult conversations that the doctors kept saying the baby would arrive when it was time. By now, it was June and mama was miserable. The doctors decided it was time for her to go to the hospital. I wanted to go and stay with her, but instead I stayed with my Nannie and my aunts and uncles in the waiting room of the hospital, insisting that I be there when the baby was born. The conversation in the waiting room centered on what we might name the baby. And of course, I had my opinion, “maybe Chris,” I shared. Others offered theirs. Aunt Lisa offered, “How about Christopher?”

Mama was in labor an extraordinary length of time and the doctor’s kept pushing her that she could have this baby naturally. However, it soon became apparent that this baby wanted out now and couldn’t find his way out alone. In a desperate cry, he began losing heartbeats and oxygen, and the team of surgeons knew it was time for a cesarean section and wheeled my mother into surgery. Mama had begun losing blood and required

several pints of additional blood. Within hours, a baby was born, a beautiful baby boy, whom my parents named Christopher Daniel. They liked my nomination of a name and mama had already decided his middle name would be Daniel after her younger brother who could not have any children. The doctor declared him “perfect” and so did I.

Several days later, we brought him home and that’s when the Big Brother role was embraced and adopted and made mine. This is the place I learned to be a caregiver, a mother, a father. And I would adopt these as roles for a brother too. I wanted to help badly and insisted on being by mama’s side at every diapering and feeding and insisting that “I can do it now, let me do it. I want to help. Let me. Let me.” Mama would give me small jobs and mentored me, showing me how to pull away the protective papering on the sticky part of the diaper, how to hold his bottle.

A vividly recurring memory during that time was peering into his baby bed and over the railing and thinking about him and how beautifully he was made and how I loved him. He was my little brother after all. He was perfect.

The sun is shining brightly through the windshield. The warmth has numbed me temporarily. I buckle my seat belt and realize that someone is waiting for my parking spot so I pull out of the restaurant parking lot, wondering about my sibling and about Jacob’s siblings, and about Travis’ siblings. Now, years later, removed from the actual hospital experience, I was an expectant father—a father full of worry but again, I was confident that everything would be okay and that Jennifer would be fine and the baby boy to come

would be fine. I pulled into the driveway at home, turned off the engine, and sat silently thinking about the need for families to verbalize their suspicions of how things began and came to be, how children who struggle came to struggle in the first place.

The Whys—Blocking It Out

It is Saturday and Carol calls to thank me for our dinner meeting and to chat about the U.S. News and World Report article, “Shane, I read the article about toxins and environmental hazards and the links they are making to children with learning disabilities. I guess I’ll always wonder how and why Jacob is the way he is, but we’re never going to know. I mean the psychologist that tested Jacob suggested that if we really wanted to figure out why that we could take him to a neurologist and we both said why would we want to put him through that. There’s just no reason.”

I respond, “Right, what difference does it really make?” I nervously twist the coiled telephone cord around and around, knowing inside that it does matter, at least it mattered to me about my younger brother.

“I mean we can’t reverse anything, but I suppose I’ll always wonder.”

I stop twisting the cord, take a deep breathe, and respond, “You know my mother had a very long labor and my younger brother went into fetal distress, losing oxygen. And nobody, no not one single medical personnel suggested that this distress could cause problems processing and thus problems learning. And it doesn’t matter, I agree. But as an undergraduate special education major, a major that I chose as a result of growing up with a younger brother who struggled to learn, the sole purpose of one of my courses was to ask questions like, “How did this happen? How’d they get this way?” You know, the medical and educational driven model of cause-effect relationships and outcomes. So as a

student, I learned about prenatal problems, problems that occur at birth, and problems that occur after birth. At first I tried to distance myself from the reality of my younger brother's experiences, but I knew I was subconsciously seeking answers. Seeing the event, as I can now, I certainly have strong suspicions that that stressful laboring situation had something to do with Christopher's oxygen levels and that that lack of oxygen indeed affected some part of his neurology. It had to."

There was silence on the phone for a moment and then as if a floodgate was opened, Carol responded, "Well, I have some, I mean I kind of wonder, I mean, I have some suspicions as to why Jacob is the way he is, although I can't confirm them."

"And that is frustrating. It's okay if you'd rather not talk about it."

"No, no, I want to. I need to. I don't know if I told you this before, but when Jacob was nine months old, he had a really bad case of colic, so bad that we had to hospitalize him for five days. He was just not getting enough oxygen. It was kind of scary."

"I can imagine."

"Typically, if you have a child with colic, you take him to the emergency room, they give him some steroids and he's fine. But not so with Jacob, I mean they could not get oxygen to this child. And they did all this stuff, all the x-rays to see why he wasn't getting air and stuff like that, but anyway, so I wonder. I do. But who knows? It's an easy thing to block out because I had no control over that I guess. Although, I do feel tremendous guilt."

"Well, I know it is hard, it has to be hard! On the one hand, it seems that by wanting to know, you are seeking definitive answers. At the same time, you have to deny the need to know, because in the end, it makes no difference. He's still your special little one and

nothing will change that, not even new information. I know it has always been important to come to grips with an understanding so that we can move on. My mother wrote a letter to my younger brother when he graduated from high school. She wanted him to know about his birth and the circumstances that surrounded it. I think it becomes important to share those experiences. They can help us understand the intense emotions involved in living with differences. Unfortunately, we learn not to talk, not to trust, and not to feel when we are placed in moments of uncertainty. And so, having a child or a sibling that has difficulty, we learn to become silent and harbor the difficulty at home behind closed doors, that way we can continue to protect the family. Some might challenge that it is about shame. But nothing could be further from the truth. At least for us, it wasn't shame. It was about protection. It is the unwritten expectation in families with children who struggle to learn. We never want to talk about it because the intense emotion is so raw. We never knew if we could trust the world with our reality. Perhaps if they knew the reality, they would judge us and label us and call us crazy. However, I'm coming to believe that it is important to peel back the layers of our experiences so that others, teachers, administrators, other parents, students themselves, and society, can experience, albeit vicariously, what it must feel like to struggle. As I am weaving my own story with yours, you will see that this story is who I have become and who I will be tomorrow. It stays with me."

"Thanks Shane. This is helpful just to verbalize the events."

I hang up the phone, wipe the tears from my eyes, and collapse on the couch, refusing to think about this any longer. I just don't know if I can help! I sleep heavily until about

3:00AM. I am awakened by thunder. As I meander back toward the bedroom, I stoop down and pick up Wally Lamb's book.

I have been thinking about my conversation with Carol and wondering why families such as my own and Jacob's family and Travis' family struggle with the need to know and the need to protect. And then I recall a conversation with my mom about Christopher. It happened when they went to eat with some friends at Shoney's. The friends had a child, Timothy, who seemed extraordinarily hyper and evidently had trouble learning—he was jumping up and down on the booth seat, crawling under the table and constantly needing attention. The details of the meal were blurry, but the conversation in the car on the way home still burns in my ears. As my mother pulled the car onto the street, leaving the restaurant, Christopher said, "Is that what I was like as a little boy? Was I hyper like that?"

Mom turned and said, "Well, you were a handful."

Christopher persisted wanting to know more. He had lived as a student who struggled to learn and now as an adult he was trying to make sense of some of his own wonderings about schooling. The conversation ended soon with Christopher saying, "I was just wondering."

Worries

Carol and Ray and Jim and Grace join me for a coffee session.

"You all know that I have spent significant time with your children and I have worries, worries about your children and children like your children. What do you worry about?"

“What I worry mostly about Jacob is really primarily his self-esteem and other kids giving him a hard time,” Carol begins and then pauses, “um, because I don’t care that he’s not a brilliant child, I just want him to be happier. I don’t want him to feel like he’s inferior that’s probably my biggest worry which seems kind of simple.”

Grace and Jim are nodding in agreement as Grace interjects, “Us also, that’s our biggest worry. We know what kind of failure and frustrations Travis has experienced and we worry about what’s going to happen to him as an adult. But we just have to live day by day. We can’t look too far into the future. It’s about survival sometimes.”

I nod and Carol continues, “I mean, Jacob, he has these huge goals and I worry that he’s going to be horribly disappointed and maybe he’ll just grow out of them. We’ve already made the mistake of telling him that you’ve got to be really, really good to be on the Braves so now he’s changed his sights to the Georgia Tech Baseball team. I want him to be realistic but I’m not sure that’s a good thing.”

“I guess,” I begin, “that our worries tend to be rooted somewhere whether they’re in vicarious experience by watching other kids or whether they are first hand accounts. No matter how and from where they develop, they are real.”

Jim nods and adds, “It’s really hard for me to talk about. It’s frustrating to know exactly what to do or how to help.” Jim begins wringing his hands.

Grace adds, “Travis knows. He knows that he’s not as bright as other kids. That is so hard to sit back as a parent and watch. It is wrenching.”

“Jacob is the same way. He beats himself up a lot about that. When he gets tired or just can’t do it anymore, he gets really upset and feels like he’s totally stupid and can’t do it and I don’t want to see him giving up on himself either.”

“He just gets frustrated so easily,” Jim adds. “He tries so hard.”

“He is usually okay, but I feel totally unequipped to deal with the meltdowns. When I do try to tell him, ‘no, no, you’re doing great, you’ve made so many strides,’ he says, ‘you have to say that, you’re my mom.’

We chuckle but the break is only momentary as Grace fights tears and agrees that Travis too has moments of breakdown, “It just seems like he always has a tiger by its tail.”

“One of the things I’ve noticed getting to know both of your families is that you have similar worries and similar experiences and those experiences persist regardless of whether your child is enrolled in a public school or a private school, the worries persist. Certainly, there are occasions probably in both social arenas that the worry over competence is greater in intensity.

Being Put on the Spot—Seeking Competence

“I hate it when he is put on the spot.” Carol begins talking about Jacob. “I want to rescue him. Just the other day, we went to Pizza Hut with some of our friends and we put some cash on the table to pay for the meal. And our friends, they are around us all the time, but they don’t know about Jacob’s difficulties. I mean I think they know, but they don’t really know. So anyway, we are sitting there and Jacob says, “How much money is that?” and Brad says, “Well, count it!”

I was so uncomfortable that I could hardly make eye contact with Jim or Jacob. Jacob tried and stumbled. It was painful, but finally Brian just sort of kind of helped finish it for him. Jacob tried. He did really well until he got to about 40 or 50, but he was using his

fingers. And I just wanted to cry and scream, “Brad, you just don’t know!” And of course, he didn’t know and would never do anything intentional like that.

Compromises by Siblings

Ray shifts the talk to another worry. “I worry about Michael. I don’t want Michael to always give in to Jacob and deny his own, his own,”

“Identity,” Carol adds.

“We are so lucky,” Ray continues, “Michael and Jacob get along so well.”

I nod and Carol continues, “I don’t know, I mean Michael is just a good kid, He really has looked after Jacob. As a toddler, if Jacob wanted a toy that Michael was playing with and started screaming because he wanted it, Michael was more than willing to give it to him and I’m saying you know you don’t have to because you were playing with it first, he can just learn that he has to wait. But, no Michael would much rather give him the toy than listen to him scream.”

“Keep the peace,” I add as my memory races from my own sibling relationship.

“Yeah, he is a peacekeeper in many ways. He takes care of Jacob. He wants him to be happy.”

I can feel that my face is warm and flush as I begin talking, “I find it very interesting and self-illuminating that Michael is a peacekeeper. I adopted that role myself. Although Christopher and I were 5 years apart in age, we were friends and I wanted to take care of Christopher. I helped him with his homework. I made sure that he had everything he needed. I watched him play. I played with him. But certainly, I remember giving in and letting him tag along with me to friends’ houses. I always kept the peace. I think it was just easier to do so sometimes, yet I, I always worried that I somehow failed to protect

him from everything. I recognized that school was hard for Christopher and I suspect that Michael sees how hard it is for Jacob, so if he can make some part of Jacob's life easier, then he's going to attempt to make things better for him. And not only for Jacob, but in succession, for you and for Ray and for Carla. I suppose in some ways we take some degree of responsibility for the family."

"That reminds me of an outing just the other day. You know about Jacob's fear of dogs. Well, I took Michael and Jacob out to the park. It was a nice evening. Michael wanted to go over to one of the bookstores to look at comics, but I insisted that we were not going shopping. So I pull up to Laurel Park and we barely get across the street and Jacob sees a dog. He becomes terrified and said, 'I'm not going, I'm not going. I'm not.' He turned around and ran for the car. And Michael, very good naturedly turned around and followed suit and got back in the van. And I said, 'Okay guys, let go to another park, so we went to another park.'" We all get out at the next park, Jacob wants to swing and so we swing. Michael went to play on the play equipment. I played with each of them a bit and then sat on a bench to do some reading. Then, a dog came up on the street. It was not on a leash and Jacob lost it. He was so terrified that he jumped out of the swing and runs on to me shouting, 'we got to go, we got to go, we got to go!' I tried to console him telling him that as long as he was swinging that the dog would not bother him. That lasted about ten seconds and then he was back over at the bench. Before I could calm him, he took off in a beeline up the hill. I had to yell at him to get him to stop because I didn't want him to run across the street. He was truly in a panic. Michael just came back to the van, didn't make a big deal out of it and told Jacob it was okay. I mean it is that kind of thing where Michael just gives in to Jacob without a question. I mean that night, I was

very accepting of it and okay with it, but there are times when it's hard for me to understand, because I don't understand. But at the same time, I know I have to treat it as something that's very real because it is very real to him. I don't why.

We sit pondering his story and then I offer, "It seems like an heightened emotion, and sometimes Jacob tries so hard and he wants to please. I remember Christopher working so hard and becoming so frustrated and bottling that frustration and that heightened emotion. And you know sometimes now, I suspect that is why so many kids that struggle blow up emotionally. They have learned to keep their emotions in question, but eventually, all the stress must be released. Such students like Christopher and Travis and Jacob don't want to disappoint teachers and parents. I want such students to know that it is okay to be frustrated that it is okay to have those kinds of emotions. Since such an experience as struggling to learn affects more than mere academic and intellectual pursuits, it seems only reasonable to consider that the emotional part of learning is impacted greatly. How difficult it becomes to learn to read or calculate or communicate if I am having a hard time understanding and processing the expectations in the first place. And moreover, I wonder if manifestation of those emotions don't come from the mere exhaustion of school or learning something new—that takes so much energy and sometimes the feelings attached are difficult to explain."

Grace interjects, "Travis used to complain about stomach aches or headaches all the time. School was so stressful that it was a precursor at times for school, psychosomatic illness due to the stress of schooling. I first I thought this is nothing but a ploy, but over time, I've come to believe that he gets so worked up that there is no doubt that the

physical manifestation is real—his stomach does indeed hurt. I know the cause may seem abstract, but the intellectual pain is manifested physically.”

“Grace is right, at times, we felt like he was trying to manipulate us so we played along, but we are very concerned about the stress that learning and schooling causes Travis and kids like him. We want him to learn some coping strategies and feel good about himself but just when we think things are going smoothly, something rocks the boat whether it’s a new skill or a teacher comment or something. It never ends.

Carol agrees nodding and Ray adds, “Jacob had become so despondent. He was really down on himself in second grade. He would call himself stupid when he went to bed at night. There would be times when Carol would have to go in and talk to him because he was so upset from his perception that he was stupid and his realization that other kids were doing better.”

My face is telling as I shake my head and confirm that it only becomes worse as students grow older and they become more conscious of the performance of peers in relation to their own performance.

Ray continued, “He felt inadequate because he couldn’t perform as well as his peers. I mean it was just heartbreaking and I mean that was one of the things that we talked about a lot when we had him tested. We talked to the psychologist who tested him and she too pointed out that he had very low self-esteem. And I felt bad because she basically said that Carol and I were brow-beating our own child, you know. We weren’t. We were doing everything that we could to build his self-esteem.

“Well, I think we all have come to understand that we cannot create a good self-esteem for Jacob and Travis but we can provide environments that foster opportunities

for success. I think your sons and my younger brother understand that school is hard and that it does not feel good to always be faced with that environment that seems so competitive, where one goal is to appear competent at any cost. They have learning problems and they know it, but they want to look like they don't. And of course, what is ironic is that there are no physical characteristics that signals any problem. And for social situations this can be very difficult since most folks expect them to respond in particular ways because of the assumption that they are like everyone else. This expectation in turn cause stress because they internally know that they are different somehow, so they pull out a mask to try to hide behind. Sometimes that mask may be humor or clowning around, but nevertheless, they tend to cope in ways that help them maintain as much dignity as possible. They are quite smart at this sort of thing. They look to their peers for modeling and then they do the same. Just the other day when I was talking with Travis, he said, 'You know I cheat Mr. Rayburn.' I put on my poker face and said, 'Really?' 'Of course,' he said, 'I had to, because I didn't know what to do. I would just look at my friends and that's how I would know what to do.' I just smiled and said, 'okay.' And you that is smart on some level, don't you think?"

Everyone smiles and laughs as I continue, "if you are in a social situation or in this case an academically influenced situation and you don't know what to do, admit it, you are going to look to your peers or the folks around you to, at the very least, look like you know what you are doing."

Travis is Travis, Jacob is Jacob, Christopher is Christopher

Grace begins, "You know Travis is just Travis. Yeah, he has problems learning but beneath the mask of school is a sensitive kid with a big heart."

Ray interects, “And Jacob is just Jacob. I never, unless I am specifically reading with Jacob or working on some academic tasks, I never think of Jacob as being anything other than a nine year old kid.”

And Christopher is who he is because of his learning disability. I enjoy who he has become because I can face the disability and know that it simply is part of him and if I can accept that, then it becomes easier to understand his idiosyncracies and such.

Jim adds, “Travis always tries to do the right thing.”

“And Jacob is very helpful and well-liked by his peers.” Carol mentions.

“And you know, we decided to send Jacob to a private school where personnel are trained to work with students who have processing problems. What is frustrating is that I don’t understand anymore than I did to begin with after talking to those folks, even after talking to the psychologist, she can’t explain Jacob’s experiences. Even after talking to you, I still don’t fully understand.”

The others agree.

Ray continues, “It’s like sitting down and reading with Jacob. I guess it was probably in first grade maybe when I would sit down and read with him at night, we’d go through and sound out a word on a page and two lines down that same word would appear again and we’d have to go through the whole process again. I didn’t understand that at all. I know I’m guilty of becoming frustrated with him and saying, ‘But Jacob we just did it up here. What did you say up here?’” Ray chuckles nervously, shakes his head and continues, ‘And he couldn’t tell me, and it’s like why can’t you tell me and I mean of course at that point I had no idea the magnitude and the depth of living with a child who struggles to process and convey that struggle to others. Now when we read together, I understand that

the recall isn't there. I still don't understand why it is not there. I mean I don't. I probably won't ever understand."

I smile and the four of them look at me, waiting for a response. I'm uncomfortable with my position, but I attempt to offer some reassurance, "I don't know that even the people—the experts—that say they understand really understand. I mean I have a special education degree. I've lived with a sibling who had similar struggles and I don't understand. I've had similar experiences with other students. It was incredibly frustrating in my first years of teaching when I would plan and teach a particular process or strategy or skill only to realize that the next day some of my students would not remember at all what we did. I would just be like what do I do here and I don't know if anybody can ever really understand, but one of the things that I have thought about so often too is that it's frustrating because it is invisible. You can't see it. It all happens between their ears. You can't open their brains and go in there examine it, 'oh there it is' and ask, 'How is it processing and where is it that it gets blocked and that sort of thing.' I suspect that sometimes it would be easier for us to understand or respond to if it were like a missing limb or something. You could see them physically struggle and be able to offer a more concrete resolution to their predicament. But Ray, I believe that your acknowledgement and recognition that you may never fully understand is critical."

Grace begins, "You know it helps just to hear your stories, knowing that another family has had a similar experience. I just feel like I don't have a good handle on what I am dealing with here. And we've known about Travis' troubles since preschool. I still don't get good answers to questions when I pose them to school teachers and psychologists and experts. But there was this one teacher just last year that made a

statement that really put a lot of things together for me. She said, ‘Travis hears what you’re saying, but sometimes it just doesn’t process for him, and she was the first person to say that. I feel really inept that I haven’t been able to put that together on my own, but I know that that continues to be difficult for me now just because I am blinded by the fact that he is my child.’”

I agree, “We, as teachers, have much to learn from your comments. If we consider that truly each day of schooling is only a flash, only a moment in time, perhaps we would place less emphasis on the all-defining high-stakes testing and know that schooling is not the only defining factor in a child’s life. The processing difficulties that your children endure persists throughout their lifetime. I know that they still exist for my brother. It impacts more than just school. It is an everyday event. Christopher faces it on the job everyday. If there is any variation in his routine, he is stirred and uncomfortable with learning the new task, no matter the degree of difficulty. But I have come to respect Christopher because of his unending ability to face such uncertainty time and time again with greater confidence each time. I doubt there will ever come a day when it will be easy, but it is easier each time he tackles the task and is successful in his attempts. Surely, he is set back by perceived failures, but that too is part of learning to live.”

Grace interjects, “Travis’ future scares me.”

Carol agrees, “I’m paralyzed by it. I can’t think that far ahead yet. It just makes you wonder how will my child get through life if understanding communication is so difficult. It’s plain scary to me.”

“I believe you will find the future to be seasonal. You will experience many of the frustrations you have experienced already again, simply in a different context or

involving a different set of circumstances. It is like being put on stage and your character always remains as a main character but all the supporting characters keep changing and so you have to keep adjusting and improvising to keep the ball of life in play. You have to be ready to act. You make decisions and those decisions have a plethora of unseen consequences, so while I've asked you all to look back, know that you look back through windows blurred with rain and as your children get older just as my brother has become an adult, you must only look back to understand the struggle. You must never look back to judge your worth or scrutinize your decisions for you made them in the very best interest of your child. You used the resources that were available and you made informed decisions. You do the best you can. There are no solutions. There is no end. Live in the moment and anticipate each day as another day to try again, a day that may be filled with miracles and others that may emanate odors of doom. There are no easy answers and few rabbits are pulled from magical hats.

I think back over my time with Travis, Jacob, and Christopher and know that this is just the beginning and at times, I am depressed by what appears to be a bleak educational future for each of them. Just when I am spiraling downward, I remember Grace's words, "Never Give Up! Listen and read the results of all the tests, but always remember that's not the final word. If we had taken test results and evaluations at face value, we would not be where we are today. And where we are today is not where we want to be, but it is much further than we would have been if we had just accepted the status quo. Never give up on your child-you just have to be there. Listen to your child. You may be surprised at how much you will learn from them."

And then the echoes of my mother's voice, "I guess I will always wonder what else I could have done, not only for Christopher but also for you. You will soon know what it is like to be a parent. Your children are the focus of everything you do and want in life. I tried to always make wise decisions. And I never, never gave up on either of you!"

CHAPTER FIVE:

EXPLORATION OF TENSIONS

In this chapter, I explain the data and the themes that guided the development of the narrative work. In developing the narrative work of this dissertation, I adopted and used Irving Alexander's (1988) method of exploring issues of saliency along with a modified version of Barney Glaser and Anselm Strauss' (1967) grounded theory method. First, I identified potential themes through a process of open coding. Upon identification, I began developing episodic narratives that later became intertwined into one multilayered narrative, in an effort to provide readers with a catalyst for experiencing the ambiguity and uncertainty of living with a family member for whom learning is difficult. Then, I returned to the narrative work and began comparing and contrasting the themes and concepts guiding the narrative. I further questioned the narrative by asking, "When, why, and under what conditions do these themes occur in the narrative?" Simultaneously, I continued searching for the connections inherent in the themes/codes. Next, I began delving into the actions and interactions among the characters and themes of this project. No doubt my commitment, interest, expertise, personal history and knowledge and skills with the topic influenced this more focused coding initiative. In the development of the narrative, understand that it is merely a cognitive simplification of a complex data set.

I crafted this narrative through the identification of an array of tensions that were at play throughout the research endeavor. These tensions were critical to understanding the thematic relationships in this project. I experienced these tensions through a certain

rhythm that provided space for resistance and more tension (Dewey, 1934), creating a rhythm that propelled me forward through the writing. These tensions, in turn, became the organizing schema for understanding the thematic relationships of this data, for it was in this constant flux of the narratives that I coconstructed the experience. I searched for social conflict, cultural contradictions, status conflict, issue of interpersonal relationships, attempts at social control, manifestations of emotional response, evidence of struggle and problem solving.

Due to the construction of the narrative as a whole and my resistance to slicing up a life, the lilt of the narrative obscured the intense analytic work. Thus, it became important that I reveal the identified themes more explicitly and succinctly. It is with this intent that I proceed with the explication of the themes of this research project. I identify each tension and then proceed with the impact of each tension among the key members of the narrative life.

Challenging the Language of Disability

When a child with a disability enters school for the first time, it poses a potential crisis for the entire family, and the families in this study experienced such a crisis. This is typically the first time the child has been forced to interact with others without the constant protection of parents and siblings. Ultimately, these children and families were subjected to professional jargon, a battery of tests, and placement recommendations were accompanied with labels. None of these school functions seemed to adequately represent the child they knew. No test and no professional understood the child beneath the label. To understand the tensions below, one must understand the societal and academic pressures on these families.

In turn, it is the language of disability and its cultural underpinnings that must be explored. Indeed, Travis, Jacob, and Christopher deviated from what was considered “normal.” However, it is important to remember, after all, that the parameters for normalcy or deviance are socially constructed. As Maya Kalyanpur and Beth Harry (1999) asserted, “if we could change our view of who had a disability simply by changing the parameters of normalcy, then a disability could not be a universally recognizable, or factual, phenomenon” (p. 13). Given a particular task in a particular setting could “disable” any given person. For example, if I were placed in the room full of physicists and expected to perform on an average level, I would fail immeasurably. Within that particular discourse group, I am disabled by the expectations of the group. As James Gee (1996) explained, mainstream discourses, those that schooling privileges, support existing power structures and the institutions that sustain those power structures. In school, for winners to exist, losers must also exist. For these families, schooling and what mattered most to society positioned their sons for failure and positioned themselves as “other.” What is valued and what is held in high esteem in society came in conflict with the “funds of knowledge” that these boys brought to school. School provided little space for demonstrations of what these children could do. Before turning to the identified tensions, I pause briefly to interrogate the ideological constraints of disabilities and problematize serving “special” students in schools.

Thomas Skrtic (1991) described special education as “the institutional practice that emerged in the 20th century to contain the failure of public education to realize its democratic ideals” (p. 46). He further argued that the positivist tradition continues to dominate the field of education and leads schools to offer a mechanistic model of

services. Moreover, too often schools have positioned parents as the source of a child's disability.

While no such overt cases were given in this study, teachers covertly suggested that this problem with schooling could be fixed if "extra" work was done at home. While Jacob, Travis, and Christopher encountered progressive teachers that were willing to look beyond the permanent folders, it was more likely and common that the recommendations for success included skills' drills and isolated, noncontextualized teaching, supporting Skrtic's (1991) contention that the special educator, even more so than the general educator, was seen as a "technician" (p. 106). He challenged researchers to adopt a "critical pragmatism" which "approaches decision making in a way that recognizes and treats as problematic the assumptions, theories, and metatheories behind professional models, practices, and tools" (p. 44). I agree with Skrtic's contention that as a cultural institution, schools must challenge the taken-for-granted programs and labels that serve to limit the zones of possibilities for students who struggle in school.

Through exploration of the narrative, I transcended the "obviousnesses" of our lives (Althusser, 1971, p. 172) and challenged the language of disability. By challenging the language, we can look anew at school struggles and begin "subverting the language of childhood disability" (Lightfoot & Gustafson, 2000. p. 71). We can consider who we are writing for and who we want to influence. This research became an act of activism. Anne Haas Dyson (1997) suggested that "our texts are formed at the intersection of a social relationship between ourselves as composers and our addressees and an ideological one between our own psyches (or inner meanings) and the words, the cultural signs, available to us" (p. 4). And I viewed these families' experiences as worthy of aesthetic attention

and rigorous consideration for expressing lived experience. After all, narrative inquiry helps us build bridges (Clandinin & Connelly, 1994).

Before turning to an exploration and explanation of the tensions identified in this research, I revisit Urie Bronfenbrenner's ecological model and elaborate upon it and expand its possibilities by using the works of James Gee (1996) and Ann Turnbull and Rud Turnbull (2001). I, then, turn to a discussion of the tensions and related research.

Revisiting Bronfenbrenner

Before reviewing Bronfenbrenner's social ecology theory that links human development and family environment, it is important to note Bronfenbrenner's historical and biographical connection to persons who struggle to learn. His theory emerged from his own childhood and his crosscultural research. His father was a physician and took a job as director of an institution for the "feeble-minded" in New York.

From time to time, Bronfenbrenner's father would anguish over the commitment to the institution of a person who was not retarded. Sadly, after a few weeks there, these people of normal intelligence would begin to mimic the mannerisms of the rest of the residents. When one of these patients came to work in the Bronfenbrenner's household, however, she gradually resumed a "normal" life. To young Urie, it was an important lesson in how family and community expectations influence human behavior.

After such an upbringing, Bronfenbrenner decided to become a psychologist.

During the course of crosscultural studies in western and eastern Europe, he was struck by the observation that Russian parents, both fathers and mothers, seemed

to spend more time with their children than did American parents. When he was asked to present his findings at a National Institute for Child Health and Human Development meeting in 1964, a woman named Florence Mahoney commented, “Why, the president ought to hear this.”

A few weeks later the White House called, and Bronfenbrenner and his wife were soon presenting these observations on Russian childrearing complete with slides to Lady Bird and her daughters. The Johnsons were impressed, especially by the pictures of the Russian preschools. One of the Johnson daughters asked, “Why couldn’t we do something like this?” (Zigler & Muenchow, 1992, pp. 16-17)

And thus, these ideas birthed the program known as Head Start. In turn and a bit later, PL94-142 passed, setting the stage for special students to be served in public education.

Bronfenbrenner’s (1979) social ecology model included the microsystem, mesosystem, ecosystem, and macrosystem, with each system reflecting activity increasingly removed from the family but nevertheless influencing it. In terms of this research project or others like it, we can apply his theory. The microsystem, considered the child’s primary system, constituted the patterns of activities, roles and interpersonal relations experienced by the family; parents, siblings, and children can be found within this subsystem. Schools, teachers, and classmates served as another separate microsystem for the child. The microsystem functioned within a mesosystem, which included the range of settings within which a family participates: extended family, medical and health care providers, school professionals and personnel. In this representation, perceptions of the schooling environment and other community organizations such as sports clubs were

included. The ecosystem encompassed both the mesosystem and the microsystem and was characterized by more remote activity that the family may not be actively involved in, but nevertheless, influences the system (i.e., mass media and educational bureaucracies). Finally, the macrosystem was described as the ideological or belief system inherent in the social institutions of a society; it involved ethnic, cultural, religious, socioeconomic, and political influences. In this study, I conjecture that it is this latter system that enveloped the families in this study and at times paralyzed their efforts to move comfortably among subsystems. In addition, Bronfenbrenner (1983) added the chronosystem which requires researchers to consider the effect of time and the changes among systems over time.

Given this theory, we can conceive of this approach to development as nested concentric circles. The activity occurring within each system is complex and interdependent to some degree. Activity occurs bidirectionally. How one navigates about these various social spheres inevitably affects human development. Bronfenbrenner (1979) believed that the greatest potential for growth and development resides within the movement among different systems, specifically movement between primary systems. In this study, home and school serve as intimate yet disparate primary settings and the potential for growth or alienation resides in the activity between the two. In addition, the child is the focus or center of each primary system. It is the interaction between the two that was of most concern within this study. I explore Bronfenbrenner's notions below by elaborating on the interactivity among the primary systems complicating the simple nested circle allusion described above (Refer to Appendix F for a diagram showing an extended model). We must delve deep within the ecological model and conjecture on the

activity in order to draw implications for relationships and human development.

Ultimately, the schooling system and the family system are in relationship with one another. When we, as researchers, adopt this model of understanding and describing families, we help change the system rather than expending energy fixing the family.

Explaining the Interactivity

Bronfenbrenner's model, then, suggests that the movement and relationship among these various systems has direct effects on the potential for development. This development includes a sense of personhood and belonging to differing, and at times, competing social groups. The notion of belonging to social groups connects to James Gee's (1996) discussion of Discourse. While Bronfenbrenner's ecological theory helps us to understand the systemic relations among the various systems, it falls short of offering how these relationships are constructed and how they are maintained and/or disturbed within social communities. Turning to James Gee's (1996) notion of Discourse supports our consideration of what happens between systems and among systems and by offering the contention that language is the mediational tool by which systems become. Furthermore, language is a medium through which self is constructed and enacted. Understanding this mediational tool empowers readers to see the "real" effects of the talk that occurs on and about families of children who struggle in school. It allows us to consider the narrative activity that occurs between systems.

Gee (1996) argued that there are many ways of knowing, doing, believing, valuing, and acting and that language as a cultural tool mediates relationships of power and privilege. He called these ways of knowing Discourses; Discourses have social and politically charged histories and are always more than just language. I argue they are

steeped in narrative, e.g., the narratives of schooling, being a sibling, self-in-relation-to-family. Furthermore, he claimed that these Discourses were actually theories about the world and relationships within the world. And finally, he suggested that the theories of our world, or what I shall call our narrative view, are “ground[ed] in beliefs” that “lead actions” and “create social worlds”; they “simultaneously explain, often exonerate, and always partially create, in interaction with histories,” (p. 21) zones of narrative possibility.

One must be attuned to differing discourses within groups, or in Bronfenbrenner’s terms, systems, in order to attain group membership. You have to be competent according to the group’s rules and ways of being and you have to act like the members of that group; in other words, you have to be “normal.” In school, Jacob and Christopher were nearly always faced with a growing need to appear competent. By the nature of the assumption of normalcy, we can assume that “deviants” exist. If in fact you deviate from the norm of the group, you cannot be a member of the group and you become ostracized. Ultimately, you become a group along with others that do not fit in, a group that inevitably become marginalized.

Our first discourse group, our family, provides us with our primary Discourse. We participate in many different discourse groups such as family groups, school groups, sports clubs, and church groups; these become the secondary Discourses within which we either conform or resist. We become positioned by the groups and the tacit rules of each group. Our travels from one group to another group are not guaranteed to be smooth or even possible, and the differing expectations of groups can create quite a quandary for us. After all, we have many selves and many faces; when challenged with an unsettling

situation of being “abnormal,” we construct other ways of being. The families in this study construct their familial identities through language and the permeability of the groups. The Discourses of these groups are always in flux and shifting within social contexts; they are products of a complex history and are subject to constant negotiation and appropriation. In other words, the rules keep changing and so it is important to be a keen observer to maintain membership.

Gee (1996) contended that people develop primary discourses and secondary discourses and that these are often conflicting. Given the power differential that is evident between certain groups, say between “teachers as experts” and families, some systems are put at risk for not being heard. People become constructed within these conflicting discourse groups and therefore, become empowered or as is more often the case, marginalized by the dominating discourse. Without even knowing it, the agents of marginalized groups become socialized into attitudes and beliefs that they would not otherwise use as descriptors of their familial “identity kit” (Gee, 1996, p. 127). In my narrative, I carefully considered the dominant narratives of Christopher and Jacob and the alternative narratives offered by their families along with interpretation as a sibling, teacher, and researcher.

Reconsidering Bronfenbrenner’s notion of systems theory, we can begin to delve into the complex interdependent relationships that are affected when a family is faced with a child who struggles to learn. Families are complex, organic systems in which each family member affects and is affected by every other part of the system (Green, 1995; Turnbull & Turnbull, 1986). Thus, families and the systems described above can be viewed as an interrelated system of interdependence. Circumstances and life events that affect one or

more parts of the system simultaneously affect the other parts of the system (Fewell, 1986; Minuchin, 1974; Stoneman & Brody, 1984; Turnbull & Turnbull, 2001).

How the “child-at-home” becomes narratively defined influences the interpretation of how the family understands and responds to the “child-at-school,” the child that appears during homework as schooling expectations bleed over into home life. The reverse applies as well: if a teacher’s understanding is limited by the narrative of the “child-at-school” and empty of the home narrative, difficulties arise when s/he attempts to communicate with family. Said another way, the narratives available to educational professionals and to families to use as tools for understanding schooling are limited to their experiences with schooling. These experiences are embedded in childhood memories and family relationships historically-situated around both schooling and non-schooling events; such memories are also emotionally charged, blurring the narrative events. Thus, the teachers and families become situated by time, place, action, and emotion. With the families in this study, the defining characteristics of the narratives of Christopher and Jacob, individually, were nearly always contradictory to the schooling narrative told about them. The contradictions made communication difficult and strained at best.

The families in this study wanted educational professionals to know and understand their children outside of the set of characteristics that academically disabled them. The academic troubles surrounding Christopher and Jacob dominated school-home conversations. The academic troubles arrived at home in the form of homework or academic recommendations for “catching up.” The time spent catching up strained relationships within families, and the academic troubles at home strained relationships.

How family members interact with one another and with members of other systems, which is inherently related to the previous histories and experiences of each agent of each system, affected the permeability of the family system. Turning again to Gee (1996), schools, families, churches, and other social groups are the locations not of a single Discourse, but of many. The historical narratives of the agents or members of each of these groups impact the space available for understanding the narrative meaning of other members. The narratives become sites for negotiation and contestation. The same narrative given in a different context is most certainly a different narrative.

In a Bahktinian sense, the conjecture that the narrative possibilities are endless makes sense if we consider our lives as texts. Bahktin (1986) used the notion of chronotope to describe how the literary settings of novels solder the components of time, place, and action and thus complicate the meanings of texts. Chronotopically, then, the meaning of the narratives in my research are infinite and multiple sites of meaning construction given that the history, context, memory, and action of each agent involved in the research could be further explored. Understanding *The Narrative Work* chronotopically suggests infinite possibilities for illustrating the complex relationships that affect the understanding of family narratives. In effect, the narratives can only be partial and selective given the historical contexts in which the narratives occur and the infinite relationships among the agents of each system.

In the current study, human relationships are at stake, so it is imperative to understand and accept that there are multiple ways in which the narratives become meaningful and enacted. The co-constructed meaning is inherently social and dependent on the multiple histories of the participants of the research and the readers of the research, namely you.

Yes, I am asking you as a reader to consider your schooling narrative, your experiences with learners who learn differently, your life as a student, and so on. In essence, what we say, how we say it, and what we do with it narratively is a product of all the Discourses to which we belong. To illustrate, in the case of this study, how Jacob's mother interacted with him regarding his homework is affected by her schooling narrative which is further affected by the narrative of her teachers and families and their schooling and so on.

This research focused on those circumstances and life events that affected social and academic development but moreover it focused on the stories that are told within school and outside of school as socializing forces. A number of researchers reviewed the literature on families and developed a framework for understanding families (Beckman & Bristol, 1991; Fewell, 1986; MacKieth, 1973; Minuchin, 1974; Stoneman & Brody, 1984; Turnbull & Turnbull, 2001). This family systems conceptual framework becomes more involved when one of the members of the family has a disability; furthermore, all members are affected by the actions of all other members.

Given the above discussion and explicit theoretical connections between Bronfenbrenner and Gee, I elaborate on several key ideas drawn from Turnbull & Turnbull's (2001) explanations of a systems framework for understanding families of persons with disabilities. Without referencing Bronfenbrenner directly, Turnbull and Turnbull, in essence, extended his model to look more specifically at families with children with disabilities. Three important assumptions in Turnbull and Turnbull's (2001) work are the (1) input/output of the system, (2) the concepts of wholeness and subsystems, and (3) the role of boundaries.

The inputs and the family interactions with these inputs produce an output. How the inputs are interpreted and experienced, in turn, affects the output of the system. I extend their discussion which seems limited to the primary system, known as the family, to include other microsystems like schools and churches. By doing so, the emphasis shifts to the activity occurring not strictly within a given system but the activity between interacting systems. Turnbull and Turnbull (2001) limited their discussion of inputs to characteristics of the family (such as the physical makeup of the family, socioeconomic status, and so on), family members' personal characteristics (such as coping styles and the type of disability), and special challenges (for example, poverty or having more than one child with a disability) without troubling the systems which create these socializing characteristics. While these inputs are important to understand the family, the discussion tends to stay on how these inputs shape the interaction of the family. My research proposes that we look at inputs on another level outside of the family and consider how inputs of other systems, namely schools, affect the outputs or communication among systems.

By adopting a systems theory approach, we must understand both the whole and the parts of that whole; in essence, understanding only the child does not mean you understand the family but understanding the family is essential to understanding the child. Moreover, to understand the child and the family, you must consider the other systems wherein family members belong. Again, Turnbull and Turnbull (2001) limit their discussion of wholeness and subsystems to the subsystems within the family. For example, how does the marital relationship affect the interactions within the family and further relationships of siblings, parental relationships, and extended family involvement?

The concern is to understand the interactions within the microsystem, which certainly is an important place to start the narrative challenge of understanding how families work. However, we cannot stop there; considering how these relationships are influenced by forces outside the family system can help us interpret the interactions within and beyond the family unit.

Related to the importance of exploring subsystems of the family, a look at cohesion and adaptability of the family helps readers and researchers consider the function of the relationships. The degree of cohesion and adaptability within a family directly affects the nature of the boundaries that become a part of systems discussions. Let me take a moment to caution that understanding relationships and the degree of cohesion and adaptability must be considered within the cultural roots of a given family; without a significant knowledge base about culture, stereotypes may persist and misunderstandings may abound. Honoring the family and the culture of the family becomes paramount in any endeavor to know families narratively. With that said, cohesion refers to the emotional bonding and level of independence within the family system and adaptability refers to the family's ability to respond and change to contextual interactions.

Adaptability requires families to work out differences when tension or stress occur.

Understand that the notions of cohesion and adaptability occur along a continuum and are often shifting back and forth given any particular situation. Again, I extend Turnbull and Turnbull's framework (2001) to understanding any system, not only the family system, so that we can look at the agents within a school system and apply these same concepts. For example, how well does a given professional work with a support teacher? The

additional information can scaffold the kinds of bridges and partnerships that we coconstruct with families.

Finally, boundaries are created through the interactions of family members with each other and through interactions with outside influences. These boundaries can be open or closed and possess varying degrees of permeability. The degree to which these boundaries are open or closed directly affects the potential for collaboration and development. Boundaries become created through the interaction of family members within the family system; other boundaries exist between agents of differing systems. Boundaries pronounce themselves between and among systems. So a father's boundary between the family and the school may be quite different from the boundary between the family and church. The permeability of the boundaries varies then from one contextual situation to another and shifts across time given changes and development within each member of the family and the family life cycle.

Understanding families narratively is complex and dynamic. The discussion above demonstrates the complexity of offering a dynamic framework that exists on a continuum, one infinitely influenced by prior histories and positions of each participant and each institution involved. I used narrative as the means for representing the thematic tensions that occurred with the systems of two families. Knowing that events and people affected each respective system and the interactivity possible among systems enables a discussion of identifying reoccurring tensions, acknowledging their impact on the development of the family, and acting on collaborative opportunities to change the way things are. The knowledge that we gain from narratively experiencing the impact of disability on families and school can change us and move us toward social action. Below,

I consider the thematic tensions specific to my study by interweaving narrative examples and pertinent research literature.

Thematic Tensions

I now turn to a discussion of three overarching tensions created by the push and pull of interactions and the interpretation of the narratives. I draw on examples from the narrative, from data sources not directly evident in the narrative, along with supportive reference to research. First, I consider the power of protection and its influence as a reaction to the events that surrounded the identification of these students. Next, I turn to a discussion of the search for normalcy and the recurring cycle of certainty and denial. Finally, I conjecture on the impact of the relationships within the family with particular attention given to the sibling relationship. I conclude this chapter with one last look at myself and the meaning of this experience.

Tension One: Protection! For Whom? From What? Where Is Security Found?

When schooling troubles arose for Jacob, Travis, and Christopher as they began their academic careers, they were not alone. Side by side, parent and child entered a relationship with school that became defined by the interactions that centered on their academic progress. In this tension of protection, families struggled to maintain an impression of normalcy. By doing so, perhaps these students could transcend what these parents feared: “I didn’t want him to think of himself as dumb!” The families protected the child and the family.

We know that highly enmeshed families have weak boundaries between subsystems and therefore can be characterized as overinvolved and overprotective, while disengaged families have rigid subsystem boundaries that serve to alleviate anxiety among family

members (Minuchin, 1974). Well-functioning families represent a balance between these two extremes. I conjecture that these families moved along this continuum and this fluctuation influenced the degree of protection that seemed warranted at any given juncture in the narrative.

This theme of protection is evident throughout the narrative and tends to organize all subsequent information. The parents of these children had an intense need to protect their children. These families expected school to be a sanctuary of learning yet faced cultural contradiction within the walls of school; they expected their children to be emotionally and academically safe in school. This expectation grew from their experiences with schooling. Rather than security being fostered and developed in Jacob and Travis, insecurity and uncertainty abounded. Due to these unsettling encounters during the early years of school, the need to protect became more and more acute and the relationship between families and school became strained. When the expectations for performance were not met conventionally, the parents found themselves cornered, as the children's struggles to learn became more apparent, comparisons were drawn between the ideal and the real.

While these parents protected their children, this protection also served to protect themselves, perhaps unconsciously. For example, when Jacob was "put on the spot" to calculate the amount of cash being paid for a pizza, Carol cringed and wanted to rescue him but that would appear too obvious. Certainly, she wanted to protect him, but the question persists—did she also want to protect the family secret? I suspect that Carol's friends discovered Jacob's difficulty as he jumped in to help him as Jacob began to flounder.

Travis and Jacob managed to protect themselves by redefining their worlds. Reinventing themselves based upon the context that interaction occurred allowed Jacob and Travis and Christopher to constantly negotiate how much they allowed themselves to be put at risk. This awareness of context and the open or closed boundaries within these contexts helped these students navigate among the social sphere (Turnbull & Turnbull, 2001). What became frustrating for these families was the constant shifting and the influx nature of the contexts. It was important for each of them to appear competent, to do the right thing. In their efforts to “learn to do school,” (Dyson, 1984) each borrowed from their peers by watching and mimicking academic–social behavior. By doing so, they appeared to be knowledgeable and at times, they even fooled teachers. These teachers backtracked, providing the benefit of doubt to sustain the idea that perhaps Travis and Jacob just needed more time—that eventually they would catch up. While on the one hand such behavior is considered rather clever, both Jacob and Travis encountered the realization that such unconsciously cooperative behavior could not be tolerated in a competitive schooling environment. After all, that would be considered “cheating” and the consequence would certainly be time-out. They were creative in their social attempts to appear competent, but the competitive arena of schooling often squashed this creativity. Travis, Jacob and Christopher typically attribute their failures to their own abilities and their successes to factors such as good luck and the assistance of others. However, these families did not allow the academic troubles to overshadow the person beneath the disability; instead, they celebrated other individual traits and interests (Turnbull & Turnbull, 1986).

During a multiage summer science camp, Jacob's brother, Michael, protected Jacob from any academic ridicule and himself from "courtesy stigma" (Goffman, 1963). The day's physics lesson required that students follow detailed, multi-step directions to create an airplane with straws, paperclips, and scrap paper. After the instructions were given, Jacob dabbled with his materials, not making an effort at the task. Michael looked up from his own project and noticed Jacob's resistance. An older boy nearby who was nearly done, looked at Jacob and said, "You better hurry. I'm almost done." Michael walked over to Jacob and firmly said, "Jacob, you gotta do this." "But I don't know what to do," Jacob replied. Michael whispered, "Come here!" and with that suggestion, Jacob joined Michael on the floor near a lab table. Activity buzzed throughout the room, so it was easy for Michael to simply complete the project for Jacob. Jacob and Michael exited the room and began to fly their airplanes. Michael's act of kindness served to protect both Jacob and in all likelihood Michael as well.

Protection from harm and stigma came to be a way of facing another day and moving forward. Bigger walls could be built if necessary and walls were torn down when trust was ascertained. However, these families faced other tensions as they moved toward acceptance. As they made moves in the direction of acceptance, routine and revisited denial hindered them from full acknowledgement, realization, and acceptance of the disability and its limiting forces.

Tension Two: Denial/Moving Towards Acceptance

During the search for normalcy, these families faced difficult questions, terrifying decisions, and the day to day realities of living with a child with a disability. Denial resonated strongly in the data of this research project. At times, it seemed that individual

members were coming to terms with the manifestations of struggle that arose from schooling only to be faced with a new set of issues facing their child and family. Neither family wanted to fully accept the notion that their children were struggling in school.

Contradictions abounded in the interactions that these parents had with teachers and specialists. Early on in the educational careers of Travis and Jacob, teachers indicated that learning problems might in fact exist. However, these same teachers assured these parents that the evident learning struggles could also be attributed to the need for time—the need for Travis and Jacob to simply mature. Although Travis’ and Jacob’s teachers had suspicions early in their educational careers and questioned each students’ abilities, these teachers also wanted to give these boys the gift of time. And so, given such hope, these parents embraced the possibility that their children were “normal” and that they simply needed more time. While these teachers had no ill-intent in the recommendations that they made and while such time-forgiving strategies indeed work for some learners, these decisions can have detrimental effects. In fact, in situations like the ones described in this research, the gift of time turned out to be less than a gift; instead, it became lost time. Thus, these early years of schooling became identified as “terrible first years.”

As a teacher, I faced uncertainty in nearly all the decisions I made regarding my students who struggled. JoBeth Allen (2002) argued that such uncertainty allows schools and in this case, families also, “to try new approaches that may benefit all” (p. 61). I battled an inner struggle, realizing that the instantaneous decisions as well as elaborated plans I executed had demonstrative consequences. While I had trained to be a special education teacher and had knowledge of living with a sibling who struggled to learn, I was unprepared for the sea of uncertainty that I faced each day in my classroom. Some

days, I felt triumph but my celebration deflated as my limitations stared back at me. I tried and tried and tried, but I failed to fix it. Those “special” students still had problems day after day. They returned to my classroom needing more assistance and reassurance. I was then flung back into making new, difficult decisions

The learning struggles that manifested themselves were ambiguous and often the frustrations exhibited themselves in Travis and Jacob’s outright avoidance of learning. For example, during the time that I spent with Jacob, when I raised the issue of school or teachers or learning, Jacob steered the discussion elsewhere saying, “I don’t want to talk about that.” Or when I raised such issues with Christopher by phone or email, he commented, “School was okay; I just didn’t like all the homework.” It was easier for them just to block it out.

These parents and my parents faced uncertainty as often, perhaps more often than I did. They not only faced uncertainty with schooling, but they also faced uncertainty regarding decisions made beyond school. For example, Carol and Jim could not agree on whether to inform the coach of Jacob’s baseball team about his disability. On the one hand, it seemed obvious—they should inform him so that he would better understand the frustrations that Jacob may exhibit. Perhaps such knowledge would help the coach consider how he gave Jacob instructions, how he explained the game, and how Jacob’s performance may be less than perfect. At the same, they both worried that by revealing the disability that undue stress may be placed on Jacob; ultimately, they feared stigmatization. The reaction of the coach could not be ascertained. The revelation may elicit prejudices from the coach and discrimination from teammates. Perhaps Jacob would be treated too differently. The uncertainty for them was maddening.

In spite of the contradictions that remained, the families moved forward in time and tried to dodge the frustrations of schooling. In these first years, ability was questioned, labels were eventually assigned and these students and their respective families became vulnerable to societal pressures to be “normal” and to meet the standard. However, that standard comes in only one size and as Susan Ohanian (1999) argued, “one size fits few.”

Labels become political markers and I contend that people’s fear of saying the wrong thing or tripping over the appropriate labels may actually stop communication. People get hung up on the words or the labels when all we really want is understanding. I believe that these social pressures of normalcy forced these families to find solace in denial, albeit temporarily. As Carol indicated, “it’s easy just to block it out.” By doing so, they maintained the illusion of normalcy.

The fathers had an especially difficult time acknowledging the degree of difficulty that their sons faced. In essence, they often denied the problem, erased it as serious, and proclaimed their sons as “all boy, disinterested and distracted.” While the families of the boys in this narrative experienced the frustrations of homework and schooling troubles, they were more often handled by the mothers. In an in-depth study of fourteen mothers, Rannveig Traustadottir (1991) found that mothers who have children with disabilities organized their lives around roles of caring: caring for, caring about, and extended caring. Other studies agreed that the largest part of the responsibility of family needs falls upon the shoulders of mother (Stoller, 1994; Renwick, Brown, & Raphael, 1998; Wickham-Searl, 1992) despite a trend toward more sharing of familial responsibilities. Thus, these fathers were able to adopt different roles, often seeing the “normal” activities of Travis and Jacob. In essence, it took a longer period of time for these fathers to reach the same

realizations as the mothers. The scope of this study does not allow for an extensive look at how gender positioned various families but is certainly a fertile area for future research.

Daily homework echoed the frustrations that Jacob and Travis endured at school. Maddux and Cumming (1983) warned if

academic learning is required in both the home and the school, a child who has difficulty learning gets very little relief. The home ceases to be a safe haven from scholastic pressures. Imagine how most of us would feel if the most frustrating, least enjoyable, and most difficult things about our work were waiting for us when we came home each day (p. 30).

Curt Dudley-Marling (2000) found similar homework troubles in his extensive study of school troubles. In contrast to these troubles, Shockley, Michaelove, and Allen (1995) developed partnerships with families and cocreated a set of parallel practices that bridged the homework gulf that often divides home and school. In social ecological terms, such an arrangement promotes development.

I remember my brother bringing home mounds of work each week that he had to “catch-up” on because he was unable to finish them in the given time allotment at school. That meant for our family, many frustrating evenings of gathering around the kitchen table and helping Christopher through the mounds of worksheets. Thus, there was a daily reminder that drug each of us out of denial. We lived one day at a time—do the homework, try to keep things moving along, alleviate any undue stress for Christopher and hope for the best for the next day. Maybe something would just click. The next morning, we could begin anew only to be faced with the exposure of our denial at the end

of the day. These daily routines allowed these families to go about their lives without being attuned to the ongoing tension created from the struggle to accept the disability but being flung back into the wringer of denial. This continual fluctuation of frustration caused only alienation and turmoil for these families when the potential for development disappeared; instead, the monotony of the routine numbed the possibility for bridging between home and school.

Given a new day, families like ours accentuated the positive and found opportunities for our loved one who struggles to experience success. Such opportunities provided the reassurance that everything was okay. Parents collected facts to disprove accusations. For example, Grace was prepared to show the kindergarten teacher that Travis could indeed color inside the lines given the mandate. Such facts and observations buttressed their hopes and their familial identity. Our inner beings watched for warning signs that there was indeed a problem. Eventually, denial turned to an acknowledged powerlessness, to the reality that the child differed from the norm. And the attention of parents shifted to learning the truth of the disability.

While it remains difficult for these families to fully accept and embrace the disabilities that their children face, they have made conscious decisions to move forward. By doing so, they do not become enveloped by the threat of social stigma. They are able to influence the way their child becomes defined beyond school, helping each find strengths and resisting the temptation to link everything to achievement in school. Certainly, societal pressures emphasize the importance of schooling and higher education, often setting up a hierarchy that unfairly puts such families at greater risk of stigmatization and alienation. The majority of the culture in the United States typically values individualism,

self-reliance, early achievement of milestones and competition (Shannon, 1995;Turnbull & Turnbull, 2001).

Schooling experiences are defined by individual outcomes and individualistic perspectives dominate the educational practices that Christopher and children like him face. It is frustrating that society expects Christopher to make all the adaptations. When will society change? In the end, I do not necessarily wish that Christopher were different. Rather, I wish society were different. I wish that it did not matter so much that some children have disabilities, that children did not need so much intellectual prowess to live a happy, fulfilling life. I wish the world were a safer place. I wish others reached out in cooperation and collectivism. My brother still faces it at every family gathering where multiple cousins congregate around a discussion of academics. The discussion usually turns to, “What do you do? Are you in school now?” And from a corner of the room, I cringe and want to yell “What difference does it really make?”

The pattern is always the same. They bring up school, Christopher’s self-worth is brought into question, and he leaves questioning his identity. He calls the neighboring state schools and technical schools only to be faced with entrance exams and more false reassurance. Not only is it important for Jacob and Travis and Christopher to realize that schooling is but one dimension of who they are, but it is important for teachers and parents as well. Potential for development exists when communication between teachers and parents is open and “indirect linkages between settings that encourage growth of mutual trust, positive orientation, goal consensus, and a balance of power” are regularly initiated (Bronfenbrenner, 1979, p. 216). I believe that only comes over time and with conscious regard by professionals and families.

The governing bodies that influence the decisions of schools on both macro- and micro-levels need to rethink the high stakes testing movement that will only serve to further discriminate based upon arbitrary pockets of knowledge. This will intensify the dissonance that already exists between groups of students. Jacob and Travis and Christopher were all attracted to sports knowledge and physical means of achievement due to the failure that they have and continue to experience on a cognitive level. There is no test that will affirm or evaluate this prowess or knowledge.

Unending worry plagued both of these families. They worried about their child's self-esteem and its accumulating impact on their development as teenagers and eventually adults. The failure and frustrations that Jacob and Travis and Christopher experienced worried their parents. Will such continual failure make them feel inferior to their peers and later to society at large?

These parents learned that what children need most cannot be bought with money. Changing schools will not fully solve the daily problems. Jacob eventually attended a private school that specifically served children with severe learning difficulties. Carol worked a part-time job just to pay for the tuition so that Jacob could attend the school. While there have been benefits to this arrangement, Jacob continues to struggle and his parents wonder if it was the right decision. Since Christopher remained in public schools, my parents still wonder what difference a private school setting could have made for Christopher. I conjecture that neither option offers a resolution to every disturbing aspect of living with a child for whom schooling is difficult.

These families are almost always faced with the gnawing tension of uncertainty. While often we are denying that the difficulty exists, every juncture presents a challenge

that shuttles us back into a muddle of uncertainty. Little remains the same on a day to day basis. Everything becomes subject to question. Knowledge is shaken as new knowledge is obtained. Nothing is a sure thing and each step seems laden with more challenges. It is a game—we feel like we do not have the rules and we are playing anyway.

Coping with the ambiguity and knowing how to help is overwhelming at times, but families persist. Families develop strategies for coping. As Mary Pipher has suggested, children need “sheltered places where they can be safe as they learn what they need to know to survive” (p. 221). With this aim to provide sheltered places for living and learning and while feeling unequipped to face each day’s challenges, these families reach a place wherein they make a public acknowledgement that they indeed may never fully understand their child’s frustrations. This crucial realization allows them to lean toward acceptance. Instead of becoming bogged down in a depressive state of pessimism that, according to Bronfenbrenner (1979) would inhibit potential growth and development, they turn to hopeful optimism and guarded realism, knowing that they must help each child create a unique pathway into the world. After love and security, all one can really do is cheer them on.

To the extent that these families found momentary relief from the tension of denial and as they moved toward acceptance, it was the relationships among family members and relationships between school and home that inevitably affected the dynamics of the family.

Tension Three: Relationships! Competing Needs . . . Who’s Responsible?

Maya Angelou once said, “At our best level of existence, we are parts of a family, and at our highest level of achievement, we work to keep the family alive.”

Living with a child or sibling who has a disability peculiarly positions family members. For families of children with disabilities, traditional symbols of achievement or rituals marking critical childhood milestones and transitions may be delayed or nonexistent. These same critical periods for siblings without disabilities may occur simultaneously, forcing the family to deal with the differing needs of individual family members (Turnbull & Turnbull, 2001; Wikler, Wasow, & Hatfield, 1981). Like other families, families with a child with a disability face the same intense societal expectations and pressures. Families display both vulnerability and strength, and when that family includes a child with a disability, the family may be both stressed and strengthened by the experience.

All of the persons in this research have needs—physical, emotional, and intellectual needs. The needs of each family member are vulnerable to the overarching need of the child who is struggling and is subject to the developing relationships across various social spheres or systems. While some needs are pushed aside or forgotten or overlooked for the greater good of the child who is struggling, the position of each family member is affected by these same interactions. The fulfillment or lack thereof directly affects the balancing act of the family.

Nixon and Cummings (1999) found that siblings of children with disabilities more frequently assume personal responsibilities for family problems and show more involved coping during family conflicts. This factor may cause siblings to face more negative family conflicts. Therefore, siblings of children with disabilities may feel socially ineffective and incompetent if they are continually involved in family conflicts that never resolve due to the perpetual effects of the disability. These feelings may relate to lower

self-concepts. A review of 20 studies indicated that by third grade, students with learning disabilities typically have lower academic self-concepts (Chapman, 1988). Unlike any other relationship, the sibling relationship provides a permanent relationship from which there is no annulment. Siblings provide perhaps the most intense, influential peer relationship in a child's life and additionally, serve as a support system for each other (Powell & Gallagher, 1993).

Child development scholars Gene Brody and Zoe Stoneman and their colleagues have contributed significantly to our understandings of sibling relationships. Brody, Stoneman, and MacKinnon (1986) noted that few studies have directly focused on the relationship of siblings' interactions to other family subsystems. Other studies by Brody and Stoneman (1986), Brody, Stoneman, and Burke (1987) indicated that sibling relationships are a function of the parent-child relationship. Stoneman, Brody, Davis, and Crapps (1987, 1989) considered the roles siblings take and activities in which siblings are engaged. They argued that the relationships cannot be understood without situating that relationship in a context. In the 1987 exploration of same-sex sibling interactions in in-home contexts, they found high levels of interaction in families with a child with mental retardation and the control families who did not have a child with mental retardation. Of particular importance to this study, they found that older brothers and sisters with a younger sibling who had mental retardation were more likely to be engaged in asymmetrical roles such as managing, teaching, and helping. The 1989 study supported this latter finding; in it, the researchers wanted to further determine role asymmetry among siblings and the affective quality of sibling relationships. They found a heightened role asymmetry adoption by older brothers and sisters of siblings with mental retardation.

They found that the less competent in language and adaptive skills, the greater the role asymmetry. Moreover, they noted that this role asymmetry only intensified with the aging of the child with mental retardation. Stoneman et al (1987) concluded that the greater role asymmetry with age sets the stage for the advocacy role that many persons of siblings with disabilities assume.

In this particular tension, I give specific attention to the sibling relationship along with the triad that is formed among the parent-child-sibling relationships. After all, whose responsibility is it anyway? Given the life circumstances of these two families, the children who struggled inherently became the responsibility of many individuals. Parker Palmer (1983/1993) claimed that “there is no selfhood outside of relationship. We must ask the question of selfhood and answer it as honestly as we can, no matter where it takes us. Only as we do so can we discover the community of our lives” (p. 17).

Only through the relationships forged in this research journey was I able to come to terms with my own narrative, my own selfhood. My conjectures simply attempt to organize the intricate and variegated experiences that I have had with my own narrative and the narratives considered in this project.

As Curt Dudley-Marling (2000) noted, schooling tensions impact relationships between parents, parents and children, parents and grandparents, and among siblings. We can only begin to understand the distress that students who struggle experience as they spend more than a third of their day in schools that consider them less than adequate. The degree to which the family recognizes and acknowledges the disability of the child who struggles becomes a pivotal point of contention in relationships. In these two families each family member wavered along distinctly different positions of acceptance. While the

narrative may, in fact, read too clean and fluid, these families faced marked degrees of acceptance and thus, were affected along a continuum ranging from unrealistic denial to full acceptance. As with other dimensions of this lived research and since these relationships are dynamic, there was no one single definitive impact of the disability on the relationships. The narrative of relationships woven in this research included my family and my friends, my present and my past along with our unknown futures. I used others' words to help me, but much of what occurred within these pages is my own intrapersonal struggle with understanding how I am affected by these narratives.

Thinking about my relationship with Christopher and being reminded of the difficulties of his existence made me uncomfortable, so uncomfortable that I elected to conceal much of the "reality" in the proceeding narrative. Instead, I created composites that served to illustrate the struggle and yet protect the parties. The section below is perhaps the culminating point of this research and for me, the most important. It answers the question of how I used narratives, both mine and others, to craft a narrative of experience. I finally recognized the potential and power of the gaps—the silent places that invited you to actively participate in the narrative. Here, I respond to those silent spaces within the narrative, the moments when readers really wanted me to say it out loud. What about the siblings you may ask? This is autoethnography after all—what about YOU? Below, I reveal the self behind the mask of author, to introduce myself, for in the end, this dissertation is more about me than it is about them. I made the choices, I chose the words, I described the emotions all with the knowledge of the limitations of language. It is my hope that in some way I have created artful scholarship—a scholarship

that will cause you to pause at the emotional experiences lived by me and my family and my friends.

As a sibling, I always felt responsible for my younger brother. I wanted to be involved in his life. I obviously wanted him to be successful, especially at school. I knew from observation how “dumb” kids were treated at school. I knew what it meant when specific students had to leave the room to go to a “special” teacher. I wanted to help Christopher avoid those difficult transitions. Ultimately, I wanted him to be normal. While I do not recollect a time that my parents sat me down and explained Christopher’s disability, I became astutely attuned to the discussions and the tensions that surrounded Christopher’s education. Prior to his entrance to school, most events and interactions with my younger brother seemed and appeared normal. It was schooling that began to define him in limiting ways. I am nearly convinced now that my high academic achievement, as a student, was somehow linked to what Christopher faced in school—the increasingly intense and equally demanding task of achieving at all. Some consider students like Christopher “underachievers” or “slow learners” when in fact, we cannot fathom the measure of courage and confidence it must take to face the intellectual minefields that these students must maneuver. They often work twice as hard and twice as long as those who perform to the “norm” and yet the norm is what gets recognized and the above norm is what gets rewarded. Students who are different face the “measuring stick” day after day. Perhaps I could achieve for both of us. I also wonder if this desire to achieve was an attempt to gain attention from my parents. Others might argue that my natural inclination to achieve was a birth order circumstance. Perhaps but its intensity was a result of living with Christopher. In any case, my achievement has turned out to be a guilt

producing challenge. Even with the completion of this dissertation, I resist. I resist the comparisons that will be drawn, even if they are drawn implicitly. I do not want a grand celebration of my achievements because such a celebration would only serve to further delineate the academic differences that exist between my brother and myself. Maybe if I did not finish, maybe if I failed, we would somehow be even. I could perhaps better relate, proclaiming, “Look, I’ve failed too. You’re okay.” I struggle with the guilt that I have a “better life.” I cannot allow myself to bask in my achievements or even admit that I deserve them. What normally would bring a person enjoyment and pleasure eludes me; instead, I’m left with stress.

Some might contend that siblings, such as myself, are forced to mature prematurely. I believe that perhaps I did. Looking back, my childhood was cut short, a contention supported by research that such premature initiation into adult roles and acceleration of social development was typical in siblings of children with disabilities (Mallory, 1986). I had to learn to be a peacemaker. I had to pick up extra chores and household responsibilities. I had to “not have too much fun.” I had to pretend that everything was perfect. I became a serious child and at times still, I remain a serious adult. I adopted the role of consummate peacemaker. I wanted to make things better for the family. My adolescence was experienced during schooling hours as I became intensely involved in school activities, such as becoming a class officer and editor-in-chief of the school yearbook. I drowned myself in responsibilities both at home and at school. If busy, maybe I could forget the intensity of the difficulties that my younger brother faced. Somehow maybe my contributions would be enough for both of us; I had to achieve for two. I owed it to him.

I was inherently more comfortable with adults than children my own age. While I do not believe that my parents' intention was for me to accept such responsibilities, as a sibling, I internally and emotionally wrapped my world around. This heightened sense of duty made me feel simultaneously helpless and fully responsible.

My childhood was far from "normal." I knew the stress that my parents were facing as they tried to meet the educational needs of Christopher. I learned to make few demands and to dismiss my own insecurities. I learned to pretend that everything was okay in my life. I learned to keep secrets. I questioned God. While I conjecture about my experiences with my younger brother, I am careful as I write. I feel the tension in my gut. The ever-so-slight hush of my internal judge. As an adult I find myself grieving that the peer that so many have, the relationship of camaraderie, is indeed different for me. There are boundaries to the conversations that I can have with Christopher; we cannot have the same conversations that other siblings have. While I am closer to fewer people, I feel far away from him at times.

Recently, my younger brother and my parents relocated to live near me. My parents are aging and my wife and I convinced them that they should move here to be closer to us, to be near their only grandchild. With even more conviction, I conveyed the intense responsibility that I claimed to take care of Christopher should something happen to them. I needed him to be close. I needed him to construct a life for himself here, so that I could observe from the sidelines and referee should that attempt go awry. Even still, my mother's hope echoes, "I hope he will not be dependent on anyone." Those roles and those struggles that I have mentioned above are still active in my current life. However, I

am learning to control their power over who I am, but I'd be lying if I denied that they are who I've become.

I've carried them into my marital relationship and into my parental relationship. At Trent's six month checkup, his doctor mentioned that there may be a problem with Trent's skull formation and wanted us to see a neurosurgeon at Scottish Rite. I was worried as any parent would be, but the intensity differed. Although I had read extensively of the affects of plagiocephaly, an environmental condition where the formation of the skull is affected creating a flattened area, I was intensely concerned about its affects on Trent. I wanted Trent to be normal. Jennifer and I worried so much that we limited how often we allowed persons outside of immediate family to see him in his cast-helmet. Fortunately, he's okay and the helmet corrected the problem. Still, I breathe a sigh of relief at each milestone that Trent exceeds.

I have struggled with whether it is my right to tell this story simply because I am capable. Through this research, I wanted everyone to change. I wanted full acceptance to my plight. I wanted to fix everything and make it better. Now, at the other end of this research journey, I realize the limitations of that expectation for this research. I cannot expect the other lives in this narrative to be changed the way I have changed. I have been afforded the luxury of seeing the whole and the individual parts. I also have made the selections and omissions. I have made the experience bearable and revealing. I've compiled a narrative that for me makes sense. I want each of them to be transformed by this experience. At times, I feel like I only brought about the reminders of the pain of this experience. And I'm not sure even still that doing so was fair to them. I have spent more than a few sleepless nights and days of anxiety over this project and even more

uneasiness and apprehension over the silent places—the places where I have been residing. This project has required a revision of self; I've been forced to reconsider and revise what I once considered was perfect. My only hope is by providing this narrative that my family and Jacob's family can identify with another, that they will find comfort and solace in knowing they are not alone. It is essential for me to be understood through this narrative, because Christopher rarely was understood.

There is little in way of research on siblings and their relationship in the schooling venture and what does exist, that is even loosely related, is contradictory. One study claims one set of assertions and another claims an opposite set; still others claim mixed results. For example, Frances Grossman (1972) interviewed college students who had siblings with mental retardation. About half of her group suggested that they had difficulties as a result of growing up with a sibling with a disability. Still, her other half of interviewees reported positive experiences in their family (i.e. increased tolerance, empathy, and altruism). Susan McHale and Wendy Gamble (1987) found no differences between children who had a younger sibling with a disability and those without in terms of number of negative or positive behaviors directed at the siblings. Still others (Wilson, Blacher, & Baker, 1989) found that some siblings expressed a high degree of responsibility for the child with a disability and viewed their interactions as positive; however, they also found that these same siblings acknowledged feelings of sadness, anxiety, and anger. Debra Lobato (1990) argued that, in general, siblings of children with disabilities do not have a higher incidence of major personality or behavior disorders than their sibling peers.

However, it must be noted that these researchers relied strictly on survey data and “measurable psychological adjustment problems.” While I have no intent of claiming that this is an exhaustive review, even my review of abstracts indicated a reliance on quantitative, measurable research including behavior rating scales, surveys. Few of these actually included “supplemental” interview data. Early studies of siblings without disabilities focused on demographic characteristics, and even more recent observational studies still tend to rely on quantifiable variables to explain the results of research. Peggy Gallagher and Thomas Powell (1989) called for research that explores the sibling relationship throughout and across lifetimes in natural environments. Susan McHale and Vicki Harris (1992) agreed that longitudinal research could provide the long-term effects of growing up with a child who has a disability; they note that these effects may be not be realized until adulthood.

No wonder little consideration has been given to siblings. I never remember being included as a component in Christopher’s educational journey except to be noted as a family factor in reports, “Christopher has one older brother.” That was my mere existence, and yet I was intricately involved. I can only conjecture that this research taboo is so genuinely intertwined in the emotional realm that “scientific” research communities find it difficult to construct an appropriate instrument that can reliably measure its affects. In addition, too often the research stories told are stories of successes and such stories hush those of us who experienced the darkness. More elaborative and much more revealing efforts can be found in literature (Lamb, 1998; Hegi, 1994) and memoir (i.e., Simon, 2002; Ginsberg, 2002; Zuckoff, 2002; Kephart, 1998; McDermott, 2000; Hankins, 2000) which I have drawn on immensely in understanding and acknowledging

my own narrative. The art of language reveals. My contribution then is another narrative, another way of considering this experience, an experience that alludes the research community. My hope in this process is that by revealing myself and crafting a narrative that allows one to experience a glimpse of the difficulty of the schooling arena of children who struggle and their families that perhaps I can experience my life more fully. To know as I have become known in this narrative is a hope that I have.

One Last Look at Me

In the opening of this chapter, I promised to turn the lens back upon my self more intensely, to ask the research question again, “How do I construct and make use of my narrative and others’ narratives in shaping an experience of difference for others?” I’m plagued with the lingering question that creeps from every corner, “Why does this matter?” The question attempts to squash my determination to finish, but like Jacob and Christopher and Jacob, I persist. I persist because there are other families—families that feel alone and desperate. I hope that this dissertation beckons them to come to my side, to hold my hand and to find some degree of solace in company. This writing marks where we have been, are now, and where we are going.

Through my years of teaching in both special education and general education settings, in inner city and suburbs, I have come to realize that the children who I worried about the most were the children who struggled the most. That comes as no surprise since I continue to watch my younger brother struggle immensely. As a result of my personal experience and the raw pain of living with a sibling for whom schooling was difficult, I reached out physically and metaphorically to such families. I always cared but it was how I reacted and responded that began to develop over time and even more intensely through

this project. With clarity of vision and this research project, I have been able to identify some of these unconscious roles that I adopted. Some of the families needed a counselor, an advisor, a helper. Nearly all of them needed a listener—someone who would share their burden. These parents and these children need others to listen to their fears, their concerns, their feelings. We all want to be heard, to be validated. And as a young teacher, I listened. I nearly always buried my personal experience as a professional. I had learned to be wary of “becoming too involved” as professors had instructed. Instead, I heard them and then I worked diligently to fix the problem and alleviate the schooling problems. I thought I was listening, but now I wonder. Perhaps I was just hearing them and what I was hearing was that they had a problem that I thought they needed fixed. If I had slowed down to really consider the layer beneath the words, they really just wanted me to listen without immediately offering a strategy that we could try. It was frustrating. Inside, I was aching, because I was failing at my attempt to make things right for children, like my younger brother. I was failing to make things better.

I also came to believe that my story did not matter so much, that what mattered was the story of the child who struggled. Looking back upon this research journey, I know that this research was a selfish endeavor. Every interview transcript reveals as much of me talking and supporting and revealing as it does the research participants. I needed them. I needed a parallel narrative by which I felt safe to lay out my own narrative and that narrative I had woven about my family and my younger brother. It was essentially clear that this narrative was becoming more and more blurred. I embraced each narrative to free my own narrative. Methodologically, I had entered the familiar and made it strange.

As a special education undergraduate student, I was enamored by the technical information that I encountered. With the appropriate battery of assessments, I could diagnose and prescribe. There was incredible security in being able to pick up a reference book and label a given case. It was empowering. I finally had control over the uncertainty. I could name it, define it and move on. By becoming a teacher, I offered a reparation. Through this research and the years of preparation for facing my fears, I have come to realize how much and how little the term “disability” actually tell us. Given the power of language, the term restricts and constricts what is possible if one follows the term to its end.

While Vygotsky (1934/1986, 1978) never specifically discusses issues of identity or subjectivities, he made the relationship between language and consciousness very clear. As individuals interact with each other, they internalize language. They consider the interrelationships mediated through language and construct worlds of beliefs and knowledge. The formation of the mind and the development of the mind are affected by the mediation of language. People come to define themselves and understand themselves through language. Who we were, who we are currently, and who we are becoming are social constructions of language.

I have been able to tap into my innermost being, my innermost feelings—understanding that these feelings and thoughts are not my own, but are collectively constructed—and give them shape through the use of language. The language that makes up this narrative experience has a particular context and was constructed under particular circumstances. The words that I have chosen are not solely my own; instead, they represent the echoes of others, words that have been adopted and adapted by me to

convey this experience (Bahktin, 1981, 1986). It has been a harrowing experience.

Gradually over time, I discovered the way through my interpersonal crisis by seeking out the narratives of others who also were struggling. The expression of their lived narratives empowered me to consider my own, to transform my feelings. I connected my story with the stories of others, bridging the ‘gulf of our essential isolation from one another.’ One of my goals has been to provoke readers to think in more divergent ways about families and children with disabilities and to empathize with the confusion, chaos, and uncertainty. Explanation may offer some clarification, but I argue that through language, specifically narrative language, readers are invited to participate in what would generally remain invisible—the terrain of our feelings.

Writing this interpretive chapter of the preceding narrative has served as a roadmap into the invisible geography of my feelings, allowing me to chart the unexpected turns. Because the web of human feelings creates its own patterns, those patterns are better evoked than explained. To name and frame with words on a page triggers the process of evocation. The emerging patterns in my writing and the obvious spiraling of my own experiences with the other research participants led to tentative insights. While the research was painful and the writing slow and arduous, ultimately, I believe it was empowering to name the pain. In these private and highly focused moments of narrativity, we understand the helix of our life for the first time. We are able to hush what we think should be and move toward redefining what is.

It allows for a shift from old patterns, outworn beliefs and attitudes to more appropriate ones that can serve us in a new time and a new emotional space. Now, instead of simply accepting the “disability,” we can understand it as only one facet of an

individual. Furthermore, we can join the struggle against the restrictive language and the power of such language on families and students. These two families and I join a number of other families that describe their child with a disability as a major catalyst for enhancing family love and commitment (Behr & Murphy, 1993; Summers, Behr, & Turnbull, 1989). By attending to the experience as one full of potential and possibility, I was able to convey an image through the power of words. It would have been easier to stagnate.

This story is not only about my strengths, good intentions, and virtues; it is also about my liabilities and my limits, my trespasses and my shadows, my hopes and my fears. As we grow from childhood into adulthood, we become walled in by expectations. These expectations can hinder who we become. Too often, the expectations are created and forged by people who are trying to categorize us and fit us into slots. From one social sphere to another—including families, schools, workplaces, and religious communities—we are expected to reflect images of acceptability. Under such pressure, who we are becomes misshapen because we are made invisible by society's prejudices. From fear, we too often betray our self to gain approval. Not only has my identity been shaped and reshaped by this research, I believe that so have the identities of the participants involved. Some may want to continue to call my behavior codependent, perhaps even countertransference. I prefer to call it finding a friend and building a bridge.

This dissertation is a selfish endeavor. It was a study that I had to do. It was a dissertation that I had to write—first and foremost for me. I had to struggle with my own narrative and its impact on the narrative that I cocreated with the many other voices. You will no doubt see my self in all its protective masks and self-serving fictions, but I also

hope that you will sense my true self. I believe that my true self and my own struggles rest upon the words of this story. In school, we learn to listen to everything and everyone but ourselves. We learn to do school by attending carefully to the cues provided from the people and powers around us. Unfortunately, such powers require that we listen to everyone and everything everywhere and we may fail to listen from within. This dissertation is a struggle against that tendency.

I have struggled to pay attention to my actions and reactions, my intuitions and instincts, my feelings and bodily states of being. Like John Dewey suggested, if we learn to consider our own responses to our experience, a text we are writing albeit unconsciously at times, we will more likely live authentic lives. I have learned that the only way to engage in an autoethnographic project such as the one here is to find the vector points where my self and another self meets. And that was the process that I engaged in. I used my own narratives as springboards into the narrative lives of others and I, in turn, used their narratives to explore my own interconnected narrative life—to hone it and to hold it up to scrutiny. In the midst of acting out this research, I discovered my own limitations and those limitations became therapeutic to the research endeavor. Selfishly, I share this part of the story here.

CHAPTER SIX:

COMING TO TERMS WITH THE NARRATIVE WORK

I'm afraid of endings but I have to end this narrative. So I've stopped. I'm not sure what this might mean for me. I'm not sure what to do now. There are still so many persistent and troubling questions. What will I do now that I have let out the demons that have cornered me so many times? And did you notice the ones that I have not released? Did you wonder about the silent places? The issues are not completely resolved. Are they? I know that it is only a matter of time when I will face some of the same difficult days and face many of the same difficult decisions. I worry about my own son now. I worry like the families portrayed in this narrative. Will he face schooling troubles and how will I respond? Or will school come easily for him?

How do I make sense of what I have written? How do I assure that I have respected the issues that have emerged? What are the scholarly connections? How do I convince a reader that this is worthy of attention? And why does all of this matter? These questions haunt me. I have avoided bringing the narrative to a close. I have tossed and turned at night over how to conclude. I've outlined several different routes by which I could accomplish the goal of a concluding chapter. I avoided these final chapters for weeks. I struggled with the incorporation of the scholarly literature. I tried pausing in various places within the narrative and discussing the pertinent literature, but I feared that I was breaking the natural flow of the narrative. I reread the first chapters of the dissertation and reread the narrative work. I visited other dissertations. I had decided on a

fairly traditional literature discussion but was disappointed in its flat presentation. I realized that maybe it was because I had disconnected myself from it. I remained paralyzed. I resisted the expectation to categorize this experience and the temptation to organize the experience. I had to get back to the heart of the matter. My goal had always been to convey emotionally what these families experience. The ultimate question remained. What to do with a final chapter?

Days turn into weeks and finally my wife Jennifer grabs both my shoulders in our bathroom one morning and says, “Shane, you can do this. You want to talk about it?”

“I guess so,” I shrug.

I attempt to leave and Jennifer persists, “Tonight, Shane, tonight.”

I spend part of the day surrounded by dissertation data. I relive the moments with Jacob and Christopher. I desperately attempt to synthesize the narrative and the metaphors inherent in the social construction of learning differences. I revisit my research questions

Jennifer puts Trent to bed and enters my office as I lounge in the oversized chair surrounded by dissertation matter. Multiple coffee mugs are scattered about the desk and bookshelves. The computer screen flashes with squiggly lines bouncing off each edge. I look up and smile meekly.

“I’m tired. I can’t think about this any longer. Let’s just go to bed,” I suggest. But Jennifer is serious about discussing the dissertation; I can see it in her face when she begins, “Shane, you have lived this so intently. You think about it constantly. So how’s the concluding chapter coming?”

“Well,” I respond, “I want to emphasize the emotional experiences of these families and the therapeutic value of this kind of research. And I want readers to understand on some level why I made the decisions I made. And I have to include the scholarly connections that are pertinent to this discussion. I know that some readers will expect a categorical explanation of the themes and a traditional discussion of the issues. And I agree that those are important; however, I desire to respect the narrative and the transactive potential that exists between the reader and this text. I can only suggest some of the tentative findings of my own rereading of this text.”

Jennifer settles in the loveseat with a wool blanket and asks, “Just tell me, what have you learned? Isn’t that what people want to know? I mean you spent so much time with Jacob and his family and you grew up with this experience. And you’ve reviewed the literature. You’ve read accounts of families who experience similar difficulties. Just talk to me.”

“Ok, remember me talking about Urie Bronfenbrenner’s (1979) ecological theory of development and the notion of systems or what I call social spheres.”

Jennifer nods and I continue, “I think that once readers consider the impact of living within a family who has a member who struggles with schooling due to an intellectual disability through the means of a narrative, then the possibility exists for them to consider the unstable terrain of moving through these various social spheres.”

I can tell from Jennifer’s face that I need to back up. I reach down and hand Jennifer the diagram and continue, “Ok, each social sphere impacts the family and the family member who struggles to learn. Each social sphere reflects bi-directional activity and dynamic relationships that increasingly are distanced and removed from the child and

family. Nevertheless, the activity that occurs in each sphere continues to dramatically influence the potential for development.”

I get a nod from Jennifer. I can sense the urgency in my gut to articulate this matter. “I have learned from this experience that perhaps the levels that pound down the hardest on families are those that seem the most removed, especially the Macrosystem which includes the ideological or belief systems of the society. It beats away at families day after day. It affects in turn how they understand the events and relationships in their lives.”

“So, are you saying that you actually studied society by studying families?”

“Hmmm,” I wonder, “To some degree yes. Much of the reaction and response from families to disability was buried beneath one single, overriding commonality. All the families I have encountered in my years teaching and researching including my family and Jacob’s family struggled on some level with one commonality. It cuts across all our discussions. At first, it did not appear to me so blatantly and then, upon analysis, it seemed that every theme I identified in some way pointed back to it. I suppose I now have an umbrella construct for talking about the narrative and this research.”

Jennifer grins, so I continue, “The most striking and elucidating construct that now organizes my discussion of this research is stigmatization.”

“Wow, so do you mean that these families feared stigmatization?”

“Hang on. Let me continue. I believe that the preoccupation with stigmatization is definitely at the very essence and heart of the worries and school-related problems discussed in this research. To the extent that students deviate from the “norm,” they likely encounter the possibility of being ridiculed, avoided, ostracized, and ultimately

discriminated against. That's what we worry about Jennifer. The whole narrative is intertwined heavily with the need to protect. While it appears that we are trying to protect the child from the school, school only serves as an extension of the outside world. I want desperately for kids like Jacob and adults like Christopher to have equal opportunities in education, socialization, and vocation, but the uncertainty of these opportunities leads family members like myself to worry and to seek opportunities to advocate on their behalf. Take Trent, we both are experiencing the emotions of protections now with our very own son. We want to protect our family member from hurt and discrimination. And thus, stigmatization. Stigmatization is defined, after all, by the existence of norms and the difference from those norms. Any difference at all can cause havoc, but having an intellectual difference in a society where knowledge and intellect is valued and highly regarded and where conformity is expected can only create problems for families. Certainly the parents involved in this project felt and conveyed an intense need to protect their children. Take either child and you could easily illustrate this theme of protection.

Jennifer raises a finger and says, "Ok, but I know I've heard you say that if you have to have a disability you want to have a learning disability. What did you mean by that?"

"I have said that before and been blinded, I suppose, by the acknowledgment of my own pain. I meant that being learning disabled was a popular disability to have if you were going to have to be disabled. But now, I believe that perhaps there is a sharp edge to this experience and that is to have an intellectual disability means having a disability that remains hidden and invisible in many situations. And coping with the emotions of that frustration is difficult, especially when the disability becomes apparent in social situations where academic knowledge and skills are required. Then, the family member is

faced with the possibility of being discovered—the cloak of competence (Edgerton, 1993) begins to unravel. This requires the family to engage in what Erving Goffman (1963) called “impression management,” where everyone tries to appear normal. Of course, this may work for some time before school starts and it may even work outside of school to some degree, but when the child is separated from the protective family by the school doors, the disability becomes pronounced. That’s when abilities get redefined and disability enters the experience. Many students that struggle with schooling learn to improvise in academic tasks and thus, they “learn to do school” (Dyson, 1984) quite well. However, trouble rumbles louder as expectations are raised and academic stakes are higher.

“Unfortunately, according to Michael Resnick (1984), studies have shown that persons with disabilities are viewed negatively by the general public. Such views even persist with some professionals including teachers, counselors, social workers and physicians. This assertion has been more recently supported by Laura Marshak, Milton Seligman, & Fran Prezant (1999). Unfortunately, these negative views still persist and since they exist, stigmatization becomes a huge and heavy burden for families. And one that warrants the attention of researchers and teachers.”

Other research (i.e., Dudley-Marling, 2000; Taylor, 1991; Taylor & Dorsey-Gaines, 1988 1991; Edgerton, 1993; Featherstone, 1980) would concur with these suggestions about stigmatization and protection. Still other writers have expressed similar experiences: Jeanne McDermott (2000) wrote about her families’ struggle with her son’s craniofacial condition, while Beth Kephart (1998) described frustrations of raising a child with pervasive developmental disorder. And now, my intimate research and my own

autobiography supports that the most stressful aspects of living with and raising a child with a disability are related to societal's reactions to that child and our internal reaction to the experience.”

Jennifer stops me again and challenges, “Okay, Shane, stop the philosophical discussion for a moment and bring this to a practical, application level for me.”

“Sure, I can do that. There are many examples within the walls of school, but let's just take testing and standardization for a moment. Certainly, testing has become an important variable in the schooling of children. It has entered that Macrosystem I described earlier. It has become rooted in what is deemed normal for the schooling era of today. It is, I fear, becoming an unscrutinized part of the discourse of schools. But I ramble, let me focus.

“Parents like the parents portrayed in this research view their children as intelligent, bright human beings with unlimited potential. They see a whole child. They consider each new accomplishment as a developmental step toward growing up. Just like Trent, I mean he has just been clapping this week and you and I are ecstatic. We supported this new skill by initiating “Pat-A-Cake” with him. We mark his every developmental milestone. We celebrate in his newly acquired ability to manipulate us.”

Jennifer laughs and goes to the kitchen to brew some coffee.

I follow and continue to talk, “Outside of school, most parents would consider their child a genius. And rightly so. After all, kids test the world, make predictions about the world, and act on the world based on what they've learned naturally. They even master language without any formal instruction. It's amazing! Each new milestone is celebrated. Parents are delightfully enraptured at first steps and first words. Each day brings a new hope. I think this notion of hope is absolutely essential to the multiple and intertwined

narratives in this dissertation. It is in someway how these families have learned to cope and to become resilient despite the systems. But I'll talk about that in a minute."

Jennifer responds, "I see what you mean. It's like children and parents represent a pseudoschool relationship long before their children ever begin formal instruction. Right?"

"Yeah, exactly. And as educators, we've got to learn to respect that and be willing to learn from families. I used to love the week before school started. Don't you remember shopping for new crayons and pencil boxes? Some families experience first days of school that are filled with happy memories and the days that follow that first day are filled with challenges and triumphs.

"Unfortunately, that ether of joy and delight will undoubtedly evaporate for some families. They will be surprised to find that their brilliant child is no longer brilliant. That's how I think the families portrayed in my dissertation felt as schooling slowly chipped away at their children. According to Sara Lawrence Lightfoot's research with families (1978), parents seem to appreciate the individualness of each child, while schools are far more likely to compare each child to each other child along a continuum of abilities and skills. These comparisons lead well-meaning teachers to misperceive the abilities of certain children. It leads educators to label children. Children like Travis become defined by what they cannot do rather than by what they are able to do. And children like Jacob and adults like Christopher may endure long-lived, devastating effects from such misperceptions. Noted educator Curt Dudley-Marling (2000), in fact, recently titled his own work with such families, *When Troubles Come Home*. So for some

families, they send their children to school and their children return with troubles—troubles that become burdens for the entire family.”

“But Shane,” Jennifer wonders, “don’t you have to have tests in schools? Are you saying that the tests are responsible for the failure?”

“Well I believe, along with notable scholars such as Curt Dudley-Marling that failure in school is a socially constructed phenomenon that should be researched and I hope I have contributed to the stories about schooling troubles that are available to the educational community through this research. You know, Jennifer, norm-referenced testing and other standardized testing instruments have regained their popularity and increasingly are being used to make educational decisions for individual children. Not only are they being used to compare educational achievements of states to other states, districts to other districts, and schools to other schools, they are also being misused to compare student to student. They were never intended for such use. Unfortunately, the trouble often is perceived to be within the child rather than in the system of testing children.”

“Okay, here’s another challenge,” Jennifer adds, “Testing is not all bad. Lots of kids do fine. Are you saying it’s different for those children that struggle?”

“Exactly!” I respond, “Children who find themselves struggling with schooling are at a greater risk for being reduced to a set of characteristics by the results of testing. The assessment procedures used with these students are inherently reductionist. These students that struggle and the learning that they struggle with is often reduced to standardized data. The child gets lost in the interpretation of the data. The results of such

testing are used because they are believed to be objective representations of a student's abilities. It would be easy for me to call such testing--evil,"

"And you have before," Jennifer grins.

"But such results alone are not evil. In fact, they can be helpful. However, when they possess power over teacher and parent observation, troubles and problems simultaneously collide. When a student seems to be failing and scores reinforce such a notion, a deficit model of education may be adopted. This deficit model is driven by a medical metaphor in which the students' difficulties are then reduced to symptoms to be diagnosed and in turn a prescription is given. Ultimately, such a model results in identifying failure within the student (Poplin, 1988). Given this knowledge, educators may then begin trying to fix the child (Sapon-Shevin, 1989). Schools can tend to be places where competition reigns at the cost of cooperation. These objective institutions seem to parade a banner, "Only the fittest will survive." And I believe that it is unfortunate that some have accepted this mantra. Some seem to say, "Well, that's just the way it is." Hogwash! It can and should be different."

Jennifer shifts in her seat and encourages, "Ok, then, I get it. The way in which tests are interpreted and used for decision making causes you great concern and worry for students who struggle to learn."

"Yes, yes, it does."

Jennifer adds, "I know lots of kids go to summer school. And other kids get special resource help. And still others get remedial assistance, right? What about those options?"

"Well, no doubt, extra attention may help some kids and schools must respond in some fashion. However, Allington and Walmsley (1995), two respected literacy scholars,

argued that while it is possible through programs like Reading Recovery to reduce the number of learners who struggle to learn to read and thus reduce the number of students who struggle to learn, it remains that “no quick fix” exists for the plethora of schooling troubles. Summer school cannot fix it alone nor can extensive remedial programs that are driven by tests that narrowly measure what reading really is. Special education is not the answer either. In fact, such programs can actually hurt the students they claim to help. Ultimately, there is no one answer. And I concur with Dick Allington and Sean Walmsley’s (1995) contention that “we need to take a perspective on literacy difficulties that starts well before school and is sensitive to what happens beyond school”(p. 255). Particularly important to me and this project is fostering a sensitivity to what life is like outside of school, providing opportunities for understanding, and offering efforts to support families. It is time that we begin to not only create programs. Instead, it is time to deconstruct the language of childhood disability as Dory Lightfoot and Ruth Gustafson (2000) suggested, “to shake up readers’ understandings of risk and disability in our society” (p. 71). And it is the interactions around such testing interpretations and program interventions that contribute to this discourse.

“In addition, the relationships between the student and the teacher and the family and the specialist are crucially important to the educational planning for such students. This notion of relationships is perhaps one of the key themes of the research. The construction of family-child-teacher relationships rests on the interactions between home and school. If these relationships break down, then again the problems become exacerbated”

“Alright,” Jennifer responds, “But I mean can you really expect teachers to become as intimately involved with families as you became in this dissertation?”

“Well, no, and you raise an important issue. This dissertation was never about suggesting that teachers respond in a particular way. Instead, I hope that the narrative provides a vicarious experience to help teachers understand how intense and raw living this way can be.”

“Ok,” Jennifer adds, ““There’s no quick fix. What are the implications and applications for your research then? Where’s the hope? How should schools respond? Can teachers become insiders? Can school become an insider? Is that possible?”

“I think that is a big question. And the answer I believe is ‘It Depends.’ I do think there are wonderful models of teachers and researchers who have cocreated beautiful ways of fostering more intimate relationships with families. Take JoBeth Allen’s work with Betty Shockley-Bisplinghoff and Barbara Michalove (1993, 1995) or Denny Taylor’s (1991, 1993) and Denny Taylor and Catherine Dorsey-Gaines’ (1988), legacy of work with families. These researchers have provided possibilities for teachers. I don’t believe that a formulaic program will work in any school and no one model will work for every school with every family. You can’t expect that. What I do challenge is that teachers try something to get to know the families of their students outside of the realm of schooling.”

“Is this like that Funds of Knowledge stuff you talk about?” Jennifer asks.

“Yes, yes, exactly. Luis Moll’s (1992) work supports the notion that getting to know the social spheres of families beyond the limitations of school walls can serve to facilitate better instructional planning and thus teachers can offer better opportunities for learning among all students.”

“Well, it seems you’ve really done some thinking Shane. But what does this have to do with Language Education? That’s important to directly address isn’t it?”

“Absolutely! On a basic level, we come to understand who we are and who we can become through language. We mediate ideas, define ourselves, and establish relationships through language. Our worldview and the social construction of reality rest upon the words that are available for our use (Vygotsky, 1978, 1986). We use words as tools for telling our lives. The narratives told in this research and the narratives that are told on these narratives serve to make available the public and private dimensions of thought through the intersection of social relationships formed via language. The perception and consciousnesses of these families become objectified through language. This narrative dissertation asks that readers engage in a transaction with a text to cocreate a meaningful poem. That is the very heart of reader response theory (Rosenblatt, 1938/1995).

“So do you mean that to some degree the point of the narrative work is for readers to consider their own response to the narrative?”

“Yes, and perhaps that is unusual to place part of the responsibility for the result of this work within the reader. However, I believe it is empowering. It asks readers to enter the research dialogue. I hope I have created spaces for that within the narrative.”

Jennifer stands and approaches me, sitting on the edge of the ottoman.

“Ok, then, what else really matters here? What can teacher educators learn? What can principals learn? What can parents and teachers learn from experiencing this experience?”

“Well, I hope that it requires them to stop and reconsider how we understand students who struggle to learn and the families that love those children. One of my challenges for teacher educators, administrators, and teachers rests in the possibility for the expansion of what we call diversity. Multicultural efforts exist and teachers are urged to be inclusive of all cultures.”

“Right, I remember how moved you were by the coursework that you took during your doctoral studies. Your thinking about race and gender and even mental illness was stretched and challenged. I know you talked a lot about social justice and the inequities that persist in classrooms.”

“Jennifer, I changed during my studies. I critically considered my own biases and my own ignorance. I was ashamed at times. I value those experiences and they are important experiences. Teacher-educators are doing a better job of helping teachers examine diversity issues through the incorporation of works by noted scholars like Lisa Delpit (1995), Guadalupe Valdes (1996), and Gloria Ladson-Billings (1994). But there is a group that seems to continue to be missing from course syllabi.”

Jennifer raises her eyebrows and I continue, “Persons with Learning Differences. I wonder, Jennifer, what might happen if we expanded the umbrella of diversity to include learning diversity? How might we learn to teach students differently?”

“But aren’t preservice teachers required by law to take a special education class?”

“Yes, they are, but unfortunately, such coursework tends to be a survey and students are more or less are given a list of characteristics for each disability recognized in schools. I believe we have to do more than that. We have to thoughtfully and purposely plan to devote parts of every course to the consideration of learners who deviate from the

norm. Perhaps such an effort will help teachers examine how they approach learning differences in students and how to plan for that diversity. I've become sorely disappointed by the availability of material that addresses this need more directly. The major educational publishing groups provide only a minimum of related support. We need more stories, stories like the one I've told. Such stories may provide "zones of possibilities" for helping teachers become more empathetic teachers. Perhaps exploration of these these stories will encourage teachers to move beyond tolerance to advocacy. If we are to meet the challenge of educating children who struggle to learn, we have to learn more about these students—more than just a label."

"So you want teachers and administrators to understand that these students that struggle are differently-abled rather than simply disabled?"

"You took the words right out of my mouth. Perhaps we can understand the struggle as variability. That's it. And I want that for all teachers, not just special educators. We need a new language for talking about learning differences. When we begin to subvert the language of disability and challenge the assumptions about such students, we will begin to realize that perhaps a new disability emerges, that is an instructional disability. The problems with learning need not be found within the student; instead, I contend that they may be found in the instruction."

"Wow, this issue is complex. So what about parents? I remember you saying that you wanted your dissertation to reach a wider audience. How do families fit into our conversation about implications?"

I begin to talk and feel a knot form at the top of my throat. Jennifer listens intently as I try to convey my desire.

“I want probably more than anything for families to know that they are not alone. I want them to read the narrative work and realize that other families experience similar quandaries. I want families to forgive themselves. I want them to find strength to face the day to day challenges of this uncertain experience.”

Jennifer hands me a tissue, scoots in next to me, and reaches her arms around my shoulders. For several moments we remain quiet and then I finish, “That’s it Jennifer. That’s all I want.”

We sit in silence for several moments and then Jennifer gently prods, “Shane, have you thought of a tangible way that you could communicate your concerns and your research to teachers and families?”

“Actually, JoBeth suggested that I consider writing a letter to such families and another letter to educational professionals.”

“Sound just like what you need to do!” she responds. I’ll give you a refill.

As she heads downstairs, I gaze at the computer screen and begin to type, “Dear . . . “

CHAPTER SEVEN:

TAKING ACTION: TWO LETTERS

I've reviewed Rosalie Maggio's (2001) ever-popular How to Say It series of writing help books, the books that claim on the cover to provide you with "choice words, phrases, sentences and paragraphs for every situation." I cannot find a section that will help me write the letters that need to be written—letters to families with children with disabilities and the educational professionals that work with those same children. Instead, I follow my heart and decide just to begin.

These letters are appropriate in that they can perhaps serve the community and society at large in a way different from the full dissertation.

A Letter to Families

Dear Families,

It is likely that you are reading this letter because your son or daughter or brother or sister or someone you care immensely about is struggling in school. Perhaps a teacher gave it to you or a friend who knows that you spend many nights awake worrying about what may happen with/to your child at school the next day. When it comes to living with a person with a disability, I am an insider. I have the scoop. Ask me, I know. I have a younger brother who has struggled to learn and continues that struggle today as an adult. My dissertation research focused on my experiences as a sibling and as a special education and general education teacher. I spent extensive time with my family and another family who also had a child for whom learning was difficult and for whom

school was an uncomfortable place. As I began to siphon through my memories and to challenge the language of disability, I offered a different set of stories than those heard in a school's lounge. It was through the crafting of those narratives that I understood myself and my younger brother differently. Ultimately, I stared stigmatization in the face and proposed that we revisit our own stories and that we question what lies just beneath the surface of schooling for persons for whom learning is a struggle. While I cannot tell you that my experience will be just like yours, I want to share some of my insights and some of my hopes for you. And I suspect somewhere within these words you may see yourself.

First, you are not alone. As a member of a family with a child who learns differently, I know that above all else, you genuinely care about your child. You worry about your child and you protect your child at every juncture. Find a support system and talk to someone; tell your story. Begin a journal; document your experience. It was very affirming for the families in my study to know that other families faced the same maddening uncertainty. They felt less alone and vicariously strengthened their morale. Read everything you can find. You might start first with books like *From the Heart: On Being the Mother of a Child with Special Needs*, a collection of essays edited by Jayne Marsh or *Living with a Brother or Sister with Special Needs* by Donald Meyer and Patricia Vadasy or *Uncommon Fathers: Reflections on Raising a Child with a Disability* edited by Donald Meyer.

Home and school serve as intimate yet disparate primary settings and the potential for growth or alienation resides in the activity between the two. However, these families did not allow the academic troubles to overshadow the person beneath the disability; instead, they celebrated other individual traits and interests. I

encourage you to take action. Become an integral part of your child's education. While you might hear the voices in your head saying, "you don't know what you're talking about," remind those voices that you are your child's first teacher. You possess intimate knowledge about your child and the ways in which he/she learns. You know him/her better than any other person. Consider his/her earliest achievements. What were the circumstances that supported that learning? Insist on learning opportunities that honor those circumstances. Not only is it important for Jacob and Travis and Christopher to realize that schooling is but one dimension of who they are, but it is important for parents and teachers as well.

Make your home a sanctuary with a safety net for your child. Know that tomorrow will hold a new set of challenges, ones different perhaps from the day before. Reserve your energies. Determine what is important and how you can best help your child. The families in my study struggled over what was best for their respective children; they made decisions. One family withdrew their child from public school and the other remained in public school. Neither would tell you that they are convinced it was the best decision, but it was right for them at the time.

Resist the temptation to give in. Never give up hope. Teachers face the same maddening experience of not knowing what to do. I was flung back into making new, difficult decisions every day that I faced my students, especially the ones who seemed to struggle the most. Labels become political markers and I contend that people's fear of saying the wrong thing or tripping over the appropriate labels may actually stop communication. People get hung up on the words or the labels when all we really want is understanding.

After love and security, all one really can do is cheer them on.

Sincerely,

Shane Rayburn

3886 Alexandria Drive

Gainesville, Georgia 30506

Jshane1039@aol.com

A Letter to Educational Professionals

Dear Educational Professional,

It is likely that you are reading this letter because a parent gave it to you, a parent that wants you to act on behalf of their child or perhaps another professional is sharing it with you because it helped them redefine what they knew and what they accepted as fact about children with disabilities. When it comes to living with a person with a disability, I am an insider. I have the scoop. Ask me, I know. I have a younger brother who has struggled to learn and continues that struggle today as an adult. My dissertation research focused on my experiences as a sibling and as a special education and general education teacher. I spent extensive time with my family and another family who also had a child for whom learning was difficult and for whom school was an uncomfortable place. As I began to sift through my memories and to challenge the language of disability, I offered a different set of stories than those heard in a school's lounge. It was through the crafting of those narratives that I understood myself and my younger brother differently. Ultimately, I stared stigmatization in the face and proposed that we as educational professionals revisit our own stories and that we question what lies just beneath the surface of schooling for persons for whom learning is a struggle.

First, we can begin by inviting families into conversation with us about their children. We can listen differently and give parents time to respond. We can build bridges between home and school and create partnerships for effective change. Rather than communication being one direction, we can insist on a two-way, open system of communication where all voices are respected.

Consider using a dialogue journal with families that have children who struggle. Write a personal letter to families, sharing more about you than just academic and professional knowledge. Ask family members to introduce the child through a personal letter that could include dreams and fears. Call a child's parent in the middle of your day just to tell them of the child's success. Ultimately, in all you do—honor family voices.

Through this research, I realized that no test and no professional could really understand the child beneath the label without the complete context of family. We, as educational professional, need families to fill in the gaps. We need them to challenge our view of their child, to offer an alternative to the static results of tests. We need both parents and siblings. The families in my study did not allow the academic troubles to overshadow the person beneath the disability; instead, they celebrated other individual traits and interests.

The contexts of home and school serve as intimate yet disparate primary settings and the potential for growth or alienation resides in the activity between the two. What is valued and what is held in high esteem in society came in conflict with the “funds of knowledge” that these boys brought to school. School provided little spaces for demonstrations of what these children could do. Let's change the direction of knowledge. Instead of always privileging school knowledge, let's begin to bridge what

kids already know with the new knowledge we want them to coconstruct. Let's become creative in our invitations to learning. There are many and varied ways of entry into learning.

Some of the teachers that families talk about covertly suggested that the child's problem with schooling could be fixed if "extra" work was done at home. And so, as you can imagine, these families spent inordinate amounts of time and energy and in some cases money to provide that "extra" time and "extra" effort, but to no avail their children still struggled the following year. It seemed that this extra time became lost time. Homework became a terrible extension of the school troubles that each child experienced at school. Homes should be a sanctuary, a place of security. Be creative when it comes to homework. How can it be helpful instead of hurtful? How can we redefine what it means to "catch-up"?

When it comes to homework and curricula and high-stakes testing and standards, no matter what legislators may insist or what federal reforms may enact and claim, one size fits few and more children are left behind when such a mandate is given. Not only children with disabilities are affected, but those children for whom English is a second or third language are also put at risk as well as children that come with different cultural backgrounds than the mainstream. This continual fluctuation of frustration will only cause alienation and turmoil for these families and the potential for development becomes threatened.

It is important for children, families, and educational professionals to realize that schooling is but one dimension of who these children are. They are so much more.

I am convinced now that my high academic achievement, as a student, was somehow linked to what my younger brother faced in school—the increasingly intense and equally demanding task of achieving at all. Some consider students like my brother “underachievers” or “slow learners” when in fact, we cannot fathom the measure of courage and confidence it must take to face the intellectual minefields that these students must maneuver. They often work twice as hard and twice as long as those who perform to the “norm” and yet the norm is what gets recognized and the above norm is what gets rewarded. Students who are different face the “measuring stick” day after day.

Education is a political matter and how you respond or your lack of response determines your position. As children are labeled for the sake of providing a more appropriate education, limits and boundaries are also prescribed. Labels become political markers, and I contend that people’s fear of saying the wrong thing or tripping over the appropriate labels may actually stop communication. People get hung up on the words when all families really want is empathy and understanding.

Begin the conversation and make your voice heard. Speak back to the tests. Offer another version of the story. Find a friend and pass this letter on.

Sincerely,

Shane Rayburn

3886 Alexandria Drive

Gainesville, Georgia 30506

Jshane1039@aol.com

REFERENCES

- Alexander, I. E. (1988). Personality, psychological assessment, and psychobiography. In D. McAdams & R. Ochberg (Eds.), *Psychobiography and life narratives* (pp. 265-294). Durham: Duke University Press.
- Alexander, T. M. (1987). *John Dewey's theory of art, experience, and nature: The horizons of feeling*. NY: State University of New York.
- Allen, J. (2002). With the best intentions: Agents, impetus, and consequences of placement decisions. *Reading and Writing Quarterly*, 18(1), 39-66
- Allen, J., Shockley, B., & Michalove, B. (1993). *Engaging children*. Portsmouth, NH: Heinemann.
- Allington, R. L., & Walmsley, S. A. (Eds.). (1995). *No quick fix: Rethinking literacy programs in America's elementary schools*. NY: Teachers College Press and the International Reading Association.
- Althusser (1971). *Lenin and philosophy and other essays* (B. Brewster, Trans.). New York: Monthly Review Press.
- Angrosino, M. V. (1998). *Opportunity house: Ethnographic stories of mental retardation*. Walnut Creek, CA: AltaMira.
- Ayers, W. (1998). I search, you search, we all search: Biography and the public voice. In C. Kridel (Ed.), *Writing educational biography: Explorations in Qualitative research* (pp. 235-244). NY: Garland.

- Bakhtin, M. (1981). *The dialogic imagination: Four essays by M. M. Bakhtin* (M. Holquist, Ed.; C. Emerson, & M. Holquist, Trans.). Austin: University of Texas Press.
- Bakhtin, M. (1986). *Speech genres and other late essays* (V. W. McGee, Trans.). Austin: University of Texas Press.
- Barthes, R. (1975). *The pleasure of the text* (R. Miller, Trans.). NY: Hill & Wang.
- Bateson, M. C. (1989). *Composing a life*. NY: Plume.
- Beckman, P. J., & Bristol, M. M. (1991). Issues in developing the IFSP: A framework for establishing family outcomes. *Topics in Early Childhood Special Education, 11*, 19-31.
- Behr, S. K., & Murphy, D. L. (1993). Research progress and promise: The role of perceptions in cognitive adaptation to disability. In A. P. Turnbull, J. M. Patterson, S. K. Behr, D. L. Murphy, J. G. Marquis, & M. J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 151-164). Baltimore: Brookes.
- Bell-Scott, P. (Ed.). (1994). *Life notes: Personal writings by contemporary black women*. NY: W. W. Norton & Company.
- Bell-Scott, P. (Ed.). (1998). *Flat-footed truths: Telling black women's lives*. NY: Henry Holt and Company.
- Berleant, A. (1991). *Art and engagement*. Philadelphia, PA: Temple University Press.
- Bloome, D. (1985). Reading as a social process. *Language Arts, 62*, 134-142.
- Bloome, D., & Egan-Robertson, A. (1993). The social construction of intertextuality in classroom reading and writing lessons. *Reading Research Quarterly, 28*, 304-333.

- Bochner, A. P., & Ellis, C. (1996). Talking over ethnography. In C. Ellis & A. P. Bochner (Ed.), (1996). *Composing ethnography: Alternative forms of qualitative writing* (pp. 13-45). Walnut Creek, CA: AltaMira.
- Bochner, A. P., & Ellis, C. (1992). Personal narrative as a social approach to interpersonal communication. *Communication Theory*, 2, 165-172.
- Bochner, A. P., & Ellis, C. (1999). Which way to turn? *Contemporary Ethnography*, 28, 500-509.
- Bochner, A. P., Ellis, C., & Tillmann-Healy, L. (1997). Relationships as stories. In S. Duck (Ed.), *Handbook of personal relationships: Theory, research, and interventions* (2nd ed., pp. 307-324). NY: John Wiley.
- Bochner, A. P., Ellis, C., & Tillmann-Healy, L. (1998). Mucking around looking for truth. In B. M. Montgomery, & L. A. Baxter (Eds.), *Dialectical approaches to studying personal relationships* (pp. 41-62). Mahwah, NJ: Lawrence Erlbaum.
- Brandes, S. (1982). Ethnographic autobiographies in American anthropology. In E. A. Hoebel, R. Currier, & S. Kaiser (Eds.), *Crisis in anthropology: View from Spring Hill, 1980* (pp. 187-202). NY: Garland.
- Britton, J. (1970/1993). *Language and learning*. Portsmouth, NH: Heinemann/Boynton.
- Brody, G. H., & Stoneman, Z. (1986). Contextual issues in the study of sibling socialization. In J. J. Gallagher & P. M. Vietze (Eds.), *Families of handicapped persons: Research, programs, and policy issues* (pp. 197-217). Baltimore: Brookes.

- Brody, G. H., Stoneman, Z., & MacKinnon, C. E. (1986). Contributions of maternal child-rearing practices and play contexts to sibling interactions. *Journal of Applied Developmental Psychology, 7*, 225-236.
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Bronfenbrenner, U. (1983). The context of development and the development of context. In R. M. Lerner (Ed.), *Developmental psychology: Historical and philosophical perspectives* (pp. 147-184). Hillsdale, NJ: Erlbaum.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspective. *Developmental Psychology, 32*, 513-531.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.
- Bruner, J. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Buechner, F. (1991). *Telling secrets: A memoir*. NY: Harper Collins.
- Calkins, L.M. (1991). *The art of teaching writing* (2nd ed.). Portsmouth, NH: Heinemann.
- Chapman, J. W. (1988). Learning disabled children's self-concepts. *Review of Educational Research, 58*, 347-371.
- Clandinin, D. J., & Connelly, F. M. (1994). Personal experience methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 403-412). Thousand oaks, CA: SAGE.
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Jossey-Bass.

- Cofer, J. O. (1990). *Silent dancing: A partial remembrance of a Puerto Rican childhood*. Houston, TX: Arte Publico Press.
- Coleman, M. (1997). Families and schools: In search of common ground. *Young Children*. July 1997, 14-21.
- Coles, R. (1989). *The call of stories: Teaching and the moral imagination*. Boston: Houghton Mifflin.
- Commeyras, M., & Guy, J. (1995). Parole officers and the king's guards: Challenges in understanding children's thinking about stories. *Language Arts*, 72, 512-516.
- Connelly, F. M., & Clandinin, D.J. (1988). *Teachers as curriculum planners: Narratives of experience*. NY: Teachers College Press.
- Curran, (1989). Reexamining traditional assumptions. In *Working with parents* (pp. 17-31). Circle Pines, MN: American Guidance Service.
- Davies, B. (1993). *Shards of glass: Children reading and writing beyond gendered identities*. Cresskill, NJ: Hampton Press
- Delgado-Gaitan, C. (1990). *Literacy for empowerment*. NY: Falmer Press.
- Denzin, N. K. (1989). *Interpretive biography*. Thousand Oaks, CA: SAGE.
- Derrida, J. (1978). *Writing and difference* (A. Bass, Trans.). Chicago: University of Chicago Press.
- Dewey, J. (1916). *Democracy and education*. New York: The Free Press.
- Dewey, J. (1934). *Art as experience*. NY: Perigree.
- Dewey, J. (1938/1963). *Experience and education*. NY: Collier.
- Dixon, C. N., Frank, C. R., & Green, J. L. (1999). Classrooms as cultures: Understanding the constructed nature of life in classrooms. *Primary Voices*, 7(3), 4-8.

- Dorris, M. (1994). *Paper trail*. NY: Harper.
- Dudley-Marling, C. (2000). *When school troubles come home*. Portsmouth, NH: Heinemann.
- Dyson, A. H. (1984). Learning to write/learning to do school: Emergent writers' interpretations of school literacy tasks. *Research in the Teaching of English*, 18, 233-264.
- Dyson, A. H. (1989). *Multiple worlds of child writers*. NY: Teachers College Press.
- Dyson, A. H. (1993). *Social worlds of children learning to write in an urban primary school*. NY: Teachers College Press.
- Dyson, A. H. (1997). *Writing superheroes: Contemporary childhood, popular culture, and classroom literacy*. NY: Teachers College Press.
- Edgerton, R. B. (1993). *The cloak of competence*. Berkley: University of California Press.
- Eisner, E. W. (1998). *The enlightened eye: Qualitative inquiry and the enhancement of educational practice*. Upper Saddle River, NJ: Merrill.
- Ellis, C. (1991a). Emotional sociology. In N. Denzin (Ed.), *Studies in symbolic interaction* (pp. 123-145). Greenwich, CT: JAI.
- Ellis, C. (1991b). Sociological introspection and emotional experience. *Symbolic Interaction*, 14, 23-50.
- Ellis, C. (1993). 'There are survivors': Telling a story of sudden death. *Sociological Quarterly*, 34, 711-730.
- Ellis, C. (1995a). Emotional and ethical quagmires in returning to the field. *Journal of Contemporary Ethnography*, 24, 68-98.

- Ellis, C. (1995b). *Final negotiations: A story of love, loss, and chronic illness*. Philadelphia, PA: Temple University Press.
- Ellis, C. (1995c). The other side of the fence: Seeing black and white in a small Southern town. *Qualitative Inquiry*, 1, 147-167.
- Ellis, C. (1996). Maternal connections. In C. Ellis, & A. P. Bochner (Eds.), *Composing ethnography: Alternative forms of qualitative writing* (pp. 240-243).
- Ellis, C. (1997). Evocative autoethnography: Writing emotional about our lives. In W. G. Tierney, & Y. S. Lincoln (Eds.), *Representation and the text: Re-framing the narrative text* (pp. 115-139). NY: State University of New York.
- Ellis, C., & Bochner, A. P. (1992). Telling and performing personal stories: The constraints of choice in abortion. In C. Ellis & M. G. Flaherty (Eds.), *Investigating subjectivity: Research on lived experience* (pp. 79-101). Newbury Park, CA: SAGE.
- Ellis, C., & Bochner, A. P. (Ed.). (1996). *Composing ethnography: Alternative forms of qualitative writing*. Walnut Creek, CA: AltaMira.
- Ellis, C., & Bochner, A. P. (2000). Autoethnography, personal narrative, reflexivity: Researcher as subject. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd) (pp. 733-768). Thousand Oaks, CA: SAGE.
- Ellis, C., & Flaherty, M. G. (1992). *Investigating subjectivity: Research on lived experience*. Newbury Park, CA: SAGE.
- Ellis, C., Kiesinger, C. E., & Tillmann-Healy, L. M. (1997). Interactive interviewing: Talking about emotional experience. In R. Hertz, (Ed.), *Reflexivity and voice* (pp. 119-149). Thousand Oaks, CA: SAGE.

- Emerson, R. M., Fretz, R. I., & Shaw, L. L. (1995). *Writing ethnographic fieldnotes*. Chicago: University of Chicago Press.
- Fewell, R. R. (1986). A handicapped child in the family. In R. R. Fewell, & P. F. Vadasy (Eds.), *Families of handicapped children: Needs and supports across the life span* (pp. 3-34). Austin, TX: Pro-Ed.
- Fishman, S., & McCarthy, L. (1998). *John Dewey and the challenge of classroom practice*. NY: Teachers College Press.
- Foucault, M. (1977). *Discipline and punish: The birth of the prison* (A. Sheridan, Trans.). NY: Vintage.
- Foucault, M. (1977). *Language, counter-memory, practice* (D. F. Bouchard, Trans.). NY: Cornell University Press.
- Foucault, M. (1978). *The history of sexuality, Volume 1: An introduction* (R. Hurley, Trans.). NY: Routledge.
- Frank, A. W. (1991). *At the will of the body: Reflections on illness*. Boston: Houghton Mifflin Co.
- Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.
- Gallagher, P. A., & Powell, T. H. (1989). Brothers and sisters: Meeting special needs. *Topics in Early Childhood Special Education*, 8(4), 24-37.
- Gallas, K. (1994). *The languages of learning: how children talk, write, dance, draw, and sing their understanding of the world*. NY: Teachers College Press.
- Gallas, K. (1998). *"Sometimes I Can Be Anything": Power, gender, and identity in a primary classroom*. NY: Teachers College Press.

- Gee, J. P. (1996). *Social linguistics and literacies: Ideology in discourses* (2nd ed.). London: Taylor & Francis.
- Geertz, C. (1983). *Local knowledge*. NY: Basic Books.
- Ginsberg, D. (2002). *Raising Blaze*. NY: HarperCollins.
- Giroux, H. (1985). Critical pedagogy, cultural politics, and the discourse of experience. *Journal of Education*, 167(2), 22-41.
- Glaser, B. G., & Straus, A. L. (1967). *The discovery of grounded theory*. NY: Aldine de Gruyter.
- Goffman, E. (1963). *Stigma*. Englewood Cliffs, NJ: Prentice Hall.
- Goodman, K. (1986). *What's whole in whole language?* Portsmouth, NH: Heinemann
- Gornick, V. (1996). "The memoir boom." *Women's Review of Books*, 13, 1-5.
- Green, J. L., & Bloome, D. (1997). Ethnography and ethnographers of and in education: A situated perspective. In J. Flood, S. B. Heath, & D. Lapp (Eds.), *Handbooks of research on teaching literacy through the communicative and visual arts* (pp. 181-202).
- Greene, M. (1978). *Imagination and aesthetic literacy*. In *Landscapes of learning* (pp. 168-184). NY: Teachers College Press.
- Greene, M. (1995). *Releasing the imagination*. San Francisco, CA: Jossey-Bass.
- Grossman, F. K. (1972). *Brothers and sisters of retarded children: An exploratory study*. Syracuse, NY: Syracuse University Press.
- Hankins, K. (1998a). Cacophony to symphony: Memoirs in teacher research. *Harvard Educational Review*, 68, 80-85.

- Hankins, K. (1998b). Cacophony to symphony: Memoirs in teacher research. In B. S. Shockley, & J. Allen (Eds.), *Engaging teachers: Creating teaching and researching relationships* (pp. 13-26). Portsmouth, NH: Heinemann.
- Hankins, K. (2000). *Writing through the storm: Teaching as hermeneutic*. Unpublished doctoral dissertation, University of Georgia.
- Hardy, B. (1977). Narrative as a primary act of mind. In M. Meek, A. Warlow, & G. Barton (Eds.), *The cool web* (pp. 12-23). London: Bodley Head.
- Hayano, D. M. (1979). Auto-ethnography: Paradigms, problems, and prospects. *Human Organization*, 38, 113-120.
- Heath, S. B. (1983). *Ways with words*. NY: Cambridge University Press.
- Heath, S. B. (1991). The sense of being literate: Historical and cross-cultural features. In R. Barr, M. L. Kamil, P. B. Mosenthal, & P. D. Person (Eds.), *Handbook of reading research: Volume II* (pp. 3-25). White Plains, NY: Longman.
- Hegi, U. (1994). *Stones from the river*. NY: Simon & Schuster.
- Heider, K. G. (1975). What do people do? Dani auto-ethnography. *Journal of anthropological research*, 31, 3-17.
- Igoa, C. (1995). *The inner world of the immigrant child*. Mahwah, NJ: Lawrence Erlbaum.
- Jamison, K. R. (1995). *An unquiet mind: A memoir of moods and madness*. NY: Vintage.
- Kalyanpur, M., & Harry, B. (1999). *Culture in special education: Building reciprocal family—professional relationships*. Baltimore: Brookes.
- Kephart, B. (1998). *A slant of sun: One child's courage*. NY: Quill.

Kiesinger, C. E. (1995). *Anorexic and bulimic lives: Making sense of food and eating*.

Unpublished doctoral dissertation, University of South Florida.

Kotlowitz, A. (1991). *There are no children here*. NY: Doubleday.

Kozol, J. (1991). *Savage inequalities: Children in America's schools*. NY: Crown.

Kozol, J. (1995). *Amazing grace: The lives of children and the conscience of a nation*.

NY: Harper Collins.

Krieger, S. (1991). *Social science and the self: Personal essays on an art form*. New

Brunswick, NJ: Rutgers University Press.

Kvale, S. (1996). *InterViews*. Thousand Oaks, CA: SAGE.

Ladson-Billings, G. (1994). *The dreamkeepers: Successful teachers of African American children*. San Francisco, CA: Jossey-Bass.

Lamb, W. (1998). *I know this much is true*. NY: Harper Collins.

Latham, A. (Ed.). (1999). *William Shakespeare's As You Like It*. NY: Arden

Lawrence-Lightfoot, S. (1994). *I've known rivers*. NY: Penguin.

Lawrence-Lightfoot, S. (1999). *Respect*. NY: Perseus.

Lawrence-Lightfoot, S., & Davis, J.H. (1997). *The art and science of portraiture*. San Francisco, CA: Jossey-Bass.

LeCompte, M. D., & Preissle, J. (1993). *Ethnography and qualitative design in educational research* (2nd ed.). NY: Academic Press.

Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). *Narrative research: Reading, analysis, and interpretation*. Thousand Oaks, CA: SAGE.

- Lightfoot, D., & Gustafson, R. (2000). Subverting the language of childhood disability: Literary criticism and transformative fiction. *Journal Curriculum Theorizing*, 16, 71-88.
- Lincoln, Y. S., & Guba, E. G. *Naturalistic inquiry*. Thousand Oaks, CA: SAGE.
- Lobato, D. J. (1990). *Brothers, sisters and special needs: Information and activities for helping young siblings of children with chronic illnesses and developmental disabilities*. Baltimore: Brookes.
- Lubeck, S., & Garrett, P. (1990). The social construction of the “at-risk” child. *Journal of Sociology of Education*, 11(3), 327-340.
- Mackieith, R. (1973). The feelings and behavior of parents of handicapped children. *Developmental Medicine and Child Neurology*, 15, 329-338.
- Maddux, C. D., & Cummings, R. E. (1983). Parental home tutoring: Aids and Cautions. *Exceptional Parent*, 13(4), 30-33.
- Marshak, L. E., Seligman, M., & Prezant, F. (1999). *Disability and the family life cycle*. NY: Basic Books.
- McAdams, D. P. (1993). *The stories we live by: Personal myths and the making of the self*. NY: Guilford Press.
- McBride, J. (1996). *The color of water: A black man’s tribute to his white mother*. NY: Riverhead.
- McCaleb, S. P. (1994). *Building communities of learners*. NY: St. Martin’s Press.
- McDermott, J. (2000). *Babyface*. Bethesda, MD: Woodbine House.

- McGinley, W., & Kamberelis, G. (1996). *Maniac Magee and Ragtime Tumpie: Children negotiating self and world through reading and writing. Research in the Teaching of English, 30*, 75-113.
- McHale, S. M., & Gamble, W. C. (1987). Sibling relationships and adjustment of children with disabled brothers and sisters. *Journal of Children in Contemporary Society, 19*, 131-158.
- McHale, S. M., & Harris, V. S. (1992). Children's experiences with disabled and nondisabled siblings: Links with personal adjustment and relationship evaluation. In F. Boer and J. Dunn (Eds.), *Children's relationships with their siblings: Developmental and clinical implications* (pp. 83-100). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: Jossey-Bass.
- Michrina, B. P., & Richards, C. (1996). *Person to person: Fieldwork, dialogue, and the hermeneutic method*. NY: State University of New York Press.
- Miller, P.J., & Mehler, R.A. (1994). The power of personal storytelling in families and kindergartens. In A.H. Dyson, & C. Genishi (Eds.), *The need for story: Cultural diversity in classroom and community* (pp. 38-56). Urbana, IL: National Council of Teachers of English.
- Minuchin, S. (1974). *Families and family therapy*. Cambridge, MA: Harvard.
- Moll, L. C., Amanti, C., Neff, D., & Gonzales, N. (1992). Funds of knowledge for teaching: Using a qualitative approach to connect homes and classrooms. *Theory Into Practice, 31*, 132-141.

- Moll, L., & Greenberg, J. B. (1990). Creating zones of possibilities: Combining social contexts for instruction. In L. C. Moll (Ed.), *Vygotsky and education: Instructional implications and applications of sociohistorical psychology* (pp. 319-348). NY: Cambridge University Press.
- Nodelman, P. (1996). *The pleasure of children's literature* (2nd ed.). White Plains, NY: Longman.
- Ochberg, R.L. (1994). Life stories and storied lives. In A. Lieblich, & R. Josselson (Eds.), *The narrative study of lives: Exploring identity and gender* (pp. 113-144). Thousand Oaks, CA: Sage Publishers.
- Ohanian, S. (1999). *One size fits few: The folly of educational standards*. Portsmouth, NH: Heinemann.
- Paley, V. G. (1979). *White teacher*. Cambridge, MA: Harvard University Press.
- Paley, V. G. (1990). *The boy who would be a helicopter*. Cambridge, MA: Harvard University Press.
- Paley, V. G. (1997). *The girl with the brown crayon*. Cambridge, MA: Harvard University Press.
- Palmer, P. J. (1983/1993). *To know as we are known: Education as a spiritual journey*. NY: Harper Collins.
- Paterson, K. (1977). *Bridge to Terabithia*. NY: Harper Collins.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, CA: SAGE.
- Pellegrini, A. (1996). *Observing children in their natural worlds*. Mahwah, NJ: Lawrence Erlbaum.

- Pianta, R. C., & Walsh, D. J. (1996). *High-Risk Children in Schools*. NY: Routledge.
- Pipher, M. (1996). *The shelter of each other: Rebuilding our families*. NY: Ballantine Books.
- Polkinghorne, D.E. (1989). *Narrative knowing and the human sciences*. NY: State University Press.
- Poplin, M.S. (1988). The reductionist fallacy in learning disabilities: Replicating the past by reducing the present. *Journal of learning disabilities* 21, 389-400.
- Quindlen, A. (1998). *How reading changed my life*. NY: Ballantine.
- Reed-Danahay, D. E. (Ed.). (1997). *Auto/Ethnography: Rewriting the self and the social*. NY: Berg.
- Renwick, R., Brown, I., & Raphael, D. (1998). *The family quality of life project*. Toronto: University of Toronto.
- Resnick, M. D. (1984). The social construction of disability. In R. W. Blum (Ed.), *Chronic illness and disabilities in childhood and adolescence* (pp. 29-46). Orlando, FL: Grune & Stratton.
- Rhodes, L. K., & Dudley-Marling, C. D. (1996). *Readers and writers with a difference* (2nd ed.). Portsmouth, NH: Heinemann.
- Richardson, L. (1994). Writing: A method of inquiry. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 516-529). Thousand Oaks: SAGE.
- Richardson, L. (1997). *Fields of play: Constructing an academic life*. New Brunswick, NJ: Rutgers University Press.
- Richardson, L. (2000). Writing: A method of inquiry. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* 2nd ed. (pp. 923-948).

- Ricouer, P. (1981). *Hermeneutics and the human sciences* (J. B. Thompson, Trans.). NY: Cambridge University Press.
- Ricoeur, P. (1984). *Time and Narrative* (V. 1) (K. McLaughlin, & D. Pellauer, Trans.). Chicago: The University of Chicago Press.
- Riessman, C. K. (1993). *Narrative analysis*. Newbury Park, CA: SAGE.
- Roller, C. M. (1996). *Variability not disability: Struggling readers in a workshop classroom*. Newark, DE: International Reading Association.
- Ronai, C. R. (1992). The reflexive self through narrative: A night in the life of an erotic dancer/researcher. In C. Ellis & M. G. Flaherty (Eds.), *Investigating subjectivity: Research on lived experience* (pp. 102-124). Newbury Park, CA: SAGE.
- Ronai, C. R. (1995). Multiple reflections of child sex abuse: An argument for a layered account. *Journal of Contemporary Ethnography*, 23, 395-426.
- Ronai, C. R. (1996). My mother is mentally retarded. In C. Ellis, & A. P. Bochner (Eds.), *Composing ethnography: Alternative forms of qualitative writing* (pp. 109-131). Walnut Creek, CA: AltaMira Press.
- Rose, M. (1995). *Possible lives*. NY: Penguin.
- Rosen, H. (1986). The importance of story. *Language Arts*, 63, 226-237.
- Rosenblatt, L. (1938/1995). *Literature as exploration* (5th ed.). NY: Modern language Association.
- Rosenwald, G. C., & Ochberg, R. L. (Eds.). (1992). *Storied lives: The cultural politics of self understanding*. New Haven, CT: Yale.

- Sapon-Shevin, M. (1989). Mild disabilities: In and out of special education. In Biklen, D., Ferguson, D.L., & Ford, A. (Eds.), *Schooling and disability: Eighty-eighth yearbook of the national society for the study of education*. The University of Chicago Press.
- Schlink, B. (1997). *The reader*. NY: Vintage.
- Shannon, P. (1995). *Text, lies, and videotapes*. Portsmouth, NH: Heinemann.
- Shockley, B., Michalove, B., & Allen, J. (1995). *Engaging families: Connecting home and school literacy communities*. Portsmouth, NH: Heinemann.
- Simon, R. (2002). *Riding the bus with my sister: A true life journey*. Boston: Houghton Mifflin.
- Skrtic, T. M. (1991). *Behind special education: A critical analysis of professional culture and school organization*. Denver, CO: Love.
- Smagorinsky, P. (1999). The world is a stage: Dramatic enactment as response to literature. In B. J. Wagner (Ed.), *Building moral communities through drama* (pp. 17-36).
- Stake, R. E. (1994). Case studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research*. Thousand Oaks, CA: SAGE.
- Stoller, E. P. (1994). Teaching about gender: The experiences of family care. *Educational Gerontology*, 20, 679-697.
- Stoneman, Z., & Brody, G. (1984). Research with families of severely handicapped children: Theoretical and methodological considerations. In J. Blacher (Ed.), *Severely handicapped young children and their families* (pp. 179-214). Orlando, FL: Academic Press.

- Stoneman, Z., Brody, G. H., Davis, C. H., & Crapps, J. M. (1987). Mentally retarded children and their older same-sex siblings: Naturalistic in-home observations. *American Journal of Mental Retardation*, 92, 290-298.
- Stoneman, Z., Brody, G. H., Davis, C. H., & Crapps, J. M. (1988). Childcare responsibilities, peer relations, and sibling conflict: Older siblings of mentally retarded children. *American Journal of Mental Retardation*, 93, 174-183.
- Stoneman, Z., Brody, G. H., Davis, C. H., Crapps, J. M. (1989). Role relations between children who are mentally retarded and their older siblings: Observations in three in-home contexts. *Research in Developmental Disabilities*, 10, 61-76.
- St. Pierre, E. (1997). Methodology in the fold and the irruption of transgressive data. *Qualitative Studies in Education*, 10, 175-189.
- Strathern, M. (1987). The limits of auto-anthropology. In A. Jackson (Ed.), *Anthropology at home* (pp. 59-67). London: Tavistock.
- Summers, J. A., Behr, S. K., & Turnbull, A. P. (1988). Positive adaptation and coping strengths of families who have children with disabilities. In G. H. S. Singer & L. K. Irvin (Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (pp. 27-40). Baltimore: Brookes.
- Swadener, B. B., & Lubeck, S. (Eds.). (1995). *Children and families "at promise": Deconstructing the discourse of risk*. NY: State University of New York.
- Taberski, S. (2000). *On solid ground*. Portsmouth, NH: Heinemann.
- Taylor, D. (1983). *Family literacy: Young children learning to read and write*. Portsmouth, NH: Heinemann.
- Taylor, D. (1991). *Learning denied*. Portsmouth, NH: Heinemann

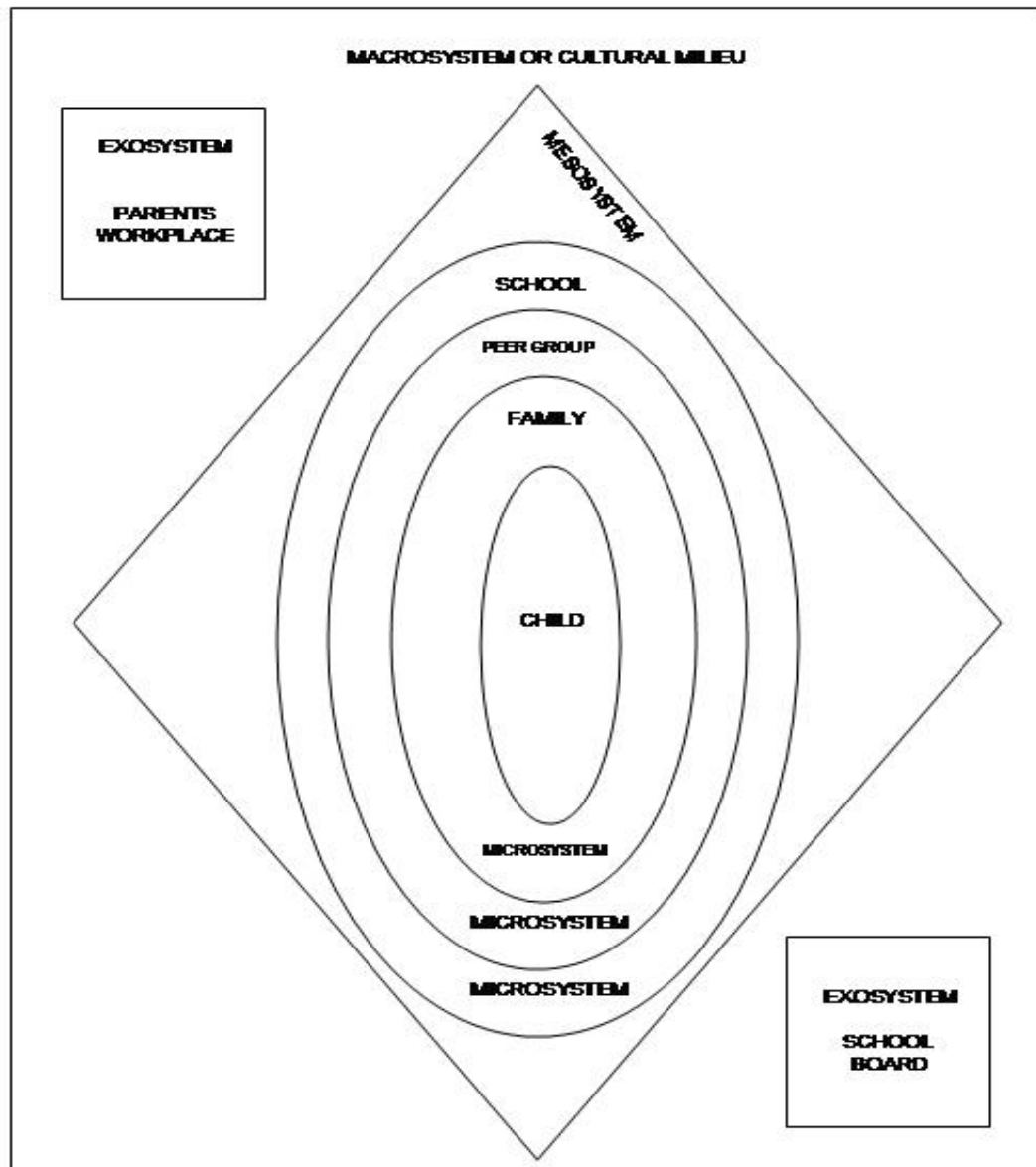
- Taylor, D. (1993). *From the child's point of view*. Portsmouth, NH: Heinemann.
- Taylor, D. (1996). *Toxic literacies: Exposing the injustice of bureaucratic texts*.
Portsmouth, NH: Heinemann.
- Taylor, D., & Dorsey-Gaines, C. (1988). *Growing up literate: Learning from inner-city families*. Portsmouth, NH: Heinemann.
- Tierney, W. G., & Lincoln, Y. S. (Ed.). (1997). *Representation and the text: Re-Framing the narrative voice* (pp. 37-56). NY: State University of New York Press.
- Tillmann-Healy, L. (1996). A secret life in a culture of thinness: Reflections on body, food, and bulimia. In C. Ellis, & A. P. Bochner (Eds.), *Composing ethnography: Alternative forms of qualitative writing* (pp. 76-108). Walnut Creek, CA: AltaMira.
- Tillmann-Healy, L. (1998). *Life projects: A narrative ethnography of gay-straight friendship*. Unpublished doctoral dissertation, University of South Florida.
- Traustadottir, R. (1991). Mothers who care: Gender, disability, and family life. *Journal of Family Issues*, 12, 211-228.
- Traustadottir, R. (1995). A mother's work is never done: Constructing a "normal" life. In S. J. Taylor, R. Bogdan, & Z. M. Lutfiyya (Eds.), *The variety of community experience: Qualitative studies of family and community life* (pp. 47-65).
Baltimore: Brookes.
- Turnbull, A. P., & Turnbull, H. R. (1986). Stepping back from early intervention: An ethical perspective. *Journal of the Division of Early Childhood*, 10, 106-117.
- Turnbull, A. P., & Turnbull, H. R. (2001). *Families, professionals, and exceptionality: Collaborating for empowerment* (4th ed.). Upper Saddle River, NJ: Merrill.

- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. NY: State University of New York Press.
- Van Maanen, J. (1988). *Tales of the field: On writing ethnography*. Chicago: University.
- Voloshinov, V.N. (1973). *Marxism and the philosophy of language* (L. Matejka, & I.R. Titunik: New York: Seminar Press.
- Vygotsky, L. (1934/1986). *Thought and language* (A. Kozulin, Trans.). Cambridge, MA: The MIT Press.
- Vygotsky, L. (1978). *Mind in society*. Cambridge, MA: Harvard University Press.
- Wells, G. (1986). *The meaning makers: Children learning language and using language to learn*. Portsmouth, NH: Heinemann.
- Welty, E. (1983). *One writer's beginnings*. Cambridge, MA: Harvard University Press.
- Wertsch, J. V. (1985). *Vygotsky and the social formation of the mind*. Cambridge, MA: Harvard University Press.
- White, E. B. (1952). *Charlotte's web*. NY: Harper Collins.
- Wickham-Searl, P. (1992). Mothers with a mission. In P. M. Ferguson, D. L. Ferguson, & S. J. Taylor (Eds.), *Interpreting disability: A qualitative reader* (pp. 251-274). NY: Teachers College Press.
- Widdershoven, G. A. M. (1993). The story of life: Hermeneutic perspectives on the relationship between narrative and life history. In R. Josselson, & A. Lieblich (Eds.), *The narrative study of lives Vol. 1* (pp. 1-20). Newbury Park, CA: Sage Publishers.
- Wikler, L. (1983). Chronic stress of families of mentally retarded children. *Family Relations*, 30, 282-288.

- Wikler, L. Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Attitude of parents and professionals about adjustment to mental retardation. *American Journal of Orthopsychiatry*, 51, 63-70.
- Wilson, J., Blacher, J., & Baker, B. L. (1989). Siblings of children with severe handicaps. *Mental Retardation*, 27, 167-173.
- Witherell, C., & Noddings, N. (1991). *Stories lives tell: Narrative and dialogue in education*. NY: Teachers College Press.
- Zigler, E., & Muenchow, S. (1992). *Head Start: The inside story of America's most successful educational experiment*. NY: Basic Books.
- Zinsser, W. (1998). *Inventing the truth: The art and craft of memoir*. NY: Mariner Books
- Zuckoff, M. (2002). *Choosing Naia: A family's journey*. Boston: Beacon.

APPENDIX A

Bronfenbrenner's Ecological Theory of Development



APPENDIX B

Interactive Interviewing: Possible Topics/Prompts

For the child who struggles to learn, tell me about . . .

1. what you would like to learn.
2. what is difficult/easy for you.
3. how you learn best.
4. your favorite school activity.
5. what you do when you get frustrated trying to learn something new.
6. who you would go to for help when you learn something new and why.
7. what you wish your teacher knew about you.
8. when you first started to read/write.
9. a good student you know.
10. what school is like.
11. what you do really well.
12. what you know a lot about.
13. your friends.
14. your hobbies.
15. your fears and worries.
16. your parents, brothers, sisters.
17. your teachers.
18. times in school when you are happy/sad.
19. times in school when you feel confident/frustrated.
20. how you might feel if you got a book as a gift.
21. what books/music you like.
22. what you like to watch on television.
23. what clubs you are a member of.

For parents, tell me about . . .

1. your child's birth.
2. your child's schooling experiences.
3. the first experiences of realizing that your child learned differently.
4. about your school experience and how that compares to your child's experiences.
5. what you desire most for your child.
6. what you wish every teacher knew before they started teaching your child.
7. your child's peers and friends.
8. how schools treat your child who learns differently.
9. what you do to help your child.
10. how your child learns best.
11. how your child learned to read.
12. what is difficult/easy for your child.
13. how your child relates to adults and peers.
14. how your child relates to siblings.
15. your child as a baby/toddler.
16. when your child is anxious/fearful.
17. what your child worries about most.
18. what you love most about your child.

For siblings, the above prompts will be adapted accordingly. I will consult such prompts for discussion included in Allen, Michaelove, & Shockley's *Engaging Children* and Taberski's (2000) *On Solid Ground*.

APPENDIX C

Data Sources: Jacob and His Family

Data Source	Temporal/Quantity Information
Transcripts from Interviews	June, July, August 2000; Total=258 pages
Teacher Correspondence—Conference Notes	1996-2000; Grades K, 1, 2, 3
Audiocassettes of Informal Talks: these represented occasional 10-15 minutes of recording, i.e., while we walked to the park.	May-September 2000; Approximately 18 hours
Psychological Testing Results, Eligibility Reports, Language Assessments, Individual Education Plans	July 1998; March 1999; June 1999; May 1999; May 2000 Total=53 pages
Report Cards	1996-1999; Grades K, 1, 2, 3, and Summer School
Photo Albums	Limited to field experience when participants would use pictures to talk about experiences, both formally and as part of informal talks, primarily childhood photos.

APPENDIX D

Data Sources: Christopher and His Family

Data Source	Temporal Information
Transcripts from Interviews	June, July, August 2000; Total=152 pages
Teacher Correspondence—Conference Notes	1982-1997; Grades K-12
Psychological Testing Results, Eligibility Reports, Language Assessments, Individual Education Plans	May 1983; May 1984; September 1984; December 1984; January 1985; December 1985; September 1986; May 1986; September 1987; October 1987; December 1987; May 1987; May 1988; May 1989; May 1990; May 1991; April 1992; May 1993; August 1993; September 1993; May 1993; April 1994; June 1994; January 1995; June 1996; August 1996; May 1997; September 1997 Total=276 pages
Report Cards	1982-1997; Grades K-12
Photo Albums	Limited to field experience when participants would use pictures to talk about experiences, both formally and as part of informal talks, primarily childhood photos.
Christopher's School Scrapbook: A collection of both photos and artifacts, compiled by Christopher's mother as a gift for graduation documenting not only school events but hobbies, sports events, and other interests.	1982-1997; Items spanning years in school

APPENDIX E

Overlapping Data Sources

Data Source	Temporal Information
Email from both families	Chronologically arranged from March 2000-September 2002; 211 pages representing over 150 contacts
Researcher Box: Artifacts from the Field	Contents representative of 2000-2003
Personal Journal	I have been journaling since early in my graduate school career. Within the journals, there are periods of increased activity and journaling and a range of influences are evident (1994-2003).
Researcher Journal	March 2000-March 2003
Researcher Calendar	March 2000-September 2000
Teacher Journal	I kept a teaching journal spanning my three years of teaching in public schools. (1993-1996). A form of teacher journaling became part of my graduate teaching assistantship but took more of a digital form, as I reflected on class meetings and planned for subsequent classes (1997-1999).
Quote Journal	Karen Hankins influenced me to keep a quote journal during a conversation in January 1997 while I was enrolled in a narrative course. (1997-2003)
Personal Photographs	Piles of photographs reaching back to my childhood. (1970-2003)
Class Photos	Specifically class photos (both candid and formal) my three years of teaching (1993-1996)
My School Scrapbook: A collection of both photos and artifacts, compiled by my mother as a gift for graduation documenting my school journey	Playschool-High School (1975-1990)
Marginal Responses: Memoirs (i.e., Beth Kephart's <i>A Slant of Sun</i>), Fiction (i.e., Wally Lamb's <i>I Know This Much Is True</i> , Nonfiction (i.e., James Britton's <i>Language and Learning</i>), Poetry (i.e., Rita Dove's <i>Selected Poems</i>), Writing Books (i.e., Natalie Goldberg's <i>Wild Mind: Living the Writer's Life</i>)	When my quote journal was not nearby, I marginally noted connections to my life in books. This became a more systematic activity during doctoral studies (1997-2003)

APPENDIX F

An Extended Model of Ecological Theory

MACROSYSTEM – ATTITUDES / IDEOLOGIES

