“SHE'S WRITING HER OWN BOOK”: A CASE STUDY OF FAMILIAL AND EDUCATIONAL IDEOLOGIES OF DISABILITY

by

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(Under the Direction of Jennifer Graff and Usree Bhattacharya)

ABSTRACT

The purpose of this digital case study was to explore the multiple ideologies of disability that exist within one family and the varied ways these ideologies are laden with power and constituted, through interactions with other family members and select educational stakeholders and the documents shared. Using a framework of Critical Disability Studies, data was collected virtually alongside a family within the disability community and a select educational stakeholder over the span of three months. Data sources include virtual interviews, observations, and documents. Findings indicated that both individual and shared lived experiences of disability inform ideologies of disability, which are continually constituted. These findings have implications for literacy researchers, teachers, teacher educators, and families within the disability community.

INDEX WORDS: Disability, Critical Disability Studies, Language Ideologies, Case study, Family Research

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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

2022

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August 2022

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For my family, my support system throughout this process. Our shared experiences inspired me, and your constant encouragement and endless love sustained me.

ACKNOWLEDGEMENTS

Completing this dissertation would not have been possible without so many wonderful mentors, family members, and friends. Without their guidance, companionship, and grace, I wouldn’t be the scholar or human I am today. I would like to extend my deepest thanks to these individuals, while acknowledging that there are so many more whose names are not featured who made this journey so memorable.

To Jennifer Graff and Usree Bhattacharya, my amazing advisors: Thank you both so much for your constant support and encouragement. You each brought distinctive expertise and knowledge that strengthened my research and writing exponentially. Together, you both have shown me how to be a kind, compassionate, and thoughtful mentor, and my hope is that I can show the same care to my own future students.

To Donna Alvermann: Thank you for always believing in my work and pushing me to think more deeply and explore new theoretical possibilities. With each new suggested reading, my understandings of disability and theory deepened. While I may have had more questions than answers, you encouraged me to continue “onward.”

To Kathy Roulston: Thank you for creating such a sound methodological foundation for my research. Your classes and the communities we all co-created were truly the highlight of my PhD journey.

To Stacia Long: Thank you for being my best friend throughout the past five years. You have always given me the most brilliant, generative feedback and been the first to celebrate my successes. I couldn’t have done this without you by my side.

To my writing group: While we may have earned the reputation of the “gossip group,” our sessions were such a bright spot in the roughest of weeks. You each are such brilliant scholars, and I am grateful to have learned and grown alongside you all.

To my mother: There aren’t enough words to describe how much you mean to me, especially throughout this experience. I am forever grateful for example that you set for me throughout my childhood, as a loving, hardworking, independent, beautiful, strong, and fierce woman. I love you, Mama.

To my father: Thank you for your sense of humor, delicious food, and for “saving” Mama and me 26 years ago. We’ve proved that nurture definitely outweighs nature. Love you, B.

To my brother: I am so incredibly proud of the man that you’ve become. When so many said that you would never succeed, you’ve proved them all wrong. Your determination and persistence inspire me, and I can’t wait to see all of the amazing things you’ll continue to accomplish. Thank you for making me a big sister. I love you, Spence.

To Michael: I can’t imagine my life without you, encouraging me, pushing me, believing in me, and taking care of me during these final few stages of the dissertation process. To me, you are Batman. I love you, and I can’t wait for so many more adventures with you.

To Max and Lola: You both have brought so much joy into my life. Your smiles, cuddles, and kisses were always a salve for my tired soul after long days of writing. Thank you for always warming my feet, reminding me to go outside for a walk, and for being my constant companions.

To the Smiths: Thank you for opening your home and sharing your lives with me, including the difficulties and the accomplishments and the joy and the pain of the disability experience. I connected with and learned so very much from each of you, and I am forever grateful that you chose me to share your stories.

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INTRODUCTION

My ideologies of disability have continually evolved since my brother's autism diagnosis almost 20 years ago. As a child, the ways I viewed disability first shifted in response to my parents' inability to discuss the topic with me. Looking back, I believe that my parents thought that I just inherently knew that my brother had a disability. However, they never spoke of his diagnosis, and I never asked about it for fear of disrupting the façade that we had created to make it appear to everyone that everything was *normal*. These formative experiences led me to conceptualize and internalize disability as a destructive force. Disability had broken down communication between my parents and myself.

As I grew older, I became resigned to never receive answers from my family, but I also became curious to learn more about disability in order to understand how it had changed my family's life so greatly. To do this, I turned to outside resources, specifically online tools. During my quest to find information about my brother's disability, I read blog posts written by siblings and talked to other siblings of individuals with disabilities[1] in virtual forums. Through this investigation, I discovered that my own experiences were not unique, as many others faced similar circumstances of silence and aversion. Through these discussions with other siblings, I reflected on the myriad forces that shaped and still inform my ideologies of disability, including the conversations I did and didn't have and the media I consumed.

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[1] Throughout this dissertation, I use both person-first and identity-first language to represent my own continually developing understandings of the discourse available to describe the disability community. My discursive decisions are discussed more detail in Chapter 3.

During this introspection, I felt shame, fear, anger, love, happiness, and curiosity, and these emotions and observations eventually transformed into motivation. Inspired by my own and my family's experiences, I found a passion for education. I wanted to help families so badly in some way, and I saw teaching as a means to directly impact many of the ways disability is initially framed for young children through inclusive classroom communities, the texts they read, and their teachers' own actions. In my first classroom and the school I taught, I saw families who were grappling with their own disability diagnoses and the helpful resources that were provided during that time. I also observed fellow teachers' conversations surrounding disability that focused solely on the perceived deficiency of students with disabilities, the lack of representation of disability in our school's library, and the meager support teachers were given by administration to accommodate their disabled students.

While pursuing my PhD, I have seen disability constructed in powerful ways by the absence of acknowledgement. Through the required courses for preservice teachers that still include labels like *exceptional students* or *students with special needs* and the unwillingness to make older buildings accessible, in compliance with the Americans with Disabilities Act (ADA) (Perez, 2019), I realized that differing and potentially damaging understandings of disability were pervasive and widespread in my own communities and beyond. Through these instances, I saw how those in power sought to control and normalize disabled bodies (Dreyfus & Rabinow, 1983), ultimately inspiring my alignment with Critical Disability Studies (CDS). These noticings in my classroom and at the university reminded me of my first personal and negative experiences of disability.

While my parents didn't openly share their thoughts on disability and their experiences surrounding disability during my adolescence, we have slowly begun to voice how we now see disability affecting our lives today and our futures. I no longer see disability as destructive or deficient. Rather, I view disability as a concept that is constantly in flux, just as my understanding of the phenomenon has been since my brother's diagnosis. My journey toward my current views led me to contemplate how other families within the disability community navigate and explore their own complex ideologies of disability, what resources they use in those processes, and how we, as educators, impact this journey.

Statement of the Problem

Within the expansive field of Disability Studies, the emotional and physical impacts of having a child (Davis & Carter, 2008; Gilson, et al., 2018; Resch et al., 2012; Singer, 2006) or a sibling (Bischoff & Tingstrom, 2007; Gorjy et al., 2017; Perenc & Peczkowski, 2018; Ross & Cuskelly, 2009; Shivers & Dykens, 2017 et al., 2017; Wofford & Carlson, 2017) with a disability have been extensively researched. Additionally, individuals' own experiences of living with a disability have been recently explored (Ferri; 2011; Finger, 2006; Linton, 2007; McBryde Johnson, 2017; Mintz, 2007; Sherry, 2005; Wong; 2020). The goal of this preexisting body of research is to provide interdisciplinary support for the different individuals that makeup the disability community and their varying needs. However, these same individuals' ideologies of disability have yet to be explicitly investigated. Research that delves into ideologies of disability considers the larger social contexts that inform understandings of disability and, lasting change that positively affects the disability community cannot be enacted without these considerations.

The field of language and literacy education has similarly sought to unpack the experiences of both students and families within the disability community. In particular, past scholarship has worked to investigate the practical implications of inclusive literacy practices with students with disabilities (Flewitt et al., 2009). Within these investigations, researchers present differing ideologies of disability and views of students with disabilities. Two distinctive decisions made by researchers exist within these publications, including the omission of the term *disability* when identifying students (Lacey et al., 2017; Lawson et al, 2012; Oakley, 2017; Price-Dennis et al., 2015; Valtierra & Siegel, 2019) and the promotion of participation of students with disabilities through an alignment with the social model of disability (Flewitt et al., 2009; Kliewer et al., 2006). While these discursive, practical, and theoretical moves speak to various institutional discourses, the research doesn't overtly acknowledge the ideologies of disability that have informed these decisions. Despite this oversight, ideologies of disability woven into the literature have the power to impact multiple stakeholders' understandings of inclusivity and disability, and these understandings, in turn, inform literacy practices.

Most noticeably, the literacy practices of families within the disability community have been extensively explored. Researchers study issues of language and literacy use within the familial context of the disability community, including familial roles in the literacy development of children with disabilities (Adams et al., 2015; Keilty & Galvin, 2006; Koppenhaver et al., 2001; Ricci, 2011; Robinson et al., 2016), strengthening the relationships between educators and families within the disability community (Hunter et al., 2017; Schoorman et al., 2011), and the evolution of literate identities of children with disabilities and their parents (Compton-Lilly, 2016; Kabuto, 2016; Skinner et al., 1999; Whitehouse & Colvin, 2001). Despite this increased attention within the sphere of language and literacy education, more broadly, much of this scholarship involving students and families within the disability community has continually failed to consider ideologies of disability and incorporate broader social contexts into their work.

The importance of exploring the larger social context of ideologies of disability can be facilitated through the study of the interdependence between socially situated language practices and the social, economic, and political structures in which these practices occur (Cavanaugh, 2020). As literacy educators, looking deeply into this relationship between language practices and power structures can help us understand the connections between language use and the inequalities imbedded within our society (Cavanaugh, 2020). When focusing specifically on the disability community and their experiences in educational contexts, language ideologies can help us deconstruct the damaging institutional ableism that is woven throughout educational policies and practices (Phuong, 2017).

This case study was built upon the foundational work included above and sought to accomplish the same goals cited by previous research but through different means. In order to improve the educational experiences of students with disabilities, an emic perspective of the lived experiences of students, their families, and their educators was considered. To gain transformative knowledge of these nuanced and complex experiences, familial ideologies of disability were the primary focus of this study. By studying these ideologies and their continual constitution alongside a family in the disability community, we, as literacy educators, can work to create equitable educational policies and practices that truly align with the lived experiences of the disability community.

Purpose and Overview of the Study

The purpose of this study was to explore the multiple ideologies of disability that exist within one family and the varied ways these ideologies are laden with power and constituted, through interactions with other family members and select educational stakeholders and the documents exchanged. For this qualitative digital case study, the overarching research question was: *In what ways do family members and educational stakeholders constitute one another's ideologies of disability in and across familial spaces?*

To answer this question, I designed a digital case study that focused specifically on ideologies of disability. In particular, I worked to craft a methodological design that acknowledged the “partial, contestable and contested, and interest-laden” nature of culturally constructed concepts like disability and the ideologies that inform these concepts (Woolard & Schieffelin, 1994, p. 58). Within the context of the case study, I worked alongside the Smith family that consists of Narise, Jenny, Michael, Riley, and Narise’s teacher, Mrs. Tammy. The Smiths’ familial spaces served as the primary site of data collection which included completing virtual interviews and observations and document analysis.

Overview of the Methods

Disability is incredibly complex concept that traverses multiple contexts. Disability can be understood as a political category, an object used to understand a capitalist society, a phenomenon produced through social and cultural practices, an ontological experience, and an identity (Goodley et al. 2019). Families (Turnbull & Turnbull, 2001), discourse (Bové, 1995), and ideologies (Leonardo, 2003), are also intricate constructs constituted by economic, social cultural, and political forces. Thus, understanding one family’s ideologies of disability that circulate within and through familial spaces through discourse needs a research methodology that can take into consideration these often in-flux concepts. Critical Disability Studies (CDS), grounded in postconventional understandings of disability, offers a view of disability “both as a critical lens and as a lived reality for researchers and participants” (Kerschaum & Price, 2017, p. 98). The lived experience of those within the disability community includes interacting with family members, discourse, and ideologies, and CDS seeks to acknowledge these interactions in the formation of new and progressive theory and practice. As Goodley et al. (2019) posit, “A key purpose of theory is to understand and intervene in the social world” (p. 976).

Aligning with praxis, CDS's commitment to criticality is twofold. Scholarship that is supported by CDS, first, must build upon the foundational theories and models that have informed its creation, including the medical and social models of disability. Understanding both the history and the material conditions of disability are vital to moving forward in theory and in application (Shildrick, 2012). Second, CDS encourages the critical analysis of these same models by recognizing the integration of feminist, queer, postcolonial, and critical race theory within the field (Goodley et al. 2019). Following the critical turn, scholars who employ CDS continually question preconceived and current understandings of disability in order to discover the potentiality of disability and the multiplicity of possibilities that are inherent within the disability experience (Shildrick, 2012). Using CDS as a methodological tool, this study draws upon multifaceted views of disability to explore how families within the disability community navigate their varying ideologies of disability, what resources they use in their navigations, and how, we, as educators, impact this journey.

Definition of Terms

The following terms are organized in alphabetical order. The accompanying definitions represent my own personal exploration of these terms informed by prominent scholarship within the fields of language and literacy education, applied linguistics, and CDS.

Disability

It is important to define disability within the context of my own research. The Americans with Disabilities Act (ADA), as a prominent piece of legislation in the United States, legally defines *disability* as "a physical or mental impairment that substantially limits one or more major life activity," and this definition may include a disability that has been either "recorded" or "regarded" (n.d., para. 2). The ADA's notion of "regarded as having a disability" aligns with the commonly accepted understanding of disability as a social phenomenon, and impairment serves as the central tenet of this definition. Contrastingly, having a “record of” a disability entails “that the person has a history of or has been misclassified as having a mental or physical impairment… even though the person does not currently have a disability” (ADA, para. 1)

Within my work, I use the ADA’s concept of a “regarded” disability. With this definition, I consider both participants’ own personal interpretations of disability to determine their inclusion in the study and a medical diagnosis which can be understood, too, as a social construct. Both determinations allow for an expansive view of disability that considers multiple understandings of the complex concept. The specific way that disability is represented in my work is indicative of my own personal definition that is continually evolving and changing, along with the prominent discourses that have informed my current understandings of disability. Garland Thomson’s (1997) work reflects this continuum of understanding and positions physical impairment and, thus, disability as “never absolute or static” but “dynamic, contingent conditions affected by many external factors and usually fluctuating over time” (p. 13).

When I began this study, I sought to portray this flexibility by creating the term (*dis)ability* that contains a set of parentheses that separates two integral pieces of the word: *dis* and *ability*. Unlike the severe slash associated with a binary (*dis/ability*), the parenthesis inserted into the word acts as a means of movement. My use of the term was a depiction of the endless constitution and reconstitution of the social concepts of disability and ability (Schalk, 2017). However, as I continued in my work and exploration of disability activism, I chose instead to use *disability*, a discursive choice made by both scholars (Linton, 2017; Overboe, 1999; Shildrick, 2012; Titchkosky, 2006) and activists (Ableism is Trash, 2022; Autistic Truth, 2022; Disability Reframed, 2021; Talk Disability, 2021; Neuro Different, 2022) within the disability community.

This decision also aligns with one of the integral components of the disability rights movement: Nothing About Us Without Us (Charlton, 1998). With this alignment, I acknowledge and listen to the disability community on disability issues (Disability Reframed, 2021; Talk Disability, 2021). I further discuss the semantic progression of the term disability in detail in Chapter 3.

Discourse

Moving past traditional linguistic understandings of discourse as only "language-in-use" or "real language," I conceptualize discourse as a dynamic concept that includes multiple forms of human action and interaction (Blommaert, 2005, p. 2). Cameron (2001) similarly shares that discourse is "language use *in any medium*" (p. 10). In this view, discourse is not simply written text, it is spoken language, bodily movements and gestures, pictures drawn by hand or using computer software, and so much more. Throughout each component of this study, during interviews, observations, and document analysis, discourse is used to convey meaning in many different ways. Context is key to understanding these different meanings (Rymes, 2016). The context, bounded by both physical and discursive borders, affects the meaning making process. From a critical perspective, understanding this relationship between context and discourse is imperative and a means to examine power relations and ultimately "resist the unpleasant conditions that often seem to control us" (Rymes, p. 101).

This conceptualization of discourse is also informed by postconventional thought. As Bové (1995) asserts, the aim of discourse is "to describe the surface linkages between power, knowledge, institutions, intellectuals, and the control of populations" (pp. 54-55). Discourse, in this way, is much more than words, as it can serve as a smaller unit of analysis to observe much larger structures and the power bound within these structures. St. Pierre (2000) further speaks to the possibilities inherent in discourse by providing questions that discourse can prompt us to ask, including “Who gets to speak?” and “Who is spoken for?” (St. Pierre, p. 485). With these questions, we can begin to examine, resist, and upend discourses of domination (St. Pierre, 2000). More specifically, these dominant discourses may be present in commonly understood and used definitions of disability.

Family

Defining a family is a process that is “intrinsically inexact and ambiguous” (Handel, 1992, p. 17), but many scholars have presented the concept of family as a system, unit, or organization that interacts in some way with other systems, units, or organizations. Turnbull and Turnbull (2001) present families as systems with both inputs and outputs. The inputs represent family characteristics that can include personal attributes and any challenges that families experience. Outputs, on the other hand, include family functions or the tasks that families complete to meet the needs of their members. Both the outputs and inputs are “dynamic and change throughout time” (Turnbull & Turnbull, 2001, p. 86).

Systems, units, and organizations are often defined by their membership, and changes in membership occur due to various inputs and outputs. For instance, familial membership has the potential to change in response to inputs, like disability, socioeconomic status, and cultural background, and outputs, such as daily care, socialization, and education (Turnbull & Turnbull, 2001). Additionally, the term *family* connotes a very personal connection—one I consider throughout this study—and that often transcends a clinical definition that relies solely on biological relationships. Valuing this individualized understanding of family, the Smiths, the participating family, and I co-created the portrait of themselves that is featured in this study.

Ideology

I define ideology as a system of beliefs, as I focus on *ideology* rather than *Ideology*. In this way, ideology is not a "monolithic entity that drives all facets of thinking" (Leonardo, 2003, p. 209). Rather, ideology, in this context, is considered a worldview or the means through which individuals make sense of and meaning from the world around them. However, this worldview must not be thought of as neutral. Instead, ideology is imbued with issues of power, and ideology can be seen as "a response to social relations of domination" (Leonardo, 2003, p. 204). This understanding of ideology relies heavily on critical theory which is often viewed as being at odds with postconventional theories—the same theories that frame my dissertation. Postconventional theorists have repeatedly rebuked ideologies as totalizing and naturalist concepts and even rejected the notion of their existence (Malesevic & MacKenzie, 2002). I discuss this tension further in Chapter 3 where I explore postconventional thought and the ways that it pushes against and past modernist concepts, particularly the concept of ideology.

Organization of the Dissertation

In the next chapter, Chapter 2, I present a literature review that outlines previously published scholarship that explores students and families within the disability community. Chapter 3 then describes the research design and methodology that guided and grounded this research. In Chapter 4, I describe the findings that explore my own determinations regarding the different ways family members and educational stakeholders constitute one another's ideologies of disability in and across familial spaces. Finally, Chapter 5 includes the conclusions and implications for these collective findings and directions for future research.

CHAPTER 2

LITERATURE REVIEW

Students and families within the disability community are often the subject of research within the vast field of Disability Studies. However, the field narrows drastically when considering research framed with the theories and theoretical models that encompass Critical Disability Studies (CDS). While the lack of research employing CDS as a theoretical lens may be due to its relatively recent emergence within the field of Disability Studies, this absence is notable, because these frameworks offer valuable new ways to acknowledge the multiplicity of the disability experience (Meltzer & Kramer, 2016). When considering research involving these same students and families within the field of language and literacy education, the pool of research shrinks even more dramatically, despite students with formally identified disabilities and their families making up a notable portion of every classroom community with 14% or 7.3 million students enrolled in special education services (NCES, 2021).

Reviewing the available research involving students and families within the disability community is crucial in understanding the ideologies of disability that exist within one family. Understanding the ideologies present in previously published research can offer critical insights into how the concept of disability is constructed for students, families, and educational stakeholders by the field of language and literacy education. To begin the process of gathering and reviewing research involving students and families within the disability community, the keywords of *students*, *family*, *disability*, *literacy*, and *inclusion* served as the foundation of my search for relevant literature. I then selected scholarship that highlighted ideological stances within both the disability community and the educational system by exploring the collective perspectives and experiences of students, families, and educational stakeholders. In the following sections, I have synthesized the scholarship that includes these individuals within the disability community specifically published in the discipline of language and literacy education. These separate sectors of scholarship build upon and inform one another in powerful and generative ways, and these connections are included in detail below. Ultimately, this foundational work guided the methodological choices featured in Chapter 3 and inspired the implications of the research detailed in Chapter 5.

Students, Families, and Disability in Language and Literacy Education

Reviewing research that explores students, families, and disability in language and literacy education more broadly presents a wide angled view of how disability and those within the disability community are included or even excluded within the larger field. In particular, this exploration of previously published research can contextualize the ideological positioning of students and families within the disability community "through institutional and discursive processes" (Phuong, 2017, p. 47). By first centering students with disabilities in this review, I employ inclusive research practices and strategies that consider and incorporate participants' identities in every step of the research process (Aldridge, 2014). Then, I focus on research conducted with families within the disability community to provide insight into the multiplicity of perspectives of the disability experience. Collectively, with the following sections, I expand upon traditional notions of disability, family, and literacy (Meltzer & Kramer, 2016). These expansive views serve as both the inspiration for and the foundation of my own research.

Students Within the Disability Community

Much of the research published in the field of language and literacy education focused on students within the disability community promotes the concept of *inclusive literacy*. Inclusive literacy expands the socially situated and multifaceted understandings of literacy, first promoted by New Literacy Studies (NLS) scholars, and advocates for pushing against traditional notions of literacy. Taking note of literacy's evolution and children's literacy practices in different social contexts, NLS scholars have long advocated for a broadened conceptualization of literacy (Lankshear & Knobel, 2011; Street; 1984). Particularly, NLS research recognizes the existence of multiple literacies and views literacy as the "socially recognized ways in which people generate, communicate, and negotiate meanings" (Lankshear & Knobel, 2011, p. 33). Inclusive literacy extends the works of NLS scholars by seeking to include children with disabilities by valuing all literacy experiences (Flewitt et al., 2009). In this way, inclusive literacy promotes inclusivity in both the literacy practices and learners it supports. While promoting inclusivity in a variety of contexts, much of the published scholarship on inclusive literacy presents diverging ideological constructions of disability, and, thus, diverging views of students with disabilities. These ideological differences impact researchers, educational stakeholders, students, and their families' understandings of inclusivity and disability, and these understandings ground and inform varying literacy practices.

Focusing on inclusive literacy, rather than solely the topic of students with disabilities in language and literacy education, provides me with the opportunity to unpack the various means through which researchers position students with disabilities and the many different ways scholars take up the term *disability* when working specifically in inclusive contexts. Milton's (2017b) definition of inclusion informs my work, as it asserts that "inclusive education can be viewed as education in which the barriers to participation are eliminated from classrooms and schools" (p. 4). My decision to pair inclusive literacy and disability further promotes the collective goals of the field of CDS and, subsequently, Disability Studies in Education (DSE). DSE lies in ideological opposition to the "entrenched pseudo-scientific foundations of special education" that dominate much of the available research on students with disabilities (Connor et al., 2012, p. 6). Highlighting research on inclusive literacy practices in the field of language and literacy education "provid[es] evidence of DSE "at work,'" and "in action" (Connor et al., p. 6).

Additionally, analyzing the use of the term disability within the literature allows us to understand the ways that language use is inherently and deeply connected to ideologies of disability. I draw on the scholarship of Irvine and Gal (2000) and Cavanaugh (2020), situated within the field of language and literacy ideologies, to continually remind me of the important connection between language use, or linguistic features, and ideology. When considering the language used in research focused on inclusive literacy, scholars' own ideologies of disability can be examined to tease apart the institutional discourses found within the scholarship and the ways these discourses reflect larger societal beliefs. Two distinctive moves regarding language use are featured in the ways that researchers attempt to explore the literacy engagement of students with disabilities: *omission of the term disability when identifying students* and *promoting participation of students with disabilities through an alignment with the social model of disability*.

Omission of the Term Disability When Identifying Students

First and foremost, I did not discover any published pieces that explicitly define disability, but these same publications do define literacy, inclusion, and inclusive literacy. The scholars' attention to clearly defining literacy, inclusion, and inclusive literacy may be attributed to their selected publication outlets and foci. Additionally, authors may make assumptions of a shared understanding of what is meant by the term disability within a particular discipline. Many of the cited pieces are featured in journals originating in the fields of special education and inclusive education, and these disciplines often focus on issues surrounding disability but not literacy engagement. For instance, within the *Journal of Research in Special Educational Needs*, Lacey et al. (2007) acknowledge that, for students with disabilities, “conventional literacy could be seen as irrelevant” (p. 149). With this acknowledgement, Lacey et al. (2007) must define conventional literacy and how it differs from inclusive literacy. However, defining disability doesn’t work toward achieving the goal of Lacey et al.’s (2007) research which is to seek out and share examples of teaching and learning practices that include students with disabilities. While these reasons for omission may align with disciplinary norms or authors’ intentions, the scholars’ exclusion of an explicit definition of disability is striking, as disability is inherently bound within definitions of inclusion and inclusive literacy.

Despite the absence of an explicit definition of disability, researchers’ language use signals their ideological positioning in regard to disability. While four scholars do employ the term *disability* (Barratt-Pugh, 2017; Flewitt et al., 2009; Kliewer et al., 2006; Milton, 2017a), five authors choose not to use the term disability in their work and instead use terms that still signal disability in various ways, either employing an asset-based or deficit lens (Lacey et al., 2017; Lawson et al, 2012; Oakley, 2017; Price-Dennis et al., 2015; Valtierra & Siegel, 2019). This avoidance is notable and aligns with the “underlying attitudes, values, and subconscious prejudices and fears that ground a persistent, albeit often unspoken intolerance” of people with disabilities that permeates society and, more specifically educational spaces (Shildrick, 2012, p. 35). The terms that are used to signal disability deficiently include the following: *students with severe learning difficulties (SLD)* (Lacey et al., 2017; Lawson et al., 2012); *learners with diverse needs*

(Oakley, 2017); and *special education students* (Price-Dennis et al., 2015). The term associated with an asset-based stance is *academically diverse learners* (Valtierra and Siegal, 2019).

Used most frequently in the literature, the term *students with SLD* derives from the Organization for Economic Cooperation and Development (OECD) that divides literacy into five levels, ranging from the first level that includes “people with very poor skills” to levels four and five that seek to categorize “people who demonstrate command of higher-order information processing skills” (Lacey et al., 2017, p. 149). The OECD is an international organization that works alongside governments, policy makers, and citizens to establish “evidence-based international standards and find solutions to a range of social, economic, and environmental challenges” (OECD, n. d.). The data produced from literacy research conducted by the OECD has implications in 38 countries around the world, but not without criticism. Specifically, within the United States, the data is used to determine the need for additional educational opportunities and targeted instruction for students across grade levels. With its varying levels, the OECD’s literacy scale has created an international standard for literacy skills and employs a deficit-based lens that focuses on what students cannot do in regard to conventional literacy practices, rather than focusing on multimodal literacy engagement. This rating system excludes and sets students apart from their peers, and the specific words used to describe the literacy levels are connotative of the damaging discourses and normative views associated with the medical model of disability that sees disability as deficient (Haegle & Hodge, 2016). In the medical model, “it is the medical diagnosis (and not the individualized needs of the child) that determines the available placement for the child” (Haegele & Hodge, p. 196). Similar discourses circulate around high-stakes literacy assessments that inform literacy levels such as these that seek to uphold “normative” standards (Erevelles, 2012). Within the featured scholarship, students with SLD are understood simply as one level of a larger literacy scale, not as individual, capable learners who can and do enjoy engaging in literacy practices. By not acknowledging disability, the term *students with severe learning difficulties (SLD)* focuses on difficulties rather than the possibilities and potentiality that is bound within disability (Goodley et al., 2019).

Attempting to acknowledge the multidimensional nature of disability, *diversity* is often used as a placeholder for disability, as seen through the use of the terms, *learners with diverse needs* (Oakley, 2017) and *academically diverse learners* (Valtierra & Siegel, 2019). Oakley (2017) does not define what is meant by the term learners with diverse needs and instead cites that the focus of the piece is the benefits of using technology with students with disabilities. Oakley (2017) further shares, “A major use of technology has been drills and games for struggling children to ‘remedy’ their learning difficulties or close the gap in the basics of phonological awareness and letter sound correspondences” (p. 162). With this goal clearly presented, one can infer that Oakley equates learners with diverse needs with students with disabilities. Exploring the implications of the use of the term learners with diverse needs presents the opportunity to explore the complicated history of the term *special needs*, as the two terms are similar in many ways. Special needs, once the preferred term by many within the disability community and beyond, has fallen from favor (Shildrick, 2012). Explaining this shift in discourse, Linton (2017) writes that *special* “can be understood as a euphemistic formulation, obscuring the reality that neither the children or education are considered desirable and that they are not thought to surpass what is common” (p. 164). *Needs*, as included in the term special needs and learners with diverse needs, is also complex and can work to position individuals as lesser than. Disability Reframed (2021) shares, “The needs of disabled people are not special. They are not extra, nor are they exceptional. They are human” (n. p.). However, by employing the term learners with diverse needs, Oakley (2017) positions particular students' needs as exceptional, rather than focusing on required accommodations that must be provided to ensure disabled students' full participation in literacy learning.

Valtierra and Siegel (2019) briefly explain their reasoning for using the term academically diverse learners. They use the term to encompass the variety of students featured in their study, one of which was a student with a diagnosed disability. Specifically, the students selected for the study were "one typically developing reader, one struggling reader receiving special education services, and one non-heritage English speaker," and these students were chosen to emphasize the benefits of inclusive literacy for all learners, not just students with disabilities (Valtierra & Siegel, 2019, p. 115). This consideration regarding the language used is valuable, as is Valtierra and Siegel's (2019) aim to "shift narrow, ability-oriented dispositions toward literacy to more expansive and inclusive conceptualizations" (p. 119). In this context, inclusivity values all learners, and inclusive literacy seeks to ensure an equitable and empowering education for all.

Promoting the Participation of Students with Disabilities

As evidenced in the previously cited studies, a noticeable group of scholars did not employ the term disability in their work. The scholars who did use the term disability did not define disability, despite the complexity disability presents as a concept. However, two of these same scholars did situate their work within CDS, particularly the social model of disability (Flewitt et al., 2009; Kliewer et al., 2006). This theoretical alignment signals the critical nature of their research, a stark contrast to the scholarship cited above. This criticality serves as the foundation of CDS and represents "a sense of self-appraisal" that seeks to reflect and assess where we, as a society, have come from, where we are at, and where we might we going (Goodley, 2013, p. 632). In particular, CDS "rethink[s] the conventions, assumptions, and aspirations of research, theory, and activism" regarding disability (Goodley, 2013, p. 632). The progression of theory and models of disability within CDS serves as an example of this reflection and reassessment. Transformative views of disability have continually given ways to new models of disability. For instance, the medical model is now positioned as an old paradigm and in contrast to the social model, while the social model has given way to postconventional models of disability (Haegele & Hodge, 2016). The literature on students with disabilities in the field of language and literacy education reflects these changes, as a growing body of research is grounded within the social model of disability (Flewitt et al., 2009; Kliewer et al., 2006). According to Goodley (2014) and Haegele and Hodge (2016), the social model of disability is the most prevalent model of disability and frequently employed by scholars across disciplines.

The popularity of the social model of disability can be seen in research published on inclusive literacy practices, as the social model of disability is only the theoretical model of disability evident in the scholarship (Flewitt et al., 2009; Kliewer et al., 2006). The use of the social model, in these contexts, is significant. In addition to being a well-known model of disability within CDS and disability activism, the social model of disability, as its name indicates, is primarily concerned within societal understandings of disability and brings issues of disability into conversations concerning social constructions, practices, and institutions (Kliewer et al., 2006). The social model of disability focuses on how society continually imposes the concept of disability on individuals with impairments (Haegele & Hodge, 2016). Specifically, when using this model, authors address the ways that disability has been set up “as a political category” and “the social, economic, and cultural barriers that prevent people with impairments from living a life like their non-impaired brothers and sisters” (Goodley, 2014, p. 7). Within this body of research, these social, political, economic, and cultural barriers include access to education, literacy, and communication opportunities (Flewitt et al., 2009).

Flewitt et al. (2009) frame their work within the social model of disability to align with the stance of New Literacy Studies (NLS) that situates literacy as a sociocultural practice. In this way, both disability and literacy are concepts that are formed by social and cultural perceptions. Focusing on early literacy experiences, this group of researchers seek to explore different literacy practices and how these practices can expand “young children’s participation in different social and communicative opportunities” found in the home and at school (Flewitt et al., 2009; p. 215). Kliewer et al. (2006), more broadly, address the larger social institutions for which reconceptualizing literacy can prove to be more difficult. Suggesting one way to combat oppressive social barriers, Kliewer et al. (2006) propose that “presuming competence and rightful citizenship in areas such as literacy development and facilitated communication may promote understanding” among individuals both with and without disabilities (p. 170). *Presuming competence* and *literate citizenship* both work in opposition to the social impositions that act as barriers for children with disabilities to fully participate in literacy practices. Presuming competence challenges educators to expand their understandings of competence and find multiple and new ways for students to demonstrate competence and engaging and connecting with others (Kliewer et al., 2015). Inherently connected to presuming competence, presuming literate citizenship ensures the literate visibility of individuals with disabilities so that they may fully participate in literacy-based activities that ultimately facilitate full participation in society, more broadly (Kliewer et al., 2006). As Kliewer et al. (2016) explain, literacy is a “critical tool of community participation” (p. 177). In order for individuals to make vital connections with others in their communities, they must be able to express themselves. Literacy facilitates this communication across multiple modes.

Simple yet meaningful acts, such as presuming competence and literacy citizenship, are practical implications of inclusive literacy. Other implications include carefully choosing the language used when working with the disability community. The scholarship cited above serves as evidence of the power of language use. As Haegele and Hodge (2016) share, “the way in which disability is defined is important because the language people use to describe individuals with disabilities influences their expectations and interactions with them” (p. 193). Further, the language used can shape the understandings of disability had by those within the disability community (Siebers, 2017). The power of language use is also evident in how families within the disability community are featured and participate in research within the field of language and literacy education, particularly through the foci of these studies.

Families Within the Disability Community

Often, when considering research conducted with and for families within the disability community, individuals with disabilities are decentered, and an emphasis is placed on family members instead. Frequently explored are the changes in lifestyle experienced by parents and siblings of individuals with disabilities. The most common findings show that having a child with a disability has the potential to impact all areas of a parent’s life, including their physical and mental health, occupation, financial security, and relationships, both familial and social (Davis & Carter, 2008; Gilson et al., 2018; Resch et al., 2012; Singer, 2006). Similarly, having a sibling with a disability can cause feelings of anxiety (Shivers & Dykens, 2017; Tomeny et al., 2017) and an increased sense of empathy (Perenc & Peczkowski, 2018).

The previously published scholarship addresses the way that disability has drastically altered daily life for so many, but, often, it fails to take into the economic, political, cultural, and historical conditions that shape experiences of disability (Meltzer & Kramer, 2016). CDS offers a means to explore these powerful forces at play by offering new theoretical and methodological perspectives and approaches. For instance, Goodley (2013) shares how CDS scholars have developed theories and theoretical models of disability, including postconventional models (Shildrick, 2009) that encompass the postmodern (Corker & Shakespeare, 2002) and poststructural (Tremain, 2005) models of disability. These models align with the lives of those within the disability community, including "the complexities of alienation and rich hopes of resistance" (p. 641). Further, De Schauwer et al., take up Goodley's (2013) call to develop praxis in CDS by combining theory and methods through postconventional research methodologies. Through the use of these innovative methods, De Schauwer et al., (2017) challenge us to rethink disability in new and generative ways.

While research involving families within the disability community has yet to experience widespread use of the theories and models associated with CDS, currents of change can be felt within the field. Within educational research, work influenced by CDS is more widespread, as Disability Studies in Education (DSE) has experienced rapid growth within the last decade (Connor et al., 2012). This influence of DSE is similarly evident in the field of language in literacy education, as seen in the research on inclusive literacy that builds upon the social model of disability cited above in the section "Promoting the Participation of Students with Disabilities." More specifically, DSE has been infused into research involving families within the disability concerning issues of literacy and language use. This smaller subfield investigates a wide array of topics but often focuses on familial roles in the literacy development of children with disabilities (Adams et al., 2015; Keilty & Galvin, 2006; Ricci, 2011; Robinson et al., 2016; Koppenhaver et al., 2001), strengthening the relationships between educators and families within the disability community (Hunter et al., 2017; Schoorman et al., 2011), and the construction of literate identities of children with disabilities and their parents (Compton-Lilly, 2016; Kabuto, 2016; Skinner et al., 1999; Whitehouse & Colvin, 2001).

Familial Roles in Literacy Development

The first subset of literature that focuses on families within the disability community, in relation to their language and literacy experiences, explores the social implications of disability and the methods employed by families in collaboration with educational stakeholders to initiate or participate in various literacy practices. Situated within the field of speech and language pathology, Adams et al. (2015) specifically address an intervention for students with social communication disorders with hopes to improve both language processing and pragmatic and social understanding. Working closely with families, the researchers base their own study on the need to produce interventions that integrate "different therapy approaches where communication needs extend beyond language" (Adams et al., p. 295). This stance promotes an inclusive model of literacy (Lawson et al., 2021), as the study uses a *neuroconstructivist approach*. Lawson et al. (2021) share that a neuroconstructivist approach advocates for and values the use of different and multiple modes of communication and expression often employed by members of the disability community.

Similarly, Keilty and Galvin (2006), from the field of special education, collaborate with families within the disability community, as they detail recommended practices in early intervention that "advocate for supporting the family as the primary facilitator of the child's development" alongside therapists, educators, and medical practitioners (p. 219). Situating families at the center of their work, the research team observed adaptations family members engaged in during routine, everyday activities like familial conversations, mealtimes, and play. These adaptations then facilitated opportunities for emergent literacy development. Adaptations, in this context, are "modifications made to the social and physical environment that are attuned to the unique characteristics of the child to facilitate participation, exploration, and discovery" (Keilty & Galvin, 2006, p. 220). Keilty and Galvin provide in-depth descriptions of each of the families featured, as readers are invited to come to know each family. The researchers also insert commentary on the various adaptations that were used by parents. For instance, one family featured had their child with a vision-related disability feel dishware and utensils before a meal began. This routine then translated to book reading during which parents encouraged their child to feel and search the pages of their books to find Braille letters. Keilty and Galvin's (2006) work highlights inclusive yet expansive understandings of both literacy and disability that mirror those promoted by NLS and CDS.

Ricci (2011), also situated within the field of special education, focuses on home literacy environments and adaptations but specifically explores children's interests in reading and emergent literacy skills children with Down syndrome. Within Ricci's work, the home literacy environment is defined as the "frequency and nature of literacy-related activities in the home, most notably shared parent-child reading" (p. 597). In this context, *home literacy environment* isn't used to only describe a physical location. Instead, Ricci (2011) uses the term to describe conditions that are conducive for literacy development within families' homes. Observing this act of reading across a multitude of families that include children with Down syndrome, Ricci noted that parental beliefs, expectations, behavior, and, hence, their ideologies significantly shape home literacy environments and children's behavior. For example, Ricci claims that parental support and nurturing literacy practices, including dialogic reading strategies, increase mutual enjoyment during story time. Additionally, Ricci promotes parental training in interactive reading strategies. This training boosts parental confidence, increases expectations, and facilitates the development of literacy-rich home environments and early reading instruction that ultimately foster the reading skills of children with Down syndrome.

Similar to Ricci (2011), Koppenhaver et al. (2001) explore familial storytime and the benefits of parental training to promote literacy engagement with children with disabilities. Koppenhaver et al. (2001) focus specifically on mother-child storybook reading and how this practice can support early communication development girls with Rett syndrome (RS), a rare neurological genetic disorder that affects nearly every aspect of a child's life, including the ability to speak, walk, eat, and breathe. In this context, Koppenhaver et al. (2001) use augmentative and alternative communication (AAC) and voice output technology as an intervention to enhance the ways mothers were able to interpret their child's attempts at communication. By presuming competence in their children, as mentioned above in Kliewer et al. (2006) 's powerful work, the mothers featured in Koppenhaver et al.'s (2001) study "sought meaning in nonconventional communications, accepted it, and encouraged it" (p. 408). Presuming competence, in turn, positively impacted their children's communicative abilities and growth, specifically in the areas of labeling, symbolic communication, and use of switches and other learning technologies.

Robinson et al. (2019), too, investigate the powerful practice of parent-child story time and unpacks the pleasurable engagement with books among children and young people with disabilities. Using inclusive literacy as a conceptual framework, the researchers note that personalization, sensory and social stimulation, and repetition guided by parents increased children's enjoyment of reading. At the close of the study, Robinson et al. (2019) noted various positive impacts of pleasurable engagement with books for children within the disability community, particularly focused on the areas of development, well-being, and social inclusion. In particular, books were used to develop other kinds of reading—"reading of the social world" (Robinson et al., 2019, p. 100).

Relationships Between Educators and Families

In research that looks into the complex relationships between families and educators within the disability community, families and students also engage in the difficult task of "reading" and, thus, navigating the world around them (Robinson et al., 2019). For instance, Schoorman et al. (2011) acknowledge the multitude of challenges for immigrant families as they try to understand the policies and practices involved in special education referrals. Acting as participant-researchers, Schoorman et al. (2011) accompanied parents of the students they had previously tutored as they attended parent teacher conferences. This collaboration worked to "enhance greater home-school-community partnership" (Schoorman et al., 2011, p. 33). In particular, Schoorman et al.'s (2011) work emphasizes that these partnerships are especially needed among language minority populations, where the diagnosis of disabilities and the experiences that follow are often fraught with various issues. As vital members of the partnerships promoted by Schoorman et al. (2011), educators must re-think and expand their professional duties to include advocating for families that are under-represented.

Hunter et al. (2017) also conceptualize an interdisciplinary "team approach" to enhancing the development of children with disabilities, particularly in regard to early literacy skills within the school and home environment (p. 167). Evidenced through their work designing and facilitating literacy workshops for students and families within the disability community, they stress the vital role that parents and caregivers play in young children's literacy learning and how educational stakeholders can provide targeted support for both parents and caregivers. Further, Hunter et al. (2017) speak to the importance of considering social and cultural contexts when planning literacy workshops to reflect the unique needs of the families involved. Incorporating these contextual considerations requires collaboration, awareness of the diverse environments young children live, and adapting to, rather than interrupting, families' daily routines.

Both Schoorman et al. (2011) and Hunter et al. (2017) discuss issues that arise for families within the disability community regarding their access to literacy resources and practices. Many of these same families are also affected in different ways by their other intersecting identities and roles. For instance, in Schoorman et al.'s (2011) study, the family researchers collaborated with faced challenges during the special education referral process due to their status as English Language Learners (ELLs). Hunter and colleagues (2017) describe the obstacles faced by families from low socioeconomic backgrounds regarding eligibility for special education services. Different interacting factors impact families' lives, as varying systemic conditions reproduce conditions of equality (Goethals et al., 2015). Disability is just one of the many identity categories that play a role in this continued oppression, because disability does not exist in isolation from other identity categories, including but not limited to gender, religion, income, age, cultural background, and family status. As Phuong (2017) asserts, "Students with disabilities are not a monolith and may have intersecting institutional identities" (p. 48). Families within the disability community, similarly, are not a monolith.

The work of Cohen et al. (2015) seeks to address the intersections of these identities by investigating the impact of informal support, including caregiving, financial assistance, encouragement, and social companionship, on families within the disability community, focusing specifically on Latino mothers. Cohen et al. (2015) explore informal support, because, within the Latino community and other marginalized groups, numerous barriers exist when families within the disability community seek formal support, such as disparities in health care services and institutional services. These difficulties, in turn, make it likely that families with marginalized identities must depend on informal rather than the formal support provided by educators and healthcare professionals. The implications of Cohen et al.'s (2015) study implores practitioners to broaden their understandings of the roles that other adults within the household occupy, including the social support provided by the extended family network, and design interventions that meet the needs of all individuals within a familial unit, not limiting contact and support to solely the biological parents or primary caregivers of children. Support systems of families from various cultures are vast and vary, and the different shapes these systems take must inform our interactions with families (Cohen et al., 2015).

Holloway et al. (2014) include this broadened understanding of familial roles in their research by considering the support provided by the spouses and partners of mothers, who are often considered the primary caregivers of children with disabilities. Specifically, Holloway et al. (2014) look at the division of activities related to caring for children with intellectual disabilities (ID) within Latino families. Patterns of activity distribution reaffirm previous studies' findings that show that mothers are likely to complete far more household tasks than their spouses or partners, greatly affecting their life satisfaction and levels of stress (Davis & Carter, 2008; Gilson et al., 2018; Resch et al., 2012; Singer, 2006). Most notably, Holloway et al. (2014) claim that "structural factors may be as important as ideological ones in shaping the engagement of fathers and mothers in the daily routines of family life" (p. 120). These structural factors include language issues, poverty, discrimination, geographic mobility, and a lack of familiarity with the U. S. education system. Instead of imposing new routines, interventions and programs should consider these structural factors in order to complement ongoing familial routines (Holloway et al., 2014). Examples include scheduling educational events and opportunities during times that are convenient for employed parents and other caregivers and ensuring that information is available at all times and accessible, either online or on paper.

The evolving literate identities of family members within the disability community are intertwined with and informed by many of these structural factors and critically impact the literacy engagement of families. Educators must similarly seek to understand and attend to these identities in their pedagogies and practices. Within the context of this study, the Smith family identifies as a multiracial family. This identity, along with other intersecting aspects of their identity are intertwined with disability and situated within sociohistorical contexts (Phuong, 2017). As I collaborated with the Smiths, I considered these aspects of their identities and how these identities impacted their multifaceted participation in research practices.

The Evolution of Literate Identities

The scholarship that explores the evolution of literate identities of family members is of particular interest when considering ideologies, as it often involves looking closely at the discourses that circulate within one family while considering larger social contexts. Compton-Lilly (2016) presents one such study in which multiple discourses of literacy and schooling are "taken up, challenged, modified, negotiated, and abandoned by participants across time" (p. 224). In Compton-Lilly's (2016) work, discourse is defined as "the habitual ways community members use language to process experiences often involving particular words and phrases across contexts and events" (p. 225). This distinction is important, as this definition of discourse considers the variety of shapes that a community may take, including a family, classroom, school, or local disability community, and how these various communities can impact the meaning making process across time and space. These discourses were analyzed by collecting several sources of pertinent data, including student and parent interviews, classroom assessments and discussions, and writing samples. This continual interaction with and interpretation of various discourses, including both familial and larger historical discourses, informed the meaning making of one family, as they negotiated their own identities and experiences surrounding literacy and schooling.

Although the family Compton-Lilly (2016) worked alongside did not explicitly express that they were members of the disability community, their experiences speak to the power of discourses to inform both parents' and children's beliefs about important concepts like schooling and literacy. These concepts also serve as foundational elements of the evolution of literate identities of families within the disability community. Kabuto (2016) uses language as a way to examine the larger belief systems that inform the evolution of literate identities within the disability community more specifically. Speaking to the social, cultural, and historical factors that have shaped the construction of disability labels by a mother and son, Kabuto's (2016) study highlights the socially constructed nature of disability, aligning with ideologies that compromise CDS and DSE.

Whitehouse and Colvin (2001) similarly address disability labels and focus on how families are, as a whole, *read*. Reading, in this sense, means to make assessments grounded in deficit discourse regarding families' capacity and character based on varying familial characteristics. Most often, families are read based on their language use, ethnicity, culture, and class. The act of reading families is a common occurrence across institutional boundaries and many stakeholders, including teachers, researchers, government workers, and reporters, are a part of this process. Reading families and the accompanying discourse that is used to describe families, in turn, informs "judgements about which families are worth and/or wanting" (Whitehouse & Colvin, 2001, p. 212). Further, this same discourse often labels families and their literacy practices as deficient. By including two separate families' stories, Whitehouse and Colvin push against this damaging discourse and encourage educators to dialogue with families to understand and see the complexity of the disability experience.

Skinner et al. (1999) introduce narratives as a way for families, specifically mothers, to share this complexity with others. In these narratives, mothers of children with disabilities focused on the questions of “How can I make sense of what happened to my child?,” “What does it mean for me and my life?,” and “What is its meaning in the larger world?” Parents then “juxtapose[d], synthesize[d], and orchestrate[d]” both their cultural and religious understandings of disability to answer these questions in their narratives (pp. 481-482). Together, the work of Whitehouse and Colvin (2001) and Skinner et al. (1999) reinforce the power of language and the ways that language can be used to inform ideologies, by both limiting and expanding views of disability, particularly familial experiences of disability.

Collectively, the researchers cited in this section incorporate broader social contexts within their analysis. With this contextual consideration, CDS and DSE continue to influence research on disability and families within the disability community by presenting new and innovative ways to conceptualize and portray disability. In particular, CDS and DSE can help researchers and educators come to understand the lived experiences of individuals within the disability community. This understanding can shape the ideologies of disability that circulate within the field of language and literacy education, throughout P-12 classrooms and teacher preparation programs. The ideologies of disability had by one family within the disability community, informed by discourses, events, and artifacts, specific to the context of this research, are explored at length in the findings featured in Chapter 4. Then, additional implications of exploring and sharing familial ideologies of disability are presented in Chapter 5.

CHAPTER 3

METHODOLOGY

The research design and methodology featured in this chapter describes the research process applied throughout the study. I used the method of digital case study, grounded in Critical Disability Studies (CDS), to explore the ways that family members and select educational stakeholders' ideologies of disability are constituted in and across familial spaces. Together, digital case study and CDS work to provide an in-depth and richly detailed view of one family's complex and intertwined ideologies of disability and show how these ideologies are continually constituted. The following research question guided this exploration: *In what ways do family members and educational stakeholders constitute one another's ideologies of disability in and across familial spaces*?

Understanding the ideologies of disability of members of the disability community has widespread implications in the field of education. Most noticeably, understanding their ideologies can and should inform how disability is both theoretically framed and positioned in the practices of teacher preparation programs across higher education institutions. The courses housed within these programs often position disability as deficient, rather than an everchanging and identity-affirming concept (Allday, 2013; Hollingsworth et al., 2016; Rausch et al., 2022). Researching and then acknowledging the complexity of the disability experience can shape the ways various courses in teacher education programs promote providing an inclusive environment to meet the needs of the disability community. In addition to first acknowledging the complexity of disability, promoting an inclusive curriculum involves considering all the intersecting identities and roles of an increasingly linguistically, culturally, and racially diverse student population and their families that comprise the disability community.

This case study then seeks to share this complexity by featuring the lived experiences of one family within the disability community and how they navigate and conceptualize these experiences. Below, I share the foundations of CDS that support this exploration by detailing the prominent models of disability featured within CDS and with which of those models my research aligns. Then, I present the design of my digital case study, including data collection and analysis, and the implications for this design.

Theoretical Framework: Critical Disability Studies

In *Disability Visibility: First-Person Stories from the Twenty-First Century*, Alice Wong (2020), disability activist and author, writes, “Disability is mutable and ever-evolving. Disability is apparent and nonapparent. Disability is pain, struggle, brilliance, abundance, and joy. Disability is sociopolitical, cultural, and biological” (p. xxii). Wong’s captivating volume is a collaborative collection of stories that have created a space for the disability community to share their experiences while honoring the past and disability history. Specifically, when editing *Disability Visibility*, Wong sought to increase diverse representations of disability in mainstream media, as many representations are often static, if present. Critical Disability Studies (CDS), as a field, seeks to encapsulate the multitude of possibilities found within the disability experience described by Wong and other contributors. Through research and the creation of new theories and models of disability, scholars situated within CDS continually protest and push past preconceived boundaries that exist within a disabling society (De Schauwer et al., 2017; Shildrick, 2012).

Inspired by the goals of disability activism to achieve sociopolitical gains and understand the historic and material conditions of disability, CDS is a relatively broad field of academic study that is expanding exponentially from various disciplines and draws from different theoretical resources, including feminism, postmodernism, queer theory, critical race theory, phenomenology, and psychoanalysis (Shildrick, 2012). The material conditions of disability encompass all the factors that inform the concept of disability that exist *outside* of the body, most noticeably socio-political issues (Ginsburg & Rapp, 2013; Goodley, 2013). Work situated within CDS is infused with critical pedagogy and critical theory, as the goal of CDS is twofold. First, CDS encourages the use of theory to examine the material conditions of disability. Second, scholars within the field of CDS promote education as a means to resist long held and damaging views of disability (Goodley, 2014). In this way, CDS provides educators of varying grade levels with the tools to collaborate with their students to critically analyze and ultimately dismantle oppressive structures, both seen and unseen by students, that affect their lives in and out of the classroom (Ware & Hatz, 2016). Within CDS, various models and theories of disability, including the medical, social, and postconventional models of disability, provide a necessary framework for unpacking societal, political, cultural, and medically oriented understandings of disability (Shildrick, 2012).

Social Model of Disability

Two distinct models are most often referenced within current CDS scholarship: the social model of disability and the postconventional models of disability. The first model, as previously discussed in Chapter 2, is the social model of disability. The social model of disability was labeled and formulated to mirror the social practices that have become associated with disability and to combat the previously prevailing medical model of disability. The medical model of disability reinforces a view of disability that is typically understood through a medicalized gaze (Goodley, 2014). When diminished through the medical model, disability is seen as a condition that is to be either diagnosed or erased (Goodley, 2014). Contrastingly, the social model of disability does not focus on the problematization of one's body but instead finds issue with problems of access, support, community participation, and acceptance that have been created by a disabling society (Goodley, 2014).

Postconventional Models of Disability

Much of the research within CDS aligns with the social model of disability (Hosking, 2008), but select scholars have seen this model simply as a "starting point" and have brought postmodern concepts into their research (Shildrick, 2012, p. 30). Postmodernism, more broadly, works against oppressive modernist paradigms and seeks to distance us from and make us question legitimizing societal beliefs about self, truth, language, power, and knowledge (Flax, 1990). Specifically, CDS takes up postmodern approaches to challenge historical and material conditions of disability (Shildrick, 2012). However, postmodernism alone cannot continue to expand the field and serve as "final answers" to questions surrounding disability, because, as Shildrick (2012) asserts, "the work of critique is to keep alive the very process in which questioning itself generates new potential" (p. 31).

Similar to postmodernism, poststructuralism serves a way to continually question commonly held truths and knowledge supported by modernist paradigms. However, poststructuralism focuses more intensely on language. Promoting "the instability of meaning" (Best & Kellner, 1991, p. 21), poststructural critique investigates the variability of language and explores how "language operates to produce the very real, material and damaging structures in the world" (St. Pierre, 2000, p. 481). These structures include but are not limited to categories, binaries, and hierarchies. In particular, poststructural theorists work to unravel binaries that have been historically established and upheld in Western scientific, political, and cultural discourses (St. Pierre, 2000). Here, it is important to acknowledge that the understandings that ground poststructural critique of binaries and power structures are drawn from long held Western epistemological constructions. Drawing from Foucauldian (1981) concepts, Bhattacharya (2011) explains that binaries embedded in literacy scholarship are “sustained by violent institutional forces and that enforce and generate them” (p. 181).

When considering CDS, the poststructural view of disability is concerned with disrupting the historically entrenched ability/disability binary, as both sides of the powerful binary are constituted and reconstituted repeatedly by various social, cultural, and economic forces (Goodley, 2014). Not to be confused with the social model of disability, poststructural views of disability also analyze materiality in contemporary society, and, further, they investigate how disability is constructed at the nexus of different binaries, including immaterial/material, idealist/real, and object/subject (Goodley, 2014). Here, it is important to note that binaries do not facilitate the comparison of differences between concepts. Instead, binaries represent the complex relations of power had between two concepts, and disability is, thus, constituted through these relations of power by social, cultural, and economic practices (Goodley, 2014; St. Pierre, 2000). As Goodley (2014) posits, “Disability only ever makes sense in relation to ability” (p. 58). Again, the idea of a reciprocal relationship between disability and ability is grounded in Western and humanist thought that is bound within binaries that create and sustain asymmetrical power dynamics (Bhattacharya, 2011; St. Pierre, 2000).

Poststructuralists then seek to intervene in the spaces that uphold these binaries and disrupt damaging power dynamics. St. Pierre (2000) states, “deconstruction is not about tearing down but about rebuilding… It is not a destructive, negative, or nihilistic practice, but an affirmative one" (p. 481). Following this understanding of deconstruction, reshaping the ability/disability binary presents ample opportunities to observe modernist oppressions, to view power structures in transformative ways, and to rethink the historical conditions and assumptions that facilitate the continued existence of the binary in order to affirmatively rebuild the concept of disability (St. Pierre, 2000).

The integration of postmodernism and poststructuralism has developed a new model within the progression of theory that informs CDS which Shildrick (2012) labels *postconventional*. Postconventional scholarship, employing postmodern and poststructural theory, uses critique as a means to analyze prevailing models of disability. My research lies within the postconventional paradigm of CDS, as I engage in both postmodern and poststructural methods of critique. Specifically, this dissertation focuses on both the epistemological and discursive forces that comprise postconventional scholarship, as individual ideologies are informed and represented by both societal language use and larger systems of belief surrounding disability (Cavanaugh, 2020).

As the theoretical underpinning for this digital case study, CDS, drawing from postconventional theories of disability, centers disability "both as a critical lens and as a lived reality for researchers and participants" (Kerschbaum & Price, 2017, p. 98). Focusing on participants' ideologies of disability allows me, as the researcher, to address the ways ideologies are a part of participants' "lived reality" (Kerschbaum & Price, 2017) and "grounded in real practices and social institutions" (Leonardo, 2003, p. 211). In the context of qualitative research, Kerschbaum and Price (2017) define *lived reality* as the lived experiences and reflections upon disability that generate transformational knowledge that can contribute to more equitable practices. Through the exploration of familial ideologies of disability, this dissertation presents the lived reality of one family within the disability community, as represented by their individual and collective perspectives and language use, in and across familial spaces.

Postconventional Models of Disability and Ideology. In order to situate the concept of ideology within the postconventional paradigm of CDS, a brief exploration of ideology, particularly in regard to poststructural critique and language use, is warranted. Scholars within the field of education have advocated for a "post-structural rehabilitation" of the concept of ideology (Leonardo, 2003, p. 3). Fusing together critical and poststructural conceptions of ideology creates *ideology critique*, an analytical tool that uses a discursive understanding of ideology to look at issues of inequality. An analysis that involves ideology critique stems from the belief that, "at the heart of ideology, is the problem of social relations of domination made intelligible through discourse" (Leonardo, 2003, p. 204). These connections between ideology, power, and discourse can also be found throughout research on language ideologies which are "sets of beliefs about language articulated by users as a rationalization or justification of perceived language structure and use" (Silverstein, 1979, p. 193). Within this study, language structure use often serves as the focus, as the discourse of family members and educational stakeholders within the disability community can highlight their ideologies of disability and, more broadly, societal understandings of disability that have influenced these individual ideologies.

Language ideologies are, too, concerned with issues of power, as they are "often the site of social struggle and contestation" (Piller, 2015, p. 7). I focus specifically on the discourse of participants, the ideological positions associated with discourse, and the power that is imbued within these ideological positions. With these foci, language ideologies, as a foundational theoretical framework becomes “a valuable point of departure” (Cavanaugh, 2020, p. 55). In this way, language ideologies allow me to explicitly articulate the relationship between language, power, and social, cultural, and historical contexts, and then CDS assists in uncovering and understanding how these same ideologies operate in the lives of those within the disability community (Cavanaugh, 2020).

Ideologies of disability are ever-present in the participant family members’ lives and investigating how these ideologies operate in and across familial spaces—where family members live, learn, grow, and love—calls attention to the power inherent in these ideologies. Exploring the power evident in familial ideologies of disability can illuminate larger systems of power, as these larger systems inform individual ideologies (Cavanaugh, 2020). In turn, individual ideologies can also create and inform larger ideological frameworks (Fleming, 2015; Hasselbacher, 2018). Engaging in digital case study research allows for this intensive exploration of the ideologies of one family and its individual members, societal understandings of disability, and how power shapes ideologies in both noticeable and subtle ways.

Digital Case Study

Many different methods are available when designing and conducting qualitative research, and one must consider the scope and purpose of the research before selecting a particular method. The method of case study focuses on “the singular, the particular, [and] the unique” (Simons, 2009, p. 4). When considering this focus, case study is an ideal method for analyzing complex concepts like disability, family, discourse, and ideology (Simons, 2009). Leonardo (2003) shares the ideologies are “never complete but instead [are] evolving and modifying” continuously (p. 209), and disability (Goodley et al., 2019), families (Turnbull & Turnbull, 2001), and discourse (Bové, 1995) are, similarly, concepts that are in flux and subject to much study and scrutiny. Understanding one family's ideologies of disability that permeate familial spaces through discourse requires a method that can take into consideration the very intricate systems that informs and seek to define these concepts.

The method of case study has many additional defining characteristics that aid in this intricate investigation of familial ideologies of disability including increased researcher involvement and malleable methods. In every step of the research process, the researcher makes decisions that affect the data presented at the close of a study. Simons (2009) posits that, with case study, the self "is the main instrument in data gathering, interpretation and reporting" (p. 9). This active role that the researcher takes leads to gaining intimate knowledge of oneself as a qualitative researcher and of the research context. This autonomy also allows the researcher to select the methods that can best assist in the answering of the posed research questions and create a customized research protocol (Yin, 2018).

This customized research protocol was invaluable as I worked alongside multiple members of the participant family and a select educational stakeholder. In particular, the construction of an embedded single-case design was needed to take into account the multiple layers of the "richness and complexity of families" while still valuing each member's perspectives (Taylor, 1997, p. 4). An embedded single-case design allowed me to focus on individual members of the larger participant family, as family members can be seen as subunits within the larger, original case (Yin, 2018). Collecting and analyzing data with and from multiple family members speaks to the diversity of the disability experience, because each family member, with or without a disability, encounters and experiences disability differently in their lives (Goodley, 2013). As Schalk (2017) notes, the disability experience is expansive and involves "multiple ways of moving, thinking, communicating, and being in the world," (p. 7) and individuals within the disability community each have a different approach to interpreting the world through the lens of disability. Postconventional models of disability within CDS similarly echo this divergence of experiences and support an ontological understanding of disability as uncertain, unstable, contingent, and reflexive (Corker & Shakespeare, 2002).

Digital Design

The digital nature of this particular study assisted in collecting data that reflects the multilayered and nuanced nature of the disability experience. As Pink et al. (2016) note, “There is more than one way to engage with the digital” (p. 8) and participants used various virtual spaces to explore their individual ideological understandings of disability, specific to the context of this study. All participants, excluding Narise, were able to select the ways that they engaged in the study virtually, and, with this individualized engagement, they were then able to share their own perspectives of disability. Narise’s parents determined her continued engagement in the study, and their decisions shaped her participation and the ways she, ultimately, was unable to share her perspectives of disability.

Due to social distancing guidelines instigated by the COVID-19 pandemic, I was required to work with participants within these virtual spaces and integrate various digital technologies into the study design. To account for these changes, I use the term *digital case study* to describe this particular study. Digital ethnographic methods substantially informed the research design. I engaged in “mediated contact” with the participant family through the use of different digital resources, including the Zoom online communication platform, telecom software, email, and text (Pink et al. 2016, p. 3). These digital resources are described in detail below in the section entitled, “Data Sources and Collection.” This flexibility provided by the digital sphere aligns with the malleability of case study methods (Yin, 2018) and presented the opportunity for participation that otherwise would not have been possible during a pandemic.

Participants and Setting

In case study research, bounding is "highlighting the predetermined scope of a study" (Bhattacharya, 2017, p. 26). While the bounded nature of case study may initially seem ill-fitted for research involving everchanging concepts, it is important to note that a case study focuses on the delimitation of a case (Merriam, 1998; Yazan, 2015). The case, once determined, can be viewed as "a specific, complex, functioning thing" or an "integrated system" that "has a boundary and working parts" (Stake, 1995, p. 2). These boundaries are determined by the research questions, context, phenomenon studied, participants, physical location, and time. Often, a case can be bounded around an individual person, event, or entity over a particular period of time. Small groups, such as families, can also serve as a case (Yin, 2018) as in this study. In this way, this case study focuses only on one small segment of the much broader intersections of the complex concepts of disability, family, discourse, and ideology.

Bounding this particular case involved increased participant input. The boundaries of a case are often difficult to define due to varying contextual conditions (Yin, 2018), but my desire to continually center disability in the study facilitated an *interdependent research approach* (Kershbaum & Price, 2017), thus increasing the steps involved in the bounding process. An interdependent research approach entailed that both the participants and I "recognize[d] our mutual dependence on one another as we collaborate[d] together to construct access," particularly regarding what aspects of our lives we shared with one another (Kershbaum & Price, 2017, p. 100). Examples of an interdependent research approach in this study include the collaborative process that Jenny, the mother within the participant family, and I engaged in to schedule observations and the determination of the digital tools we used for interviews, observations, and sharing documents. Both examples are explored in detail in the "Data Sources and Collection" section below.

Understanding that "the single most defining characteristic of case study research lies in delimiting the object of study, the case," (Merriam, 1998, p. 27) Jenny and I worked together to determine all possible participants and create reasonable and clearly defined boundaries of participation. We shared our own definitions of family, including who Jenny saw as being members of her immediate family, and determined the spaces that we would access during our time together, in addition to the schedule and frequency of data collection. This collaborative bounding process was continually negotiated between myself, as the researcher, and the participant family (Yin, 2018). We revisited these boundaries periodically throughout the study to ensure that they aligned with our collective views and objectives. This bounded system is described in detail below by first introducing the participants, including the members of the Smith family and the selected educational stakeholder, Mrs. Tammy, and then the setting(s) in which we all collaborated.

Participation Criteria and Recruitment Process

Turnbull and Turnbull (2001) share that "there are simply too many characteristics that affect a family to justify your picking any one characteristic or type of family" (p. 89) as the basis for selection, but for the purposes of my research, the participants were selected based on their membership within the disability community. This membership was determined and disclosed by the family during recruitment, and details regarding the recruitment process are included below. Within the context of this study, membership in the disability community is defined as having an a “regarded” disability, being a family member of an individual with a “regarded” disability, or a professional that works closely alongside an individual with a “regarded” disability (ADA, n. d.). This definition aligns with my own understanding of being a member the disability community, despite varying views on membership (Pulrang, 2019). Following this definition, membership within the disability community was included in the eligibility criteria and featured throughout the initial stages of the study within the recruitment flyer and consent forms. This self-determination as a member of the disability community was critical, as I wished to understand familial ideologies surrounding disability specifically. Determining additional requirements was difficult, as familial structure varies greatly (Turnbull & Turnbull, 2001). However, as a part of the inclusion criteria, the participant family had to contain one parent and one or more children with a “regarded” disability, as informed by the Americans with Disabilities Act (ADA, n. d.).

Additionally, the child with a disability needed to be enrolled in school or other educational support services. Other logistical requirements included having access to consistent and reliable internet service that allowed for multiple virtual interviews and observations to take place, because, as Pink et al. (2016) posit, “variations in bandwidth speeds also shapes the practices” of research (p. 9). Collectively, these designations were critical for completing the study.

Recruitment

I recruited the participant family virtually through multiple outlets. Initially, I attempted recruitment through personal connections with the local disability community. I distributed my recruitment materials, including a recruitment flyer that can be found in Appendix A, within a weekly newsletter that is sent digitally to families who use the services of Exceptional

Individuals[2], a local nonprofit organization for families within the disability community. Exceptional Individuals is widely known as a haven for families within the local disability community, as it provides opportunities and programming for disabled children and young adults, their parents, and siblings with a wide array of extracurricular activities and additional support. Unfortunately, after four weeks, I had not received any interest in participation from families who receive Exceptional Individuals' weekly correspondence.

In hopes of recruiting participants from the local disability community that don't use the services of Exceptional Individuals and those who live in other geographical locations, owing to the many possibilities of participation facilitated the digital format of my study, I distributed my recruitment materials across social media, including in the large Facebook groups Qualitative Research in Education and FetchIt.org. Qualitative Research in Education is a collection of scholars, overseen by administrators Dr. Kakali Bhattacharya, Dr. Sheree Cook Alexander, and Dr. Krystal Rawls, who work to foster a collaborative network that promotes and facilitates sharing, learning, exploring, and researching alongside other qualitative methodologists. FetchIt.org is organized around local communities and brings together families and support services, as individuals post their needs or offerings in hopes to connect with others who meet their needs or require their services, including childcare and other tasks.

From these two Facebook groups, four different families completed the recruitment survey before the second recruitment period of one month ended. In order to select the family that would ultimately participate in the study, I reflected on the inclusion criteria, including children's ages, enrollment in educational services, and membership in the disability community, as discussed above, and eliminated all other participants except those that specifically met the

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[2] All names used in the study are pseudonyms.

criteria. Additionally, I considered the communicative abilities of the potential participants, as I wanted to have the participant with a disability involved in every stage of the research process. The communicative abilities were not limited to verbal speech, as I wanted to create “new ways of moving (Dolmage, 2014) in and around research methodologies” and value all means of communication that participants may use, including multimodal and embodied participation (Kerschbaum & Price, 2017, p. 100; see also Dolmage, 2014). For example, participants could communicate through Augmentative and Alternative Communication (AAC) that facilitates multimodal and embodied expression. AAC includes both unaided and aided modes of communication. Unaided modes of communication can encompass gesture, facial expressions, manual signs, and American Sign Language (ASL). Aided modes of communication are approaches “that require some form of external support” such as a communication board with symbols, computers, or handheld or tablet devices that generate speech (American Speech-Language-Hearing Association, 2020). Ensuring that participants with disabilities are included in the research process allows me to continue to center disability and value “disabled people’s lived experiences to generate transformational knowledge that can contribute to more equitable practices” (Kerschbaum & Price, 2017, p. 98).

Ultimately, the Smith family was chosen based on the inclusion criteria and other familial characteristics that I thought would serve as additional areas of exploration as they relate to ideologies of disability. Specifically, the Smiths’ familial structure, made up of two parents and two children, one with and one without a “regarded” disability, the mother’s role as an experienced educator, and the many ways they communicate, including the use of adaptive sign language, Picture Exchange Communication System (PECS), and a communication board.

Together, these attributes provided rich details about varied ways that ideologies of disability are constituted in and across familial spaces within the disability community.

The Smith Family

The Smith family is comprised of Narise, Jenny, Michael, and Riley. Their individual family names were self-selected, with Jenny and Michael selecting Narise's pseudonym. Additionally, their family name was agreed upon by Jenny, Michael, and Riley. The pseudonyms have special meaning to every member and were chosen to reflect a favorite memory, beloved family member, or hobby or interest. Collectively and individually, the Smiths are loving, insightful, sincere, and hopeful. At times, the Smiths are also unsure, frustrated, exhausted, and stressed. While these feelings are all intertwined and intermeshed in their ideologies of disability, they are also critical elements of who they are as a family and individuals.

The descriptions featured above were facilitated by the connections that were forged between the Smiths and I during the research process, and this engagement was and is vital to the study. The words used to portray the participant family were chosen with intention, as I became aware of the power imbalance often experienced between researcher and participants (Shaw et al., 2019). Throughout data collection and analysis and as I present my findings, I work to continually be "conscious of how the words I use to talk about others' lives might either add to past emotional stigma or engender a sense of empowerment for the participants" (Shaw et al., 2019, p. 6). However, demographic and individualized information is also needed to contextualize the study and the participant family's critical role in the research process.

The Smiths are a multiracial family with different members identifying as Black, white, and multiracial. Their home is located in the western portion United States of America in a large city where many educational and extracurricular opportunities are available for the family. Both parents are employed full-time, and the children attend public school in two separate local school districts. When not at school and work, they enjoy traveling together across their home state and beyond, spending time with extended family members, game nights, and sitting down together for dinner each evening. Narise, Jenny, Michael, and Riley are each individually introduced below, and their familial roles and relationships are made clear. The listed order of the participants, beginning with Narise and continuing outward in her family tree, reflects my goal to continually center disability (Kerschbaum & Price, 2017), as Narise is the one individual in her family with a "regarded" disability (ADA, n. d.). With this positioning, I first turn toward Narise's lived experiences in order to generate transformational knowledge (Kerschnaum & Price, 2017). Additionally, the order of family members, following Narise, reflects their recorded amount of participation in the study. Jenny participated the most, alongside Narise, with Michael and Riley participating less, respectively.

Narise. As revealed throughout my virtual observations and conversations with the Smiths, Narise is an avid consumer of children's books, and she loves storytime with her parents, Michael and Jenny, and sister, Riley. They will read multiple books together, often the same four or five books, repetitively each day, including *Mad About Madeline: The Complete Tales* (Bemelmans, 2001), *Mr. Brown Can Moo Can You?: A Book of Wonderful Noises* (Dr. Suess, 1996), *The Wonky Donkey* (Smith, 2018), and *Five Silly Monkeys* (Haskamp, 2006). These books each have a distinctive rhyme scheme, and many are interactive in nature, prompting readers to make specific noises or sing along with the characters. The rhythm, the sounds, and stories in each of the books are a great source of Narise's happiness. Narise is also thoughtful and affectionate, dispositions that are often accompanied with her smile, as frequently noted by others. In her IEP, Mrs. Tammy, her teacher, includes, “[Narise] is caring and always smiling. She loves to hug and be helpful” (Individual Education Plan, 2020). As she is at school, Narise is often happy, considerate, and loving at home with her family. She enjoys cuddling on the couch while she watches television, helping with chores like unloading the dishwasher, and playing both material and digital games using manipulatives or her tablet on a blanket in her playroom.

Narise is also 11, and she gets easily frustrated with her parents and sister, especially when they try to style her hair or attempt to make her complete a project she doesn’t want to continue. She lets her thoughts be known through expressive language, including single words like “Yep,” “Uh huh,” and “Aditi” for “Again,” gesture, adaptive sign language, and her core board. A core board is a “low-tech” AAC device that uses high frequency words, a small number of words that make up approximately 70-90% of the language we use on a daily basis, also known as a “core vocabulary” (Page, 2021, n. p.). Core boards come in different formats, ranging from printed pictures glued or Velcroed onto poster board to applications on digital devices. Narise’s core board is an example of the former, as it is constructed from printed pictures, Velcro strips, and cardboard. Her core board contains 20 printed pictures that feature images of her routine activities, including but not limited to pictures of books, a guitar, and fruits and vegetables. Figure 3.1 features Narise using her core board to determine which activity she and Jenny will do next.

Figure 3.1: Narise selects an image on her core board.

Regarding her multiple disabilities, Narise has been diagnosed with hypoplasia of the cerebellar vermis, hypoplasia of the Corpus Collosum, mosaic duplication of chromosome 15, and epilepsy. For Narise, these genetic disorders cause difficulty producing extensive verbal speech and prevent her from being able to communicate her thoughts easily. She can make individual sounds, producing single words, but others can't understand Narise's attempts at verbal communication beyond these sounds and words. While she is able to communicate using AAC, this difficulty combining sounds to create words often causes frustration, and she struggles to regulate her emotions and behavior and engages in self harm, harms others, or acts out. Narise also has low muscle tone which decreases her stamina and stability during physical activities. She requires supervision for most tasks to ensure her safety if she spontaneously has a seizure or injures herself. This requirement causes her to have an adult with her at all times. Most often, Narise is accompanied everywhere by her mother, Jenny, with the only exception being while they are at their separate schools.

Jenny. Jenny, mother to Riley and Narise and wife to Michael, describes herself as the "checklist" for her family. She is the one that "makes sure everything happens" (Individual Interview with Jenny, 2021). Whether it's scheduling needed medical or educational appointments for Narise or planning a family vacation to the beach or a new campground, Jenny ensures that each family member is taken care of, both physically and emotionally. Corresponding to this self-disclosed role and title, she is extremely organized and never failed to remember to attend each interview and observation or answer any email. Already familiar with the technology, she knew how to operate the Zoom online communication platform we used together. These skills, she shared, were obtained in her own classroom and by virtual teaching throughout the pandemic. Jenny is an educator; she teaches eight grade math and science and has been at her current school for nine years. She also recently received her doctorate in education, and her dissertation was an autoethnography that focused on her experiences being a mother and caregiver of a child with multiple disabilities. Beyond her occupation and academic endeavors, Jenny enjoys BBQing with her family, getting pedicures with her oldest daughter, Riley, going to concerts with her close group of friends, and drawing and scrapbooking. Within her dissertation, Jenny acknowledges that caring for a child with multiple disability requires a village, and her husband, Michael, is an integral member of this village.

Michael. Michael, father to Riley and Narise and husband to Jenny, describes his role in his family as supportive when he shares, “I just run support” (Individual Interview, 2021). With this statement, he highlights that he and Jenny are partners, and they take turns performing the family and caregiving responsibilities that are required of a parent, particularly a caregiver of a child with multiple disabilities. However, Michael’s caregiving tasks don’t typically begin until he arrives home in the evening after work. Due to Michael’s and my own schedules, he wasn’t often present for observations, but, when he was, he could be seen spending time with his family, reading to Narise, watching television with Riley, or helping Jenny prepare dinner. To Michael, family is a defining part of his life, and being a father to a child with multiple disabilities has significantly impacted his perspectives of disability, including how others perceive his daughter and their family. He revealed, “It’s given me… just a different perspective on life and the challenges that you can face. People say this all the time, ‘I don’t know how you guys do it.’ We just do it. It is what it is. It’s our life” (Individual Interview, 2021).

Riley. Riley, daughter to Jenny and Michael and sister to Narise, is 17 years old and, at the time of the study, was a rising senior in high school. Similar to her father, Riley shared that she has a different outlook on life due to Narise’s disability. During our time together, she divulged that Narise “helped [her] be a better person” because “if [Narise] can do all that and still be happy, [Riley] has no excuses” (Individual Interview, 2021). This determination is seen in so many facets of Riley’s life as she strives to do her very best in school and athletics. Further, she started a part time job to obtain her goal of having more financial independence to do things that she wants to do with her friends. This time with friends is what sustains Riley and brings her the most joy. The happiness her friends bring is evident, particularly after a difficult struggle during distance learning when she was separated from her needed community. During the study, pandemic regulations were eased, and Riley was again able to attend sports practices and social events. Due to these activities, Riley often wasn’t home when observations were held, but she always made sure to be home for their family dinners each evening.

Mrs. Tammy

After the Smiths were selected to participate in the study, Jenny connected me with Mrs. Tammy, Narise’s teacher for both fifth and six grade. Although Mrs. Tammy is not biologically related to the Smith family, she is still very close with each member, particularly Narise and Jenny. Not only was Mrs. Tammy Narise’s teacher for the past two years, following the grade level structure of Narise’s school, but she and Jenny also completed teacher preparation coursework together at their local community college. Additionally, Mrs. Tammy's twin sister was Narise's teacher for third and fourth grade. Having this extensive history with the Smiths, and, thus, sharing a strong bond, Mrs. Tammy plays a vital role in the constitution of their ideologies of disability, as they do hers.

As a special educator for over 20 years and Narise's teacher for the past two years, Mrs. Tammy strives to see the myriad different characteristics of each of her students. When discussing her students and classroom environment, she shared, "our kids are not, you know cookie cutters where we all fit in the same mold" (Individual Interviews, 2021). This perspective, she revealed, was fostered by her mother and her sister, both of whom are also special educators. Visiting her mother's classroom every day and watching her prepare each evening, Mrs. Tammy told me that she came to love the profession and the students, and there was never any question about her future occupation. This passion for education filtered into every aspect of our conversation, as she recounted the texts she uses in her classes, the units she's designed, and the collaboration between different stakeholders she cultivates to meet her students' individual needs. This collaboration often extends to students' families, as parents, Mrs. Tammy, her two assistants, and her students all work together to improve students' skills, complete assignments, and come together as a community for school social events.

Narise, Jenny, Michael, Riley, and Mrs. Tammy are all members of the disability community. They all have varied experiences with disability which, in turn, impact their ideologies of disability. Below, in my subjectivity statement, I detail the evolution of my own ideologies of disability and again elaborate upon my place within the disability community. This inclusion of a subjectivity statement is needed, because, as a participant-researcher, sibling, and member of the disability community, I hold many different subject positions, all of which are "connected to specific discourses of what it means for [me] to be connected to those labels or subjective positions" (Bhattacharya, 2017, p. 35). The discourses and personal connections are woven throughout my study in my choice of language and exploration of familial ideologies of disability.

Subjectivity Statement

As I completed this study, I continually revisited my roles as a researcher and sibling and reflected on how these multiple subject positions impact research practices and the data I present. As I previously revealed, I am a sibling of an individual with a disability. My younger brother was diagnosed with autism when we were both children. The familial connection I have with my brother makes me a member of the disability community, as a sibling of an individual with a disability, although some vocal activists and members of the disability community would contest my claim to membership (Pulrang, 2019). Their objection is important to note, because valuing the varied voices of the disability community is a key tenet of CDS and, therefore, my own research (Disability Reframed, 2021; Talk Disability, 2021).

Further, as I ground my work in CDS, I acknowledge one of the primary tenets of the disability rights movement: Nothing About Us Without Us (Charlton, 1998). While I am a sibling of an individual with a disability, I myself do not have a disability. Having a disability is not a requirement when writing about and researching disability, but I feel as though situating myself as an able-bodied ally and advocate is needed. This stance is supported by critical philosophy at large that asserts that "actions of advocacy are considered right actions" (Tisdale, 2004, p. 17). As a non-disabled sibling and researcher, I have the responsibility to "not speak on behalf of, or to pre-empt the experience of, others unlike [myself], but to interrogate precisely [my] own cultural and psychosocial location as non-disabled" (Shildrick, 2012, p. 37).

Discursive Decisions

While reflecting on my subjectivity, I find it necessary to also share my discursive decisions regarding the visual representation of the word *disability* featured within this study. Within the disability community, the language used to describe disability represents “a complex web of social ideals, institutional structures, and government policies” (Linton, 1998, p. 10). My exploration of terminology associated with disability reflects this complexity, as I have worked to unpack my own encounters with these ideals, structures, and policies.

In previous scholarship, I have chosen to include a visual representation of my alignment with poststructural theory employing *dis/ability* or *(dis)ability*. However, after continuing to learn with and from the disability community through my research, I use *disability*, the representation preferred by many scholars (Linton, 1998; Overboe, 1999; Shildrick, 2012; Titchkosky, 2006) and activists within the disability community, specifically the disability activists that lead the prominent social media accounts, *Disability Reframed*, *Talk Disability*, *Neuro Different*, *Autistic Truth*, and *Ableism is Trash*. According to Linton (1998), with the use of the terms disability and disabled, scholars and activists have “attempted to wrest control of the language from the previous owners and reassign meaning to the terminology used to describe disability and disabled people” (p. 9). These changes in language serve as representations of social, political, intellectual, and ideological transformations that have occurred within the disability community and CDS scholarship (Linton, 1998). In this way, this choice to use disability itself is a decision guided by poststructuralism. As St. Pierre (2000) further notes in her exploration of the possibilities inherent in the poststructuralist practice of deconstruction, deconstruction is “about looking at how a structure has been constructed, what holds it together, and what it produces” (p. 482).

However, not all scholars and activists use disability or disabled and prefer to employ different terminology, including *people-first language* (e.g., person with a disability) and placeholders for disability like *differently abled*, *physically challenged*, and *special needs* (Shildrick, 2012). No matter the language used, I contend that, in scholarship and in our communities, we must listen to disabled people on disability issues (Disability Reframed, 2021; Talk Disability, 2021), and my personal stance and choice of language reflects this necessity. With this decision, I also acknowledge that not all disabled people are able to use verbal speech to communicate and share their preference of terminology. I do not speak *for* these individuals, nor do the scholars and activists who have selected to use the term disability (Neuro Different, 2022). In many contexts, individuals who do not communicate using verbal speech have access to AAC. As discussed above in the section entitled, "Participation Criteria and Recruitment Process," AAC includes both unaided and aided modes of communication. These modes of communication can take the shape of gestures and facial expressions, writing, drawing, spelling words by pointing to letters, pointing to photos, pictures, or written words, digital applications, and other devices (American Speech-Language-Hearing Association, 2020). As Linton (1998) shares, "Much of the language used to depict disabled people relates the lack of control to the perceived incapacities" (p. 25). However, with AAC, individuals with disabilities can take back that control and advocate for themselves across contexts and determine the language that is used to describe their own identity.

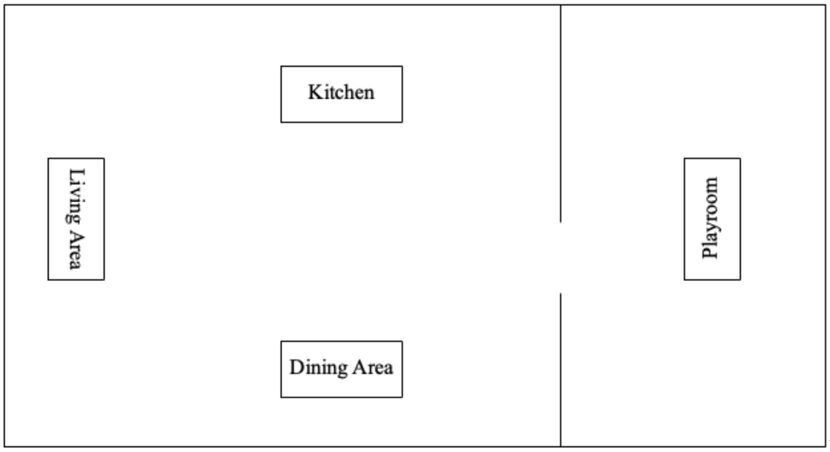
Virtually Shared Familial Spaces: The Smiths' Home

Just as the available terminology associated with disability is vast, so too is the concept of locality in digital ethnography. In digital contexts, locality considers notions of space far beyond physical location and a demarcated territory. Technology has helped to create “a world in which the digital and material domains of our lives are not separate from each other but part of the same lives and world” (Pink et al., 2016, p. 127). In this way, while I was not physically present in the Smiths’ home, I was still able to explore the site materially through digital means. Within the context of digital ethnography, materiality is conceptualized as “the physically apparent elements of places that are knowable and can be known, referred to and identified” (Pink, 2016, p. 127). To contextualize materiality in my own work, I also draw from Goodley et al.’s (2019) poststructural view of materiality within CDS that emphasizes that materiality is always relational. This understanding of materiality considers and expands Pink et al.’s (2016) definition and implores researchers to reconsider what is known, can be known, referred to, and identified within a physical space, particularly when incorporating digital technologies. This complexity of materiality is represented in this study, as the boundaries between the material and digital sites merged and were continually “constituted through the technologies” used by both the participants and I (Pink et al., p. 127).

Within my study, my understanding of familial spaces was informed by Day’s (2010) definition of familial spaces. Day (2010) defines familial spaces as the areas in which family resources, such as eating and entertainment, are managed. A family’s use of space has some predictability but is dependent on the structure of the family (Day, 2010). The Smiths and I collectively determined which spaces were featured in the study during the initial interview. The selected large space is approximately 800 square feet and includes the family’s connected living, kitchen, and dining areas and Narise’s playroom and are featured below in Figure 3.2.

Figure 3.2

Layout of Familial Spaces Observed



Each of these rooms were located on the first floor of the family's home, connected by passageways with no door, and quite open, with the ability to see into all of the other areas or rooms on the same floor. The living, kitchen, and dining areas were all located in one large room. The living area included large, comfy couches with a tv and gaming systems. The family often gathered here at the end of the day. The kitchen area was located behind the living area, where the family could still interact with others in the living area while preparing meals. Similarly, the dining area was located behind the living area, beside the kitchen area. The Smiths ate each meal at a large table in the center of the dining area. Jenny and Narise also completed their distance learning responsibilities at this table, both teaching and learning, serving as an example of the integration of educational and familial spaces during the COVID-19 pandemic (Engel, 2020). The playroom, located through a doorway from the kitchen and dining area, contained all of Narise's book, toys, and games and another large couch. Narise and Jenny could often be found in this room, on the couch or on the floor on a soft blanket, reading Narise's favorite books, completing academic activities, or engaging in art projects. These spaces offered insight into the family's ideologies of disability by providing glimpses into their lives.

Research Methods

This section includes the step-by-step process I used for data collection, management, and analysis. Table 1 in Appendix B contains a timeline with monthly markers for these stages of the research process. Throughout the study, this timeline was subject to change, as both the Smiths' and my schedules changed. These changes reflect the realities of life, as we worked to coordinate multiple schedules across time zones. This variability was expected, as is compatible with the method of case study and research conducted alongside the disability community (Kerschbaum & Price, 2017). Additionally, as Gilgun (1992) notes about qualitative family research, "families are best served by researchers who tailor their research methods to the diversities in which families are embedded" (p. 27). Despite these needed changes, the dates provided in Table 1 reflect the eventual completion of each phase.

Data Sources and Collection

Collectively and individually, virtual interviews, spontaneous conversations, recorded observations, and documents produced data that answered the posed research question: *In what ways do family members and educational stakeholders constitute one another's ideologies of (dis)ability in and across familial spaces?* Together, these sources of data work to generate a "thick description" and layers of detail of the Smiths' ideologies of disability by highlighting many different aspects of their lives (Geertz, 1973). Case study, as a method, is well known for combining multiple and varied sources of data to "capture the case under study in its complexity and entirety" (Yazan, 2015, p. 142). I find that each of these sources of data provide insight into the case. For instance, the educational documentation provided by the Smiths gives an in-depth view of the influential discourses and ideologies of disabilities that circulate within educational contexts and then, ultimately, familial spaces. This information wouldn't otherwise be available or as detailed in other sources of data. When I aggregated and compiled each source of data into one large corpus of data, I was then able to consolidate, reduce, and interpret these varied sources of data and make meaning (Merriam, 1998). Below, I explore the data collection methods I used to gather each source individually, and then, I describe my process of data analysis that analyzed the data set as a whole.

Virtual Interviews and Spontaneous Conversations

Interviews are commonly found in case studies (Yin, 2018) and are important sources of spoken data (Roulston, 2010). Ethnographic and feminist interviewing practices informed the interviewing process in this study due to their unique characteristics. Ethnographic interviewing seeks to "explore the meanings that people ascribe to actions and events in their cultural words, expressed in their own language," while feminist interviewing promotes establishing intimacy and openness through researcher self-disclosure and continual engagement with participants after the conclusion of the study (Roulston, 2010, p. 19). Together, these methods were especially well suited to explore ideologies of disability, which encompass deeply personal conceptualizations of a complex and intimate topic and circulations of power.

Initial and Individual Virtual Interviews. To explore individuals' ideologies of disability and the social and cultural forces that shape these ideologies, virtual interviews were conducted with three members of the Smith family, Jenny, Michael, and Riley, and one educational stakeholder, Mrs. Tammy, as everyday language use is often the vehicle of power relations and hidden ideologies (Cavanaugh, 2020). Engaging with both family members and a select educational stakeholder was imperative to understand the multiple discourses surrounding disability and the interactions between family members and educational stakeholders in and across familial spaces. Interviewing Jenny, Michael, Riley, and Mrs. Tammy allowed all to share their perspectives and to see how discourses and, thus, ideologies differed due to role and experiences of disability. Narise did not participate in her own individual interview because Jenny and Michael felt that Narise would not be able to answer questions on the topics addressed through her use of adaptive sign language and her customized core board. However, Narise was present during both Jenny and Michael's interviews and was asked to participate in answering various questions that were posed and concerned her. Their decision and its impact on the findings are discussed extensively in the section "Ethical Considerations and Limitations," featured later in this chapter.

All individual interviews were either audio or video recorded, took place virtually using the Zoom online communication platform or telecom software, and lasted up to an hour. Although preferred when conducting virtual interviews, the Smith family and Mrs. Tammy did not have to use a video camera during these interviews; the format of each interview was based on participants' preferences. For instance, Michael preferred to use telecom software, rather than Zoom, so we spoke using telecom software one evening. Recordings of the interviews were transcribed following each interview. These transcripts provided "rich detail for analysis" regarding how the Smith family, Mrs. Tammy, and I "co-constructed possible ways of talking about research topics," which, in this context, included disability and family (Roulston, 2010, p. 61).

The first initial interview was conducted with Jenny, because she served as the primary contact for the Smiths during the study and our schedules easily aligned. This meeting was essential to understanding the Smith family's schedule and routines. Together, Jenny and I made logistical decisions for data collection procedures, including establishing the schedule and procedures for future interviews and determining the physical spaces I could observe and how I could observe them. During this interview, we also exchanged personal information that ranged from demographics to individual beliefs and practices involving disability. As Jenny and I discussed each topic, I felt that we began to build a rapport and establish a relationship of trust. The protocol for this first interview is included in Appendix C.

After this initial interview, I conducted individual interviews with each consenting family member, including Jenny, Michael, and Riley, and Narise's teacher, Mrs. Tammy. Jenny participated in both the initial interview and an individual interview, as each interaction sought to obtain different information. Appendix D features Table 2 that contains the date and length of, in addition to the participants included in, all interviews.

During the initial and individual interviews, I partook in "guided conversations rather than structured queries" that worked toward building fluid and natural responses that still advanced my line inquiry (Yin, 2018, p. 118). The openness was inspired by both feminist and ethnographic interviewing practices which often appear highly unstructured (Roulston, 2010). With the freedom afforded by these two interviewing methods, I created open-ended questions based on the phenomenon studied. As evidenced in the interview protocols, (See Appendices E, F, and G), the questions that guided each interview were based on the initial research questions and circulate around questions of disability, family, ideology, and personal experiences.

Follow-Up Interview and Spontaneous Discussions. In addition to the initial interview with Jenny and the individual interviews with Jenny, Michael, Riley, and Mrs. Tammy, a follow-up interview and spontaneous conversations occurred at different points during the study. One follow-up interview occurred after observations and individual interviews had been completed, and Jenny participated in this interview. The follow-up interview with Jenny was shorter in length and addressed specific questions or concerns that she and I had. Specifically, the questions asked during this follow-up interview were based on the data gathered during virtual observations, interviews, and document analysis, in addition to the Smiths' feedback. Jenny had the opportunity to share her own perspectives of the events that were recorded and recount events that I did not observe. The protocol used during the follow-up interview is included in Appendix H.

Additionally, spontaneous discussions randomly occurred between the Smith family and I, as we continued the data collection and analysis process together. These spontaneous discussions took place virtually, either through email, text, or the use of the Zoom platform. During these instances, members of the Smith family and I would initiate communication with one another and ask various questions about our wellbeing, schedules, and data that had already been collected or that would be collected in the future. Most often, the conversations spontaneously occurred before or after a scheduled observation that was conducted using the Zoom platform. Both the follow-up interview and spontaneous conversations were recorded and transcribed and then transferred to my data management system within ATLAS.ti as a part of my corpus of data.

Virtual Observations and Events

While the data drawn from interviews provide a wealth of information regarding ideologies through discourse, interviews and spontaneous discussions cannot be the only sources of information in a case study (Yin, 2018). Observations, too, are critical in providing insight into a research context. In this study, 12 virtually recorded observations were conducted within the home due to the regulations enforced in the light of the COVID-19 pandemic. Table 2 in Appendix D also contains the date and length of, in addition to the participants included in, all observations. These observations, totaling approximately 12 hours, only provided a small glimpse into the Smiths' lives, but I used the observations to delve into the various unseen ways they constituted ideologies of disability in and across familial spaces. Pink et al. (2016) reinforce this claim, as they speak to how "researchers often approach unseen elements of the experience by investigating how they are manifested in these routines and activities of everyday life that can be seen and discussed" (p. 25). For instance, the Smiths did not engage in particular activities while on the screen, but they referenced these same activities and routines during observations. These acknowledgements provided valuable insight into particular ideological positions not immediately visible through virtual observations. The one follow-up interview I conducted, described above, served as an opportunity for Jenny to verbalize her thoughts on the experiences, activities, and routines that I observed and also the events that I did not experience during our time together.

To guide the virtual observations, the creation of an observation schedule allowed for additional collaboration with the Smiths and to limit and bound my observations around pivotal moments throughout the day and week. The observation schedule was determined using Google Forms where I would provide my availability, and the Smiths would then select the multiple dates and times that worked best for them. After they had completed the Google Form, I would email the selected dates to Jenny to confirm. These binding decisions made by the Smiths determined the degree of access I had to their home, and this boundary served as a means to protect their privacy. I believe that having this control influenced their willingness to open their homes and lives for observation (Lightburn, 1992).

All 12 recorded observations were included in my analysis through their presence in my field notes and journal entries, as described below. Data from these 12 observations are often included in my findings, because each moment of the observations informed my understandings of ideologies of disability. However, only seven events were selected for transcription and coded following the steps outlined in my customized analytic framework. This process is described in detail in the following section.

Events. From the 12 recorded observations, I chose seven events that were then transcribed and included as a part of analysis. Before describing the systematic process I used to select these events, I first describe the inspiration behind my rationale for selection. I refer to these select moments as *events*, informed by De Schauwer et al.'s (2017) conceptualization of disability as heterotopian (Foucault, 1967/1998) and Burnett and Merchant's (2020) understandings of literacy-as-event.

Foucault (1998) describes a heterotopia as a site that "is out of place" and "connected to all the other emplacements" or places, events, practices, and relationships (p. 178). In this way, a heterotopia is a space where the different elements present are incompatible to our current reality and do not add up to a logical whole, but these same elements are relational and recognizable from other emplacements. These heterotopian sites, often understood as in opposition to traditional understandings of time and space, then, operate to challenge reality, open up our understandings of societal notions and norms, and bring different ideologies together into one space (De Schauwer et al., 2017). De Schauwer et al. takes up Foucault's concept of heterotopia and encourages viewing disability not through the ability/disability but as heterotopian to "open up disability as multiple, as always emergent, and as intra-corporeal" (p. 2). Thinking of disability in this way, De Schauwer et al. (2017) allows for an individual with a disability to be seen as "capable of transcending the constraints that accompanying his or her embodiment and his or her categorization in a subordinate category" (p. 8). Within the context of this study, an example of a heterotopian event would be familial storytime. During that event, Narise isn't defined by her disability or restricted by any labels. Instead, she is just a child reading a book with her family, and she is free to imagine herself among the characters, adventuring in a reality that exists beyond the confines of her disability.

Similarly drawing upon the poststructural concept of relationality, Burnett and Merchant (2020) revisit the idea of literacy events, first conceptualized by New Literacy Studies (NLS) scholars. Proposing a new term, *literacy-as-event*, Burnett and Merchant (2020) bring forth three related ideas to expand our understandings of the multimodal nature of literacy. First, literacy-as-event is generated when people and things come into relation while engaging with and in literacy practices. The second and third ideas speak to the expansive notions of poststructuralism including "what happens [during an event] always exceeds what can be conceived and perceived" and "implicit in the event are multiple potentialities, including multiple possibilities for what might materialize as well as what does not" (Burnett & Merchant, 2020, p. 49). Literacy-as-event, then, helps us to explore the power that circulates during literacy practices between participants and, ultimately, challenge dominant discourses of the individualistic model of literacy. Examples of the concept of literacy-as-event within this study include the Smiths' engagement in multimodal literacy activities like painting, coloring, and modeling with clay, role playing with various toys and manipulatives, and dancing to music.

Inspired by the work of Foucault (1998), DeSchauwer et al. (2017), and Burnett and Merchant (2020), the events I have selected feature various ideologies of disability whether openly acknowledged or subtly referenced by members of the Smith family and their community. These particular events also challenged me to think of the multiple possibilities that are a part of disability by looking beyond the ability/disability binary and static understandings of disability. With these events, as a literacy educator and scholar, I was also drawn to instances where the Smiths engaged in literacy practices that aided in their multiple and complex understandings of disability. As they participated in literacy practices, I took note of the dominant discourses employed and the ways that power circulated. Examples of these events include overt discussions of Narise's multiple disabilities and prescribed medications, conversations had between all family members including Narise, engagement in inclusive and multimodal literacy-based activities, and daily chores and routines such as unloading the dishwasher or styling Narise's hair.

To select the seven events, I first watched all 12 of the virtual observations and took extensive notes about the activities that were featured, including time stamps for the beginning and end of each activity. Then, I reviewed these notes, highlighting particular instances as guided by DeSchauwer et al. (2017) and Burnett and Merchant's (2020) research. Ultimately, I narrowed down these noteworthy moments to seven events. I conceptualize these seven events as units of observation. Within observations, units help the researcher organize data in preparation for and during analysis (Lofland et al., 2006). Specifically, these units were determined following Lofland et al.'s (2006) idea of *practices*. Lofland et al. (2006) describe practices as "recurrent categories of talk or action on which the observer focuses as having analytic significance" (p. 123). Further, practices are particularly useful in identifying actions that align with "cultural beliefs or individual or collective identity" (Lofland et al., 2006, p. 123). In this way, determining specific reoccurring practices and then choosing to highlight these practices in the seven events helped to illuminate various ideologies that shape the Smiths' actions and discourse, because ideologies, particularly those related to language use, are often shaped by cultural beliefs in addition to individual perspectives (Woolard & Schieffelin, 1994). Table 3 included in Appendix I features detailed information about these seven events and the selection process.

Documents

As recorded discourse and observed behavior can inform findings on ideology formation, documents, too, have the potential to affect participants' understandings. Prior (2003) speaks to the significance of documents serving as data sources by asserting, "documents and the information that they contain can influence and structure human agents every bit as effectively as the agents influence the thing" (p. 3). Families and educational stakeholders within the disability community regularly create and exchange documents that explicitly and implicitly reference a child's disability. These documents impact multiple facets of a family's life and can include but are not limited to Individualized Education Plans (IEPs), medical records, special education referrals, and personal correspondence.

The ideologies housed within these documents can be identified through analysis, as the multiple discourses woven into these documents can be teased out, separated, and used to understand the ideologies present and the circulation of power between and amongst creators of the documents. Analyzing the discourses housed within documents separately can help illuminate the contexts in which each document was created and, in turn, intended to be read (Prior, 2003). This contextual information provides researchers with more than just information about the content of the document. Documents can reveal much about the individuals that create them including the meaning of social situations, how they define these same situations, and how they adapt to them (Handel, 1992). Specifically, when considering disability, documents can display how those who use the documents define disability and make meaning from particular situations that pertain to the disability experience. These definitions and understandings are all a part of the composition of ideologies.

The particular documents selected by the Smith family revealed much about their ideologies and which cultural, social, and historical forces inform these ideologies. While the Smiths chose which documents they would like to share, I offered them examples of documents that could by analyzed, such as notes written between family members, children's drawings and artwork, and emails from educational stakeholders. The determination of these suggestions stemmed from relevancy to the case and my own personal experience within the disability community (Simons, 2009). Ultimately, the documents the Smiths chose to share including the following:

- Annual goals and reports from various subjects, including math and English Language Arts (ELA), and skills, such as speech, handwriting, and language development;
- Individual Education Plan (IEP);
- Individual Program Plan (IPP) from Narise's local social service provider;
- Seizure Action Plan; and
- Brigance Diagnostic Inventory of Early Development II (IED-II).

Table 4 in Appendix J is a compilation of information regarding this documentation, including who created and provided each document and a brief explanation of the purpose of each document.

Field Notes and Journals

Yin (2018) shares that “your own notes are likely to be the most common component of a database,” as they stem from each step of the data collection process and take a variety of forms (p. 131). Similarly, journal entries were also created throughout data collection and were incorporated with the field notes (Roulston, 2010). By engaging in both practices, my field notes and journal entries were woven together and often indistinguishable. Throughout the duration of the study, I wrote 12 separate field notes that correspond with each of the 12 virtual observations. Additionally, I continuously wrote journal entries that I compiled in one large document, and, each time I sat down to write another entry, I would reread and expand upon previous entries and deepen my thinking about my study and research purpose. Together, these sources of data contained my own personal thoughts captured during interviews, observations, ideas for subsequent stages of data collection and analysis, and various questions that arose. These field notes and journal entries were key in helping me interpret my data by accessing “a different sense of understanding” that wasn’t readily available in other sources of data (Simons, 2009, p. 122).

Following the format of my other sources of data, I compiled all my field notes and journals digitally. I systematically transferred my field notes and journals into my database weekly. This database was housed within ATLAS.ti (Mac version 9) Qualitative Data Analysis Software (QDAS), and I discuss my use of ATLAS.ti extensively below. Additionally, this process preserved my field notes and journal entries and made them easily accessible alongside my other sources of data during data collection and analysis (Yin, 2018). Each of these methods of data collection has its own strengths and provides unique and needed insight into four complex concepts: disability, family, ideology, and discourse. The processes used to manage and analyze these separate, yet complementary forms of data are detailed in the following section.

Data Management and Analysis

To manage my data, I followed the guidelines set in place by the university's Institutional Review Board (IRB) regarding data management and storage. These regulations concern data protection and specify that data should be stored safely and securely, and confidentiality agreements must be honored (University of Georgia Office of Research). To store and back up my data, I first housed the data on my personal, password-protected computer. An additional layer of security was guaranteed by storing my data within my personal Dropbox and Google Drive accounts, which are also protected by passwords, and an external hard drive that only I have access to for backing up my data. To uphold confidentiality, Jenny, Michael, Riley, and Mrs. Tammy self-selected their own pseudonyms, and Jenny and Michael selected Narise's pseudonym, as detailed above. These pseudonyms were used in each phase of data collection and analysis. Together, these procedures worked to uphold the requirements of the IRB and my personal commitments to my participants.

Once the data had been collected and stored on my personal devices and secure cloud-based storage systems, I uploaded the data into the ATLAS.ti QDAS. Saldaña (2021) asserts that the purpose of QDAS is "not [to] actually code the data for you; that task is still the responsibility of the researcher" (p. 46). Instead, QDAS is a tool that helps researchers store, organize, manage, and reorganize data to enable analytic reflection (Saldaña, 2021). ATLAS.ti was invaluable in the analytic process, as I moved between and through the various stages of data analysis. Further, Paulus et al. (2017) state that QDAS has the potential "to make the researcher's sense-making process around data analysis more explicit" and, ultimately transparent (p. 36). In the following paragraphs, I hope to make my own analytic process clear by detailing my chosen method of analysis and providing a concise breakdown of each individual stage.

Both Yin (2018) and Simons (2009) allude to the lack of published resources on the analysis and interpretation of data collected using the method of case study. This absence is likely due to the dynamic nature of case study as a method. This freedom allowed me to craft a customized analytic framework that addressed the research questions that I posed and allowed me to explore the complexities of familial ideologies of disability. Saldaña (2021) and Vanover et al. (2021) heavily informed the creation of this modified framework, particularly the design of the five cycles of coding that were enacted. Table 5, included in Appendix K, is drawn from Vanover et al.'s visual representation of the cycles of data analysis and includes details that make up my own steps for each of the five stages.

As Table 5 reveals, the first cycle of analysis employed descriptive coding, as I really become reacquainted with my data. This step was necessary due to the large corpus of data that was collected, piece by piece, across multiple months. Once I organized the data by type and took notes of attributes across the data, I understood how each segment of data built upon and informed the others. During the first cycle of analysis, I also determined the seven events that would be included in the next four cycles of analysis, following Lofland et al.'s (2006) idea of units of observation, specifically *practices*. I then moved into the second cycle of coding. Detailing the integral step between the first and second cycles of analysis, Saldaña (2021) writes, "first cycle coding is *analysis*—taking things apart. Second cycle coding is *synthesis*—putting things together into new assemblages of meaning" (emphasis in original; p. 5). The second cycle allowed me to continue to organize my data topically but also to begin the process of coding in response to my research questions. Similarly, postconventional models within CDS advocate for taking things apart and putting them together into new assemblages of meaning, as many scholars within the field of CDS seek to deconstruct the ability/disability binary and other normative constructs in order to create new ways of being and knowing regarding disability (DeSchauwer et al., 2017).

Next, the third cycle of data began the process of "open" coding which is also known as "initial coding" or "free coding" (Saldaña, 2021, p. 148). This step involved separating the data in discrete categories and exploring complexities (Saldaña, 2021; Strauss & Corbin, 1998). The similarities and differences found led me to discover patterns in my data, a key aspect of the fourth cycle of the coding process. Before proceeding to the fourth step of analysis, it is important to note that the delineation of each of these cycles was not static or always linear. I often returned to a cycle after moving to a subsequent cycle to rethink and reformulate my codes based on new inferences and understandings. The bold arrows, located in between the "Coding" and "Memo" columns represent this recursive process. During the fourth cycle, I employed pattern coding which ultimately facilitated theme development. This stage was much more focused, as I grouped codes and data "into clusters of what 'looks alike' and 'feels' alike'" (Saldaña, 2021, p. 104). While engaging in pattern coding and determining themes, I also continued taking extensive analytic memos which, in the fourth stage, required me to respond to the research questions and to identify representative data for each theme I constructed (Vanover et al., 2021).

The memos written throughout the fourth cycle of coding truly allowed me to "not just summarize the data but to reflect on and expound on them" (Saldaña, 2021, p. 59). These reflections served as the basis for the fifth and final cycle of coding where I applied my theoretical framework of CDS, specifically postconventional models of disability, to my data in order to explain the findings that were formulated in the previous cycle. The fifth cycle allowed me to understand my place in the larger field and how my work is situated amongst previous research and theoretical work. Additionally, it is important to note that, while the fifth stage involved explicitly addressing my theoretical framework to ground my findings, CDS informed every step of my analysis. My theoretical alignment cannot be separated into one cycle alone, as it informed all of my thinking. For instance, in the second cycle of analysis, when I began to develop topical categories, I formulated these categories around concepts integral to CDS, including discourses of disability and normalcy, ableism, and medicalization. This centralization of CDS and disability is woven throughout my work and provided me with the tools to explore the ideologies of disability of the participations.

Alongside acknowledging the influence of CDS in every step of my analysis, it is also important to speak to the complexity of coding data that explores multifaceted concepts like disability, discourse, and ideology, particularly when viewed through a postconventional lens. MacLure (2013) shares, “Coding also tends to take you ‘away’ from the data—from their detail, complexity, and singularity” (p. 196). I experienced this distance when trying to determine codes for such rich and nuanced data, as I didn’t want to lose the context in which the data was produced. Further, I found it difficult to code moments that contained multimodal means of expression, because as MacLure (2015) posits, coding often “ignores the entanglements of language and matter, words and things” (p. 171). Due to this difficulty, I often revisited my codes, as detailed above, to rename codes or recode sections of data to ensure that I captured the contextualized meaning of particular concepts and documented patterns found among these multiple meanings. In this way, I also found coding to be very beneficial in organizing my data into more comprehensible units, and these units helped me to see the relations of power, language, and ideology that ultimately informed my findings (MacLure, 2015). Table 6 and Figures 3.3, 3.4, and 3.5 in Appendix L illustrate the often recursive analysis process in action, including the five cycles used.

Ethical Considerations and Limitations

The ethical considerations and limitations, particularly concerning the digital format of this study, claims of conservatism against case study research, and the limited participation of particular participants, are defining features of this dissertation and were informed by societal necessity, expansive qualitative research methodologies, and participants' preferences. Below, I explore details regarding these ethical considerations and limitations and the roles they played in the context, design, and, ultimately, implementation of the study.

Digital Differences

The COVID-19 pandemic presented and still presents many unique challenges to any research context, particularly when working with the disability community. The disability community is often seen and labeled as a "vulnerable" population in qualitative research (Shaw et al., 2019), despite the negative impact the label vulnerable has on inclusion and acceptance (Antues & Dohest, 2019), and the pandemic has only increased the struggles within the community (O'Hagan, 2020). Not only may individuals with disabilities be more susceptible to contracting the virus due to underlying medical conditions, if present (Centers for Disease Control and Prevention, 2020a), but the social and economic repercussions of the pandemic must also be taken into consideration (O'Hagan, 2020).

Working with the disability community within digital spaces presents new social limitations and possibilities. Offering new means of communication, especially during a pandemic, is one such benefit. Pink et al. (2016) write that digital media creates new and changed contexts and forms of connection, both of which are increasingly needed by many families and individuals within the disability community who are more isolated and separated from others than before the pandemic (Engel, 2020). The implementation of virtual methods not only provides a means to continue research with the disability community, but it also presents new and critical ways to engage in social practices and share experiences.

While the advantages of digitally mediated methods abound, ethical concerns are also raised, particularly when working with “vulnerable” populations. Digital platforms increase this perceived vulnerability in regard to privacy and security, as every internet user can engage in online practices that increase one’s vulnerability (Thompson et al., 2020). Ensuring that all participants were empowered in their representations and presented with multiple choices for participation was key and one way I worked to combat these concerns (Thompson et al., 2020). Additionally, clearly bounding the case and defining the field of research took care, consideration, and collaboration with the participant family. This bounding, as described earlier, was complex, as “research participants live in both online and offline domains, and often do not draw distinctions between the two” (Thompson et al., 2020, p. 3). While I viewed their “online domains” through the lens of a camera, I made inferences regarding their “offline domains” as well. The distinctions between online and offline continuously blurred, but I negotiated these boundaries with the participant family throughout the research process. As I navigated virtual spaces alongside the participant family, I always reflected upon and tailored the research practices to meet their changing needs (Gilgun, 1992).

Conservatism

While the digital differences of engaging in digital case study research can initially seem confining, so, too, can the boundaries of one's case. However, these characteristics only become limitations when perceived and interpreted through a particular lens (Simons, 2009). Fueled by the highly contextual nature of case study research, one such possible limitation is conservatism, which refers to the depiction of only a fraction of a much larger picture in research reporting (Simons, 2009). For instance, within this dissertation, I only included a "fragment of the entire historicity of a family," and this "slice of time" serves as a representation of their entire lives (Compton-Lilly, 2011; Kabuto, 2016, p. 291). As Simons (2009) asserts, many view conservatism as a limitation, because "the case study is locked in time while the people in it have moved on" (p. 24).

However, the nuanced view of reality presented within a case study has the potential to generate meaningful and transformative knowledge across disciplines (Flyvberg, 2006; Simons, 2009). Not to be confused within generalization, the information gathered while conducting case study research can be used to make inferences that are applicable in other contexts (Simons, 2009). Further, it is important to note that formal generalization is often not the aim in case study research and is not the goal of this search. Instead, the objective of case study is often particularization, or to "present a rich portrayal of a single setting to inform practice, establish the value of the case, and/or add to knowledge of a specific topic" (Simons, 2009, p. 24). With this study, my hope is to inform practice, specifically the practices of teacher preparation programs regarding the way disability is positioned and theoretically framed. By presenting the lived experiences of a family within the disability community, this study can directly shape how others, including pre- and in-service teachers and teacher educators, view disability, as a complex, multifaceted concept that is continually and contextually constituted.

Limited Participation

When addressing the topic of generalizability, Simons (2009) asserts that case study research “presents multiple perspectives, interpretations in context, and aspires to directly encounter and re-present the phenomenon it is trying to understand” (p. 167). These characteristics of the method allows the consumers of case study research to expand their understanding of complex social settings and phenomena (Simons, 2009). Within the context of this research, I present the individual perspectives of the members of the Smith family. However, the boundaries for participation determined by the Smith family limited the perspectives that are featured. In particular, Michael and Jenny did not permit Narise to participate in an individual interview. This decision, in turn, heavily impacted ways that Narise made her perspectives known. Without speaking to Narise individually and only relying on observation data and documentation, I was unable to truly learn of her perspectives of disability. Instead, I focus on her actions and multiple other modes of participation to explore the ideologies of other members of her family and her teacher, Mrs. Tammy. This focus is seen throughout the findings presented in Chapter 4.

When working with the disability community, the consent process is complex, particularly when obtaining informed consent from participants with a disability and minors (Ho et al., 2018). When contemplating informed consent with Narise, I “[gave her] caregiver[s] the opportunity to provide their opinion as to whether [she could] understand what the study involve[d] and ha[d] the capacity to provide consent” (Ho et al., 2018, p. 94). When considering what the study involved, Jenny and Michael, Narise’s caregivers, ultimately decided not to allow Narise to participate in an individual interview, but she was permitted to participate in each observation and was present for their individual interviews. This determination was based off their interpretations of Narise's medical diagnoses and observations of her daily routines, and they concluded that Narise would not be able to understand the questions posed and the broader purpose of the study. I respected their wishes, and I believe that my flexibility and the care I took in gaining their consent worked to "overcome barriers [to participation] and build trust and respect" between myself, as the researcher, Narise, her family, and her extended support network (Ho et al., 2018, p. 98).

In addition to Narise's limited participation, Michael and Riley were featured much less in the study, specifically during virtual observations, due to differing factors. Michael often worked long hours and was unable to be present for observations, and Riley did not wish to be filmed during observations but did participate off screen. Describing the often-difficult task of selecting specific methods for family research, Gilgun (1992) shares, "because we recognize familial as diverse groups, we can ask rhetorically, does one method or one perspective—even one qualitative perspective—fit these diversities? Of course not" (p. 27). In hopes to acknowledge this diversity and meet the diverse needs of the Smith family, other methods were used to explore Michael and Riley's perspectives, as they were unable or did not wish to participate in a majority of observations alongside Narise and Jenny. These methods included individual interviews and the collection of documents exchanged by the Smith family and Narise's educational support team, including Mrs. Tammy. While these sources of data were rich and full of detail and provided insight into Michael and Riley's individual perspectives, their contributions to the findings are understandably not as prevalent as Narise and Jenny's, often creating a sense of imbalance in the data presented. However, this imbalance represents the reality of families, as "families are dynamic systems that are reorganized and shaped by multiple factors and environmental events" (Mouzourou et al., 2011, p. 693). This case study highlights this dynamism, as it explores the ideologies of disability and the multiple factors and environmental events that shape the individual and collective ideologies of disability had by the Smiths and Mrs. Tammy.

CHAPTER 4

FAMILIAL AND EDUCATIONAL IDEOLOGIES OF DISABILITY

My findings in this chapter work to answer the question: *In what ways do family members and educational stakeholders constitute one another's ideologies of disability in and across familial spaces?* Specifically, in this chapter, I unpack the familial and educational ideologies of disability that I identified in the digital case study that was designed and conducted alongside the Smith family and a select educational stakeholder, Mrs. Tammy, in and across the Smiths' familial spaces. Although I collected various sources of data that highlight both the familial and educational ideologies of disability, I explore the varied and multiple ways that family members and educational stakeholders separately constitute one another's ideologies of disability within the first and second sections of this chapter. This initial division highlights the power infused in both familial and educational ideologies through the specific discourses employed by the Smith family and Mrs. Tammy. In the third section, I discuss the myriad intersections of these same familial and educational ideologies of disability and the manifestations of these intersections in the lives of the Smiths and Mrs. Tammy.

Familial Ideologies of Disability

The virtual nature of this research heavily influenced the observable familial ideologies of disability. Taking place in 2021 at the height of the COVID-19 pandemic, my interactions with the Smith family, in addition to their interactions with most of their contacts, both personal and professional, took place virtually while the Smiths were in their home. While this single geographical location may initially seem limiting, I was able to discursively explore familial ideologies alongside the participating family through virtual observations and documents shared during our time together within the digital sphere (Pink et al., 2016). This expansion allowed me to take note of the various roles held by each participating family member, the ways these roles were interconnected and supported by other roles, the routines that accompanied their roles, and the conversations within their support systems.

The customized analytic framework, informed by Saldaña (2021) and Vanover et al. (2021), helped me realize the interrelated nature of the family members' roles, support systems, routines, and conversations, and how all of these lived experiences comprise their individual and collective perspectives. Specifically, the five different cycles of coding I conducted allowed me to see how these facets of the Smiths' lives separately and collectively played a part in the constitution of their ideologies of disability. Within cycles four and five, I compiled and consolidated categories and applied my theoretical framework of Critical Disability Studies (CDS) to determine the following theme: *Familial ideologies of disability are informed by familial roles, support systems, routines, and conversations.* This section is then separated into the three smaller subsections, inspired by the initial categories that make up the larger theme regarding familial ideologies of disability: *Familial Roles and Support*; *Familial Routines*; and *Familial Conversations*.

Before I delve into the Smiths' familial roles and their support systems, I must first define *perspective* within the context of this study and how perspectives are related to ideologies, particularly ideologies of disability. Describing ideology's role in educational policy, Leonardo (2003) states, "Ideology is akin to a perspective, one which is inflected, for example, by one's racial or ethnic experience" (p. 211). In this way, one's ideologies are informed by one's perspectives in combination with their individual experiences. However, Leonardo (2003) further asserts that the aforementioned conceptualization of ideologies "lacks the heuristic punch to inform educators of the enabling and disabling way they make sense of the world, not as a given, but as constructed through discourse" (pp. 211-212). Drawing from Leonardo's (2003) understanding of ideology, within this study, I focused on the Smiths' experiences of disability and how their ideologies of disability are constructed through the discourses they engage in and with. Through the various sources of data I collected and the multiple stages of analysis, I also became aware of the Smiths' perspectives and how these perspectives, too, informed the constitution of their ideologies of disability. In the findings below, I acknowledge and explore this vital relationship between perspectives and ideologies when considering disability and expand upon the ways that these perspectives were formed and continue to be impacted.

Familial Roles and Support

Jenny's role of mother and matriarch of the Smith family is central to her perspectives of disability. Jenny revealed that she "makes sure that [Narise's] medical appointments are taken care of," in addition to serving as the individual that "handles schooling as well" (Individual Interview, 2021). These tasks are integral to Narise's wellbeing, both physically and mentally, and are no small feat. Jenny spends more time with Narise than any other family member, and Jenny describes their relationship as "attached at the hip" (Individual Interview, 2021). This closeness and their reliance on one another have significantly informed Jenny's perspectives, perspectives that she admits have continually changed as Narise has grown older and Jenny has learned more about Narise's multiple disabilities. Jenny recounts the following about how she shares Narise's disability with others, "If I'm referring to her, I say she's, um, a child with a disability, not a disabled child because, you know, she's a child first and I don't let the disability, um, define her" (Individual Interview, 2021).

Jenny's perspectives, as informed by her role of Narise's primary caregiver, was also evident throughout the 12 observations and seven selected events. Most noticeably, Jenny's continual use of asset-based discourse and her inclusion of Narise in the completion of daily household chores highlight her perspectives. Throughout her actions and her words, Jenny wishes to let Narise know that she is a vital member of their family and has her own important role. Focusing on language use, Jenny describes Narise as a "big helper" (Event 7, 2021) and tells Narise, "Good job" (Observation 6, 2021), and "I can't do it without you" (Observation 7, 2021). Additionally, Jenny praises Narise and consistently thanks her for her help. For instance, after Narise helped Jenny prepare dinner one evening, Jenny shared the following with Narise, "Thank you for your helping with dinner today. You were a big helper" (Observation 6, 2021). These positive descriptors reflect Jenny's asset-based ideologies of disability, as she is vocally sharing her perspectives of Narise's abilities and important role within their family.

In Observation 6 briefly mentioned above and in Figure 4.1 included below, Narise works alongside Jenny to complete every step necessary to make dinner for their family, including chopping vegetables and measuring oils and spices. Throughout this process, Jenny details each stage of the cooking process aloud, asks Narise if she'd like to join (e.g., "Want to help Mama cut?"), encourages her to practice various skills (e.g., "Show me again."), and guides her hands during these skills using the method of hand over hand. Narise then provides consent to participate in these activities and responds to her mother's requests and encouragement through the use of individual and collective bodily movements, hand gestures, and utterances. When Jenny asks Narise to join her, Narise responds by excitedly saying "Uh huh" and "Aditi," a word she uses to indicate "Again," walking over to join Jenny, and holding her hands out (Observation 6, 2021). Together, Jenny and Narise negotiate their own separate roles, with Jenny acting as a guide for Narise in this instance. As Narise learns more about her evolving familial roles, Jenny's ideologies of disability centered around asset-based understandings of disability and the concept of a shared humanity (Garland-Thomson, 2019) are illustrated.

Figure 4.1: Narise and Jenny work alongside one another to make dinner together.

In contrast to her use of PFL and asset-based discourse in her individual interview and the observations, Jenny also employs the descriptor *special needs*. Specifically, she uses the term when interacting with others, and this context affects her language choices. In the following excerpt Jenny shares how she specifically describes Narise to others when outside of their home and their community:

> So, I mean, I just, I often just tell people my daughter is special needs and if we go places, um, I might ask, "Oh, hey, did you, did you tell somebody that will be at the party, or, you know, a function or something like that?" "Oh, did you tell them [Narise has special needs]?" or, you know, she's very so very, very friendly. So, she takes people's hands and stuff like that. And I just say, "Oh, she's got special needs." And often, they're like "Oh that's fine" (Individual Interview, 2021).

The term special needs directly correlates to Jenny's role in relation to Narise, her perspectives of disability, and, in turn, her ideologies of disability. Often, in public spaces, Jenny feels the need to disclose the many special or specific needs that she sees as Narise having and that must be met. These perceived needs are a very real and intimate part of Jenny's life, and, to Jenny, the term special needs adequately describes this reality.

In addition to the language Jenny uses to describe Narise's disability to others outside their family, her individual perspectives of disability are made evident through the enaction of her support system, specifically the ways that she and Michael support one another in their daily tasks while fulfilling their familial roles. Throughout their individual interviews, the observations, and the documents included in the analysis, this spousal support system is featured, most noticeably in the way that Michael and Jenny share caregiving responsibilities for Narise. Although Jenny and Michael both work full-time, Jenny provides a majority of Narise's care, as she often arrives home well before Michael. However, both Jenny and Michael revealed that, as soon as Michael gets home from work, he also cares for Narise. Jenny said the following regarding the support she gets from Michael in the evenings:

> Um, and then Dad, he's here when he finally gets home, and that's when I go, "Okay, I'm not here, I'm off the clock. Dad's turn. You can ask your dad for the snack, and you can ask Dad to change the TV channel. You could ask Dad to read you the book…" Cause like I said, he works a lot of hours and so he's definitely there and helps me with all the support once he gets here from changing diapers and doing meds and getting her bathed, if I need to, getting her dressed and that kind of thing (Individual Interview, 2021).

In this excerpt, Jenny's language use highlights how she views her role as primary caretaker for Narise and how she sees Michael supporting her in this role. In particular, when Jenny says, "I'm off the clock," and "Dad's turn," she is conceptualizing her role of caretaker as an occupation, one that is completed in shifts. When Michael arrives home from work, he takes over the responsibilities and begins his "shift," when Jenny is "off the clock." While Jenny may see her role of primary caretaker as divided into shifts, Michael sees his role as father and caretaker as never ending.

Michael extensively discussed his perspectives of disability, specifically Narise's disability, in his individual interview and how occupying the role of father and caretaker of an individual with multiple disabilities has changed his life. He coined this perspective as the *always on theory*. He explains, "I have a child, [Narise]. You never stop thinking about her ever, uh, no matter if she's right in front of you or if I'm at work or I could be out of town, she could be at home" (Individual Interview, 2021). To Michael, disability is omnipresent in every aspect of his life. As detailed in Jenny's interview, Michael takes over primary caregiving responsibilities once he arrives home from work. This transition from arriving home from work to begin another type of *work* that requires intense focus and preparation for the unexpected further highlights his always on theory. Whether he is away from home and thinking about Narise or at home physically caring for Narise, he is *always on*. Michael's perspectives of this omnipresence of disability further became apparent during the observations that he participated in. One such example can be seen in Observation 3 when Michael and Narise are outside together.

During Observation 3, Michael and Narise spend time together in the evening after he arrives home from work. Narise walks around while Michael prepares to water the family's outdoor plants. Out of the corner of his eye, Michael sees Narise place a seed from the date palm tree in their yard into her mouth. He turns around and frustratedly says, "Did you pick up one of those things already? Open up your mouth and let me see. Oh, don't eat the plants. Come on, man. You don't waste any time. Do you?" (Observation 3, 2021). Michael walks over to Narise, and she opens her mouth to let him help her get the date seed out of her mouth she had attempted to eat. Jenny hears Michael and Narise's exchange from inside where she is preparing dinner, and she walks outside with a cup of water and to help Michael ensure that Narise will not choke on the hard date seed. This example is featured in the Figure 4.2 below.

Figure 4.2: Michael and Jenny work together to ensure Narise's safety.

In this interaction, Michael's perspective of being *always on* is seen. He is currently occupied with another task, but he still must be acutely aware of Narise, her disability, and how her disability impacts their activities. If he stops being *on*, Narise could be put in danger. This delicate balance is a large part of his role as one of Narise's caregivers and her father. Additionally, during the observation, Michael and Jenny's constant support of one another in their parental roles can be seen when Jenny comes outside to help Michael and, dually, Narise. As evidenced in this brief exchange, Michael and Jenny rely on each other. This interdependent support system inherently impacts their perspectives, as they continue navigating their experiences of disability together.

Michael’s perspectives of disability were further highlighted in his individual interview, as he details the differences he sees between his role of a father of a child with a disability and a child without a disability. Michael shares the following:

> So there’s a different, uh, dynamic parenting, which is associated with my uh, always on theory, because if you have a regular, I would say a child that doesn’t have disabilities like [Narise] there’s a less *on* factor, if that makes sense, because they could, you know, do things… You know, those little things that, uh, sometimes people don’t think about (emphasis added; Individual Interview, 2021).

Michael candidly speaks about the different dynamics associated with parenting his two daughters, Narise and Riley. He openly shares that, with Riley, there is a less *on* factor, particularly compared to being always on when parenting and caring for Narise. To him, Riley can do things—“little things that, uh, sometimes people don’t think about”—like play in the backyard independently while he’s occupied with another activity, and he doesn’t have to “worry about her running into the streets or picking up a piece of rock or dirt and putting them in her mouth” (Individual Interview, 2021). Before Narise was born, Michael reveals that he didn’t have to be always on, both mentally and emotionally as he completes other responsibilities, and he could engage in activities without being reminded of his caregiver role. He further shares, “There’s a part of you that is always on waiting for something, especially when I sleep. I haven’t had a good night’s sleep since [Narise] was born” (Individual Interview, 2021). As Michael shares information about his family and perspectives of disability, an implicit comparison between his daughters Riley and Narise can be noted. While Michael may not be intentionally comparing the two individuals, he is comparing their abilities and setting them apart from one another.

Riley's perspectives of disability, as a sibling, too, are shaped by comparisons. During her individual interview, I asked Riley to describe her family and the roles she occupies within her family, and she openly shared how her interactions as a sibling and with families other than her own have impacted her perspectives. She reveals the following:

> I just think about the fact that, um, if, if [Narise] wasn't [Narise], my life would be so much different. Like I'd have a "normal" sibling who would bother me all the time, and I'd have to take her to the store with her friends, and, you know, it would be so much different. And I never realized when I was younger, I didn't realize the effect having a sibling like [Narise] had on my life and like how our family works. And I see, um, like I have a boyfriend for example, whose sister is the same age as [Narise], and their relationship is so different to me and my sister. Obviously, there's less arguing, but, um, it's just like, it makes their family so much different than mine (Individual Interview, 2021).

As Michael compared Narise to a "regular" child, Riley similarly compares Narise to a "normal" sibling. Through these comparisons, Michael and Riley conceptualize "regular" and "normal" as nondisabled. Riley shares that their relationship is "different" than other sibling relationships and their relationship makes other families "so much different" than her own (Individual Interview, 2021). Moreover, her role as Narise's sibling is different. She admits that activities and interactions with Narise are or would be different than those others experienced by other siblings. Through her role as sibling of an individual with a disability and her relationship with Narise, Riley's perspectives of disability are, too, different.

While Jenny, Michael, and Riley's perspectives have been extensively explored within this section through their roles and mutual support of one another, Narise's own perspectives have only been featured through others' lenses and represented by others' words. For example, when Narise and Jenny prepare dinner together, as illustrated above in Figure 4.1, my initial focus was placed on Jenny's language use, rather than Narise's, despite evidence of Narise's participation in the exchange. This initial oversight is intentional to highlight the ways that verbal communication is often the primary means of participation in research (Ho et al., 2018; Kerschbaum & Price, 2017). However, I wish to push against this exclusive notion and actively include Narise's multimodal participation in this study. Although Narise did not participate in a private, individual interview, following her parents' wishes, she still was an active participant in every observation and present for many of her family members' interviews, as detailed in Chapter 3. Her presence and participation in these aspects of the study informed her families' perspectives and ideologies, as participants often base their responses and roles based on setting and other participants' involvement (Roulston, 2010). From these sources of data, the influence of Narise's familial participation and engagement on others' ideologies of disability can also be analyzed.

For example, while Jenny often occupies the role of teacher, Narise too occupies this role as she provides instruction on the different ways she communicates, particularly through her creation of an adaptive sign language system. This innovative system is discussed in detail in the final section of this Chapter. Additionally, Narise supports other family members, as they make large and small decisions. Throughout each observation, the guidance and direction she provides others is seen clearly in the choices that Narise makes, using multiple modes of communication, and through the consent she provides when she is asked to participate in an activity. Figure 4.3 and the accompanying transcribed excerpt from Event 1 illustrate the ways that Narise is a decision maker within her family.

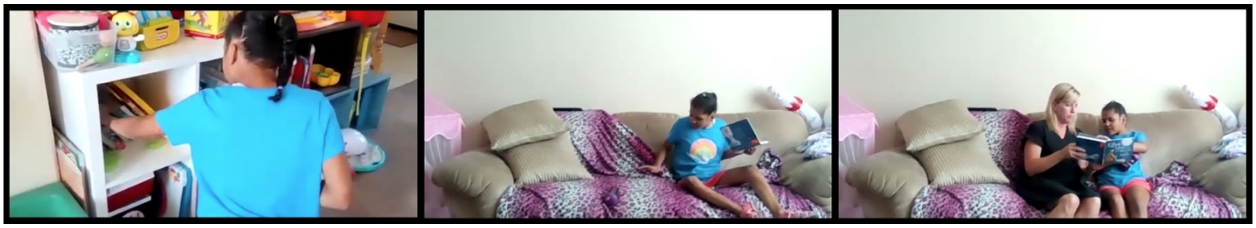


Figure 4.3: Narise selects a story to read with Jenny.

Narise: [Walks over to the bookshelf and kneels to view all the books.] Uh huh.

Jenny: Uh huh. What book are you going to pick?

Narise: [Selects *I Love You to the Moon and Back*, stands up, and turns around to walk toward the couch.] Uh huh.

Jenny: You want that book?

Narise: Yeah. [Sits on the couch, opens the book, and pats with couch cushion next to her repeatedly with her hand.]

Jenny: Okay. [Points to the couch cushion that Narise is patting repeatedly.] You want me to sit right there?

Narise: [Nods her head.] Yep.

Jenny: Okay. [Walks over the couch and sits down next to Narise.] Want me to read?

Narise: [Hands Jenny the book.]

Jenny: [Holds the book and reads the cover.] *I Love You to the Moon and Back*. [Looks at Narise] Want to turn the page for me?

Narise: [Turns the page.]

Jenny: Good job (Event 1, 2021).

In this exchange, Narise is asserting her autonomy through her use of expressive language, including hand gestures and utterances. Narise selects which book she would like to read with

Jenny, *I Love You to the Moon and Back* (Hepworth, 2015) and then indicates where she would like Jenny to sit as they read together.

In addition to the example featured in Event 1, Narise often decides what she and Jenny should have for lunch together, what she and Michael should read during storytime, and the various activities she engages in with other members of her family, like assembling a puzzle, building with blocks, or painting. This independence and ability to communicate her wishes and, further, determine the activity that follows informs her family's perspectives of disability. Narise's additional involvement in decision-making processes and how this involvement shapes her family's ideologies of disability is explored in the "Familial Conversations" section.

Shared Humanity, Comparison, and Inclusion

Throughout the data presented above, the Smiths' ideologies of disability, particularly those informed by the concepts of shared humanity, comparison, and inclusion, are highlighted. In particular, Jenny's discourses can be analyzed to gain insight into her ideologies. Across the data, particularly in her individual interview, Observation 6, and Event 7, Jenny's use of person-first language and asset-based discourse when discussing Narise's disability is notable. With this word choice, Jenny aligns her ideologies of disability with many who support disability rights and justice and actively push against "the stigma of medical diagnoses that frame [disabled individuals'] ways of being" (Garland-Thomson, 2019, p. 91). Many within the field of CDS acknowledge that *People-First Language* (PFL) signifies "a break with older and more evidently stigmatizing terms such as handicapped, retarded, crippled, and so on," (Shildrick, 2012, p. 40) despite more recently falling out of favor. As Garland-Thomson (2019) further notes, PFL semantically works to assert that *people with disabilities* or, in regard to Jenny's language use, *a child with a disability*, leads with "a shared humanity to which impairment is a modification" (p.

92). Jenny's ideologies of disability are centered around the concept of "a shared humanity" with Narise. Through the extensive amount of time she spends with Narise, she shares so many moments with Narise where their shared humanity is highlighted. As they prepare dinner together or clean up toys within their home, Jenny and Narise are experiencing activities that aren't shaped by societal perspectives of disability and the idea of impairment.

When describing Narise to others using PFL, Jenny doesn't wish to define Narise solely by her disability, and she creates a separation between impairment and other descriptors, a discursive move that mirrors the underlying tenets of the social model of disability. The social model of disability, as discussed in both Chapter 2 and Chapter 3, promotes the view that "society imposes disability on individuals with impairments" and the "terms disability and impairment are separated" (Haegele & Hodge, 2016, p. 197). This division of impairment and disability seeks to change societal views of disability, and the language most often used in association to the social model is one way to make this change. The desire to be a part of this change is reflected in Jenny's choice of language. Intertwined are Jenny's language use, her perspectives, her role as a mother of a child with multiple disabilities, and, ultimately, her ideologies of disability.

As Jenny encounters varying societal views of disability, her unique perspectives stemming from her familial roles of mother, matriarch of her family, and primary caretaker of Narise inform her language use. In different contexts, Jenny chooses to employ different terminology, such as special needs, when referring to Narise in public spaces. The term special needs has a complex history within the field of CDS and was once viewed as a "more positive designation" (Shildrick, 2012, p. 40) and is still used widely among families and educators. However, many within the disability community discourage its use and instead advocate for

PFL, because they see special needs as failing to "encompass the significance of disability" (Shildrick, 2012, p. 40).

The complexity of language and discursive choices displayed by Jenny is similar to the continual advancement and progression of disability discourse. Shildrick (2012) illustrates this movement when she writes of the policing of language that occurs both within and outside the disability community and "the illusion of perfect terminology" (p. 40). The illusion Shildrick (2012) describes has been reinforced by modernist ideals that uphold metanarratives, totalizing definitions, and singular discursive choices (Lyotard, 1979/1984, p. xxiv). As St. Pierre (2000) shares, "Theories of language in humanism generally accept the idea that there is a correspondence, an identity, between a word and something in the world" (p. 480). However, as poststructuralists attest, life and language aren't that simple. Neither is disability.

Whether using PFL or the term special needs, Jenny uses the discourses that are available to her. Her decisions regarding her language use describes her experiences and perspectives as a mother of a child with multiple disabilities and is based on her social context. If viewed through a postconventional lens, no term that Jenny employs is ever truly wrong. de Saussaure's theory of language informs this view, as "the meaning of the signified is never fixed once and for all but is constantly deferred" (St. Pierre, 2000, p. 481). The fluidity of the language used by Jenny doesn't follow a set of conventions or rules often set by the academic or activist community (Ladau, 2021; Shildrick, 2012). Instead, her discourse surrounding disability is unique to her role, her surroundings, and her individual perspectives of Narise's disability, and, simultaneously, Jenny's discourse is also framed by the larger social discourses she engages in.

In regard to other members of the Smith family, Michael and Riley's roles and individual perspectives also shape their ideologies of disability. Michael's perspectives bound within his always on theory speaks to his ideologies of disability. In particular, Michael sees disability as woven into every aspect of his life, as he must constantly remain always on, whether physically with or without Narise. Scholars within the field of CDS similarly address the same phenomenon experienced by Michael in regard to the omnipresence of disability in his life but focus on how normalcy and the accompanying ideals are insidious in society. From a postconventional stance, not only is disability constructed continually in the lives of those within the disability community, but for all of society more broadly through discourses and practices. Further, normalcy is constituted alongside disability (Goodley, 2014).

As explored in his individual interview when Michael describes his perspectives of disability, he also makes a comparison between his daughters, Riley and Narise. To explain the ways that he understands disability, he situates the concept of normalcy in direct opposition to disability. Riley also references this dichotomy when she details her family and the ways they different from “normal” families (Individual Interview, 2021). With the use of CDS as a theoretical framework, a reliance between disability and normalcy in the Smiths’ lives is made apparent. Goodley (2014) explores this symbiotic relationship in society more broadly when he writes of disability and ability. He includes, “Disability only ever makes sense in relation to ability: traces of ability can always be found in thoughts of disability and vice versa” (Goodley, 2014, p. 58). Individuals, like Michael and Riley, use ability and normalcy to make sense of disability. The dual constitution of disability and normalcy makes itself known through various means in Michael and Riley’s lives and substantially informs their ideologies of disability.

Through his *always on theory*, Michael makes sense of the ways his life has changed since the birth of his disabled daughter, especially compared to his life when he had only a child with no disabilities. To him, disability is not only omnipresent; it also represents new and different demands—all of which are consistently changing from moment to moment. Michael must remain *always on*, existing in a state of heightened alertness, because he never knows how disability may present itself within a particular context. Woodyer (2008), drawing from poststructural concepts, speaks to the unpredictability of the body and disability when sharing, “The body, the subject, is never fully determined; not bounded, but provisional, relational and enacted, in constant dialogue with objects, environments, spaces, times, and ideas” (p. 353). Michael’s understandings of disability are, too, “relational and enacted, in constant dialogue with objects, environments, spaces, times, and ideas” (Woodyer, 2008, p. 353), as he cares for his daughter from day to day. Michael’s *always on* theory illustrates how his ideologies of disability are both continually constituted and realized through comparisons informed by dominant discourses of both disability and normalcy.

To Riley, disability represents difference. As she observes others’ interactions with their siblings, she is noticeably wistful and notices that her relationship with Narise diverges from these traditional expectations of sibling interactions and relationships. In her explanation of her relationship with Narise, Riley compares her experiences with Narise and observations of other sibling relationships. This comparison has informed Riley’s perspectives and affect how she carries out her role as Narise’s sister. Her perspectives illuminate how comparison can inform the constitution of ideologies of disability.

While Riley may use comparison to conceptualize her sister’s disability, Narise continually pushes against dominant narratives of disability, as she maintains her agency and autonomy by frequently participating as a collaborator in her family’s decision-making processes through the use of multimodal expressive language. Following a poststructural reconfiguration of disability and agency, autonomy is understood “not [as] a static trait that resides wholly within the individual but is continually practiced within relations and wider social contexts" (Graby & Greenstein, 2016, p. 228). Within the disability community, the quest for autonomy is a key component of the fight for disability justice, but there is conflict over what is meant by the term *autonomy*. Most recently, theorists have returned to the social model of disability and understood autonomy as *relational* and varying context by context, often involving the support of others when needed and when requested (Graby & Greenstein, 2016).

Narise's enaction of *relational autonomy*, with support from her family members, informs their perspectives of disability and, ultimately, shapes their ideologies of disability. Narise continually reaffirms her position within her family and holds a role that combats medicalized views of disability that seek to deny her and other disabled individuals' privacy and autonomy (Graby & Greenstein, 2016). In this way, the Smiths' familial ideologies of disability are shaped by Narise inclusion in their family's decision-making processes, both large and small. Within the Smiths' home, disability doesn't mean exclusion from everyday activities or the denial of autonomy.

Based on the large amount of time she spends with Narise, Jenny's ideologies of disability go beyond the medical model of disability. While Michael and Riley both share that Narise's disability has impacted their lives and shaped their perspectives, their ideologies are distinctly different due to their varying roles, relationships, and time spent with Narise. Although Jenny's ideologies sit in opposition to the medical model of disability, the Smiths' collective experiences aren't devoid of these damaging and often confining perspectives of disability. Throughout the data collected, medical discourses are a prominent force that impacts the Smiths' perspectives. In particular, the presence of medical discourse is intertwined with disability discourse and overwhelmingly evident in the Smiths' familial routines. These routines are interconnected to their roles, support systems, and familial conversations and inform their ideologies of disability in powerful ways.

Familial Routines

The presence of medical discourse is seamlessly woven into the Smiths' daily discourse as seen in their familial routines. Both Jenny and Michael have extensive knowledge of Narise's multiple disabilities, and, specifically, Jenny has done independent research on Narise's available treatments, therapy, and medications. The countless hours of work that she has dedicated gives her the tools, specifically the discourse, to participate in conversations with medical professionals. From the information she has gained while routinely conducting research, she is able to employ medical discourse, and her use of this discourse was made evident early in her individual interview. This discourse ultimately shapes her perspectives of disability, and the time spent researching disability has assuredly informed these same perspectives. This desire to expand her knowledge of disability stems from the need to advocate for Narisse at various medical appointments and meetings. These medically oriented events have become a part of the Smiths' routines and experiences of disability, as they consistently travel to specialists across their home state.

Jenny revealed that she has saved all of the documentation involved in these appointments and meetings and her reasoning for creating this record keeping system in her follow-up interview:

> [Our recording-keeping system] actually becomes a reference. Um, there have been times where, for instance, when we first found out about the artifact, when we did the um, amniocentesis, you know, it was just an artifact, and so I had that paperwork, but then later we found out that there was more to it, and I was able to go back to that paperwork

> and just, you know, I try to line things up, and so I just, I keep it because you never know if something might change or a doctor might ask us about a diagnosis (Follow-Up Interview, 2021).

Narise’s medical documentation has become a shared living document for the Smith family and their extended community, as they are continually adding to their records based on Narise’s and their continued journey with disability. These records can and will serve as a resource not only for Jenny, but for Michael, Riley, educators, medical professionals, and other caretakers who will one day care for Narise. Moreover, these same individuals, all a part of the Smith’s support system, can become cocreators of the living document by contributing to the records and notes, and, ultimately, they can participate in advocating for Narise in meaningful ways. Through this participation, others become a part of the Smiths’ familial routines and their perspectives of disability, too, are shaped by medical discourse.

Additionally, while detailing her self-guided research, Jenny noted, “…I’ve highlighted, written notes, when I was learning what stuff meant, because there was a lot of terminology that I didn’t know what it meant” (Follow-Up Interview, 2021). In this way, Jenny becomes a coauthor of the living document that houses Narise’s medical information. She rewrites the text whenever she receives or learns new information. She is documenting her own perspectives of disability and her journey to understand the varying terms that are employed in various contexts when discussing Narise’s disability. This journey is ongoing, as detailed in the “Familial Roles and Support Systems” section above and evidenced by Jenny’s changing language use. This documentation and accompanying research processes have become an important part of her routine as a mother of a child with multiple disabilities. With each new passing medical appointment or procedure, Jenny must continually research new terminology and its meaning in relation to Narise's disability. As her repertoires expand, so do her perspectives of disability.

Alongside medical discourses, much of the Smiths' individual and collective routines revolve around medication and medical procedures. At specific times of each day, the family stops whatever they are doing to participate in the process of giving Narise her daily medications. These events may seem like a major interruption to those outside of the disability community but providing Narise medication has now just become a part of the Smiths' lives. For instance, in Event 2, excerpted below and featured in Figure 4.4, Michael and Narise briefly pause their story time so Jenny can administer Narise's needed medication at the scheduled time, noted by an alarm on Jenny's phone. In this specific event, Narise had just selected a book, *Mr. Brown Can Moo! Can You?* (Dr. Suess, 1996) for she and Michael to read together. However, right before they are about to begin, Narise must first take her medicine. The two briefly pause while Jenny gives Narise her medicine using a syringe, and Narise then drinks some water before they begin the story.

> Michael: Yeah, I know, baby, I know.
>
> Jenny: Did she pick that one out?
>
> Michael: Yes, why?
>
> Narise: [Covers her face with her hands, Narise's adaptive sign for requesting water.]
>
> Jenny: Because she had me read that. Come here. Open. [Jenny gives Narise her liquid medication in a syringe.]
>
> Narise: [Opens her mouth to take the medicine and makes a face of disgust when she swallows and turns away briefly. Then, she finishes taking the medicine.]

Michael: Good job. [He opens the book and read the title.] *Mr. Brown Can Moo! Can You?*

Jenny: You hold it. [Narise] hold it. [Jenny gestures for Narise to hold her own water cup.]

Michael: [Narise] hold it.

Narise: [She grabs the water cup from Jenny and takes a sip.]

Michael: Oh, the wonderful things Mr. Brown can do… (Event 2, 2021)

Figure 4.4: Michael and Narise pause storytime, so Jenny can give Narise her medicine. During this exchange, the commonplace nature of the administering of medicine is highlighted. Narise's disability and all of the accompanying medical routines have become such a large part of the Smiths' lives.

In addition to medical routines specific to Narise's disability, the Smiths also engage in routines that many other families experience, including physical activities like swimming, bike riding, and walking, traveling, spending time with family and friends, holding game nights, and having dinner together every evening. However, these events are similarly shaped by Narise's disability. During her individual interview, Riley details her perspectives of this time spent with family and how Narise's disability informs the ways these activities are carried out. She shares:

> We always eat dinner together. Like I noticed that some of my friends' families don't even have a dinner table or they just like take their food to their separate areas and stuff. But um, my mom and dad, they really value like family time at dinner time. And we have all types of conversations sometimes [that] are super stressful. Like we're talking about the future and stuff and sometimes they're like fun, but we always have dinner together. And in the beginning of quarantine, we use to do game nights every night… We'd play on the Wii and we'd play Board Game Island, and we'd do mini games, and [Narise] would sit there and watch us play games, 'cause, you know, she can't really play with with us, but she could, she can sit there with us and like just have fun. Like when, when we get excited, she gets excited and then we're all jumping up and down and stuff (Individual Interview, 2021).

As Riley mentions, their familial conversations are sometimes difficult due to the topics addressed, including the future, specifically who will care for Narise after Jenny and Michael are no longer able to. Riley further stated, "I actually had this conversation with them not too long ago, because, um, as they get older and as she gets older, someone is going to have to take care of her when they can't anymore" (Individual Interview, 2021). Topics such as these may not often be a part of the conversations had by families outside of the disability community, but they are routine for the Smiths. Riley's perspectives are informed by these "stressful" conversations, and her ideologies are then shaped by these perspectives. Currently, she views disability as a concept that causes tension and anxiety, and these perspectives are informed by the ways her parents frame these familial conversations. Riley revealed, "But I told them, I said, you need to start letting me in on stuff that happens with her that I don't know about, because they don't want to stress me out" (Individual Interview, 2021).

Narise also participates in these types of conversations by employing different modes of communication. In Observation 3, after Michael and Narise water the plants together, Narise sits down for dinner with Jenny and Michael, while Riley is at sports practice. In this particular instance, Narise engages in a multimodal conversation with her parents, as they ask about her food and her wellbeing. Earlier in the day, Narise had experienced a series of intense seizures. Emergency medical events such as these, stemming from her multiple disabilities, affects the ways that she can and chooses to communicate with others. However, she still participates in their familial routine of gathering for dinner, and she communicates multimodally in the conversation they all have together. Figure 4.5 and their exchange, included below, features Narise's participation in this familial routine:

> Jenny: [To Narise] Is it still hot?
>
> Narise: [She looks at Jenny but doesn't eat.]
>
> Jenny: [She brings a piece of Narise's broccoli to her mouth to test the temperature and puts it back on Narise's plate.] Did I give you both napkins? I did.
>
> Michael: Yeah, so, I mean, we were really smoked today, knocking out everything at work.
>
> Narise: [She looks at Jenny and smiles.]
>
> Jenny: [To Narise] You sure you're okay?
>
> Michael: [To Narise] A little nibble?
>
> Narise: [She looks at Michael and begins to eat] (Observation 3).

Figure 4.5: Narise, Jenny, and Michael sitting down to have dinner together.

During this observation, Narise is noticeably tired and doesn't feel well, as she is still exhausted and recovering from her seizures that she experienced earlier that day. She doesn't employ many of the modes of expressive language that she typically does, as seen across observations, including single-word utterances, hand gestures, and adaptive sign language. Instead, Narise relies on her facial expressions, prolonged eye contact, and minute body movements, such as turning her head, to relay her thoughts.

Advocacy, Acceptance, and Engagement

Together, in the ways they engage in their various familial routines, Jenny, Michael, Riley, and Narise often resist the dominant discourse surrounding disability that view difference "as exceptional, rather than to simply be part of a multiplicity of possibilities" (Shildrick, 2012, p. 31). The dominant discourse, based solely on normative and deficient understandings of embodiment, separates disabled individuals from the nondisabled and positions them as distinctly different (Shildrick, 2012). In the interviews, observations, and events explored above, the Smiths advocate for Narise using medicalized language, accept her varied medical needs, and encourage her multimodal participation in their familial routines. Continually, they are conceptualizing disability differently, despite the stringent influence of medical discourses and the medical model of disability that is so ingrained in their lives. With these understandings, the Smiths' ideologies are primarily concerned with advocacy, acceptance, and engagement.

Individually, through the compilation and editing of Narise's medical documentation, Jenny asserts her ability to affirmatively participate in medical discourses surrounding disability. As discussed in Chapter 2 and Chapter 3, medical models of disability "conceptualize disability as a biological product" (Haegele & Hodge, 2016, p. 195). Jenny works to transform the medical discourses in the documentation that are traditionally authoritative and limited into opportunities for advocacy for her daughter. This transformation entails interpreting dense jargon, creating personal notations, determining immediate and long-term implications regarding Narise's care and wellbeing, and considering the steps she and her family can take to help Narise. This information then helps her advocate for new and innovative medicines, surgeries, and treatments. Jenny shared the many different possibilities she's advocated for and included, "So, we are on, oh goodness, the 11th, 12th med that we've tried throughout the years. We've done, um, brain surgery… Uh, that was when she was five and now, she has a VNS implant" (Follow-Up Interview, 2021). With these actions, Jenny becomes a part of a larger movement of parents and other family members that are empowered in their caregiving roles and extend the call for disability rights and justice (Goodley et al., 2019).

Through their work, this part of disability community is "reclaiming a humanist normative understanding of human capacity" and moving discourses away from individualized and medicalized stances (Goodley et al., 2019, p. 988). Similarly, Jenny's perspectives have shifted, as she has learned more about disability and she and her family have continued to experience disability in multifaceted and differing ways. Her ideologies of disability have evolved into an ideology of a “shared humanity” (Garland-Thomson, 2019, p. 2), as discussed in the section above regarding familial roles and support systems. Although she participates in medical discourses, she doesn’t adhere to the medical model’s core beliefs. Instead, her actions and discourse follow a Foucauldian view of society, culture, and disability, specifically the idea of *biopower*. Within the politics of biopower, individuals “know more about their embodied and physical failings and realize they are expected to do something about it” (Goodley, 2014, p. 63). With this medical knowledge, Jenny intends to make change in her daughter’s life, influenced by her unique ideologies of disability.

Through their engagement in familial routines, Michael and Riley’s perspectives have also shifted. They both participate in these routines that are so deeply impacted by disability. For instance, Michael understands the large role disability plays in his family’s lives and, more specifically, their routines. In Event 2, explored above, Narise and Michael sit down to read a book but must immediately pause their activity for Jenny to administer Narise’s medication. This is not a big ordeal with anger or frustration expressed by those involved. Michael simply stops reading the book, supports Narise as she takes her medicine, and then immediately jumps back into storytime. Over time, disability has become a part of their routine, almost indistinguishable from other aspects, as it is tightly woven within their familial activities. Similarly, when discussing the game nights her family held during the COVID-19 pandemic, Riley asserts that Narise can “just like have fun” (Individual Interview, 2021). Narise may not engage in games as others would, but she still shares the joy that is a part of the experience of family game night and jumps up and down with her family when they get excited. To Riley, even though Narise isn’t a “normal” sibling, Narise’s disability is an integral and inseparable part of her and her family’s “normal” routine (Individual Interview, 2021).

As a vital member of her family, Narise constitutes her family’s ideologies of disability. Both Event 2 and Observation 3 highlight how Narise shape’s her family’s ideologies of disability through her expanded, multimodal participation in familial routines, including the use of adaptive sign language, eye contact, and facial expressions. In Event 2, Narise uses her adaptive sign language to request water to have after taking her medicine. Observation 3 shows Narise employing intentional eye gaze and facial expressions to confirm she’s listening and understanding her family’s conversation. As seen with the Smith’s familial roles, Narise’s participation in familial routines is not limited, and disability does not prevent Narise’s participation. Instead, the Smiths’ participatory frameworks for their familial routines are expanded and include multimodal means of expression.

Familial Conversations

Understandably, many of the Smith family’s conversations revolve around disability, as evidenced by its presence in and influence on their roles and routines and explored at length in the sections above. Yet, the inclusion of disability in their discourses often has different purposes, and each member of the family has different intentions when discussing disability informed by their differing perspectives. These intentions and perspectives represent individuals’ ideologies of disability. Two events that were selected for inclusion illustrate these differing intentions. As detailed in Chapter 3, all events were chosen using a systematic process informed by the postconventional scholarship of DeSchauwer et al. (2017) and Burnett and Merchant (2020). The seven events all feature varying ideologies of disability, highlighted through the Smith family’s roles, routines, and conversations.

The first event discussed in this section, Event 6, features a familial conversation between Michael, Jenny, and Narise. While Narise only verbally communicates briefly during these two cited events, I found it important to include her multimodal contributions to the conversation, because she is an "active participant, not only as a subject, but also an as initiator, doer, writer, and disseminator of research" with her own valuable perspectives of the disability experience (Walmsley & Johnson, 2003, p. 9). This decision is a vital element of inclusive research practices (Aldridge, 2014). In the familial conversation included below and in Figure 4.6, Michael, Jenny, and Narise weave together multiple subjects and modes of communication:

> Michael: What is this? I don't think I've ever seen this.
>
> Narise: [Looks at Michael and places more base ten blocks into the box.]
>
> Jenny: There. [Directs Narise to connect the blocks before placing them in the box.] I brought it from work, so she could connect them. You know she's quick with it.
>
> Michael: Yeah.
>
> Jenny: The rest we could probably have you just put away however you want to instead of putting them together.
>
> Narise: Uh huh. [Continues placing base ten blocks into the box and sits in Michael's lap. She then looks up at him.]
>
> Michael: She seems to be doing better.
>
> Jenny: Yeah, she's been eating good today. After I gave her, well, gave her the clonazepam and then she still had two after that.
>
> Michael: I counted two.
>
> Narise: Uh huh. [Gets up on her knees to look at Michael and make eye contact.]

> Jenny: …And then she slept till I think almost 11:30. And then once she woke up and she wanted to eat. And once I knew she was eating, then I knew she'd have a better day.
>
> Michael: Right.
>
> Jenny: [To Narise] Say we played outside a little bit today, took a shower… Want to put the rest in? Mommy's having fun building.
>
> Narise: [Looks at Jenny and begins placing the blocks back in the box again] (Event 6, 2021).

Figure 4.6: Narise, Jenny, and Michael all engage in conversation about both disability and the base ten blocks.

During the event, Michael arrives home from work, and Jenny and Narise are putting away base ten blocks. Jenny brought the blocks home from her own classroom to use in strengthening a variety of Narise's academic and fine motor skills. While cleaning up the blocks, Michael, Jenny, and Narise all discuss how Narise has done today, following a cluster of seizures the night before. By saying "Uh huh," Narise confirms Jenny's description of their day, including Narise's wellbeing. Further, Narise gets up off the floor to look in Michael's eyes as she confirms the frequency of her seizures after taking medicine. These acts of deliberate multimodal communication highlights Narise's continued participation in familial conversations. As the conversation progresses, it becomes hard to distinguish between the two subjects, as Michael, Jenny, and Narise switch rapidly between discussing the blocks and disability. Additionally, they employ multimodal means of communication, including verbal speech, physical touch, and other bodily movements.

Noticeably, Jenny and Michael's eldest daughter, Riley, has been often absent from the observations and dialogue, like the event and conversation explored above. As discussed in Chapter 3, Riley made the decision to participate in the individual interview and be present in the observations but out of the view of the camera. She didn't share the reasoning behind her decision, but I respected her wishes. The following excerpts, featured in Event 7, and Figure 4.7 are one example of Riley's participation in familial conversations:

> Narise: [Holds a bag of apples in her hands.]
>
> Jenny: [Speaks to Narise] Oh, are you grabbing an apple? Oh, are there apple slices you didn't finish?
>
> Riley: [Speaks to Jenny] Yeah, they're in the fridge. They're a little brown, but she'll be alright.
>
> Narise: Uh huh.
>
> Jenny: [Speaks to Narise and opens the fridge] Yeah? There's already some apple slices here. [Grabs apple slices out of the fridge to give Narise.] Can you put that back please? Go put it back where it goes. [Speaks to Riley] Well, that's why I started leaving them in

the plastic bag, ‘cause she would just take apples, take bites of it, and put them back in the basket.

Narise: [Places bag of apples back in basket.]

Riley: [Speaks to Jenny.] Sick.

Jenny: [Speak to Riley] And then I would find apples later on. [Speaks to Narise.] There you go. Yeah.

Narise: [Looks at Jenny and eats an apple slice.]

Jenny: We love our apples. (Event 7, 2021).

While Narise searches for apples, Jenny and Riley discuss the location of apples that have been prepared for Narise and share why they now serve and store apple slices in this particular way. By holding the bag of apples, Narise indicates that she would like an apple for a snack, and Jenny acknowledges her choice and helps her find the apple slices that have been prepared for her. Then, Jenny and Riley speak about Narise as if she isn’t there and discuss Narise’s past behavior. Similarly, later in their conversation, Jenny and Riley continue to follow the same patterns in their discourse:

Jenny: [Speaks to Riley.] Don’t show her the C-H-E-E-T-O-S, ‘cause I do not wanna clean that up.

Riley: Huh?

Jenny: C-H-E-E-T-O-S.

Narise: [Walks over to the fridge, opens the door, and looks inside for another snack.]

Riley: Oh, nuh uh.

Jenny: Don’t show her those. I don’t wanna clean that up.

Riley: I was like, pardon?

Jenny: [Speaks to Narise.] What are you showing me now?

Narise: [Looks at Jenny.]

Jenny: [Speaks to Riley and points at Narise's leg.] Little Miss Missy with her leg.

Riley: [Speaks to Jenny.] She's so full of attitude.

Jenny: Can you close the fridge please? You've already had your chocolate milk today.

Narise: [Closes the fridge] (Event 7, 2021).

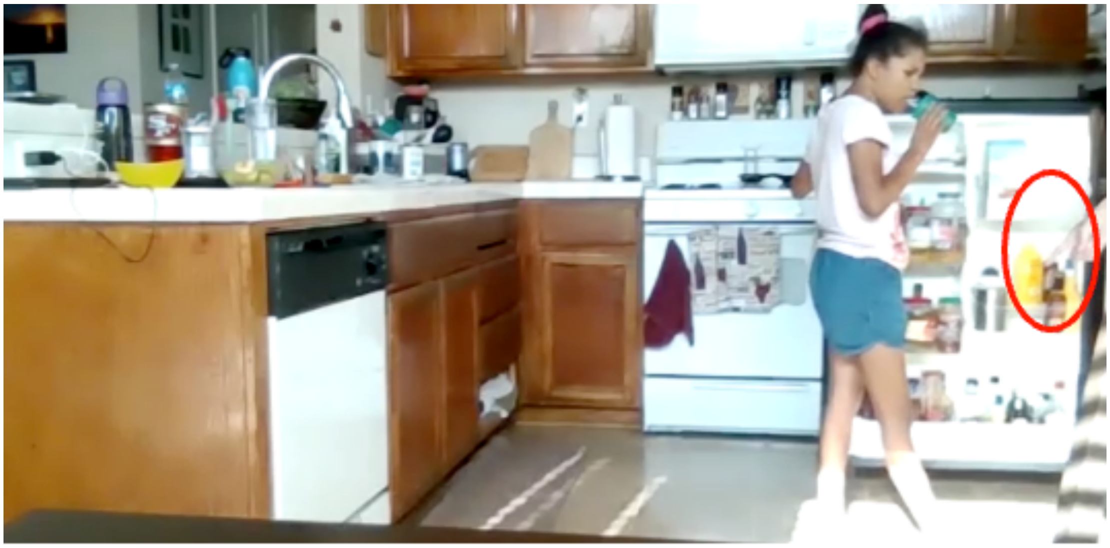


Figure 4.7: Jenny points at Narise while she engages in conversation, with Riley who is off camera, while Narise listens.

During this part of their conversation, Jenny and Riley continue to discuss available snacks, and Riley contemplates what she would like to eat from the options available in the fridge. Their discussion is interspersed with noticing of Narise's behavior and attitude.

Disruptive Moves and Everyday Ableism

In order to explore the Smiths' ideologies that are present in the events included above, a deeper analysis of their conversations is warranted. Within the first featured event, Event 6, Jenny and Narise share specific details of their day with Michael. Jenny employs medical discourse when she references Narise's medication, and Narise, Jenny, and Michael address

Narise's seizures and their frequency. Narise makes it known that she is listening to their conversation and actively participating by inserting "Uh huh," to confirm Jenny and Michael's statements regarding her health, maintaining eye contact with others while they are speaking, and positioning her body to initiate physical contact. Simultaneously, Narise, Jenny, and Michael all are also exploring a new toy and activity.

During this conversation, Narise, Jenny, and Michael acknowledge the impact disability has on their lives while participating in an activity that, in all appearances, seems so very *normal*. In this instance, Narise, Michael, and Jenny highlight how humanity and disability are intertwined within their lives and, more broadly, the lives of those within the disability community (Goodley et al., 2016). Again, the Smiths' ideologies of disability are connected to the concept of a "shared humanity to which impairment is a modification" (Garland-Thomson, 2019, p. 92). Goodley et al. (2016) expand upon the phenomenon of a shared humanity and state that moments like these "acknowledge the possibilities offered by disability to trouble, reshape, and re-fashion traditional conceptions of human…while simultaneously asserting disable people's humanity (to assert normative, often traditional, understandings of personhood" (p. 2). As they communicate with one another, Michael, Jenny, and Narise discuss the disruptive potential of disability by recounting Narise's experiences with seizures. However, this disruption doesn't keep the Smiths from asserting their shared humanity and engaging in activities that can be viewed as normative and traditional, like playing with base ten blocks as a family. While Narise's disability does disrupt their days and nights, as she has seizures, disability is also a very real and human part of who Narise is and who the Smiths are as a family. This familial conversation is informed by Michael, Jenny, and Narise's perspectives of disability as a multifaceted part of their lives.

I must also acknowledge that I understand that Goodley et al. (2016) presumedly did not intend for the term *disruptive* to be taken quite so literally. Yes, *disruptive* can be understood as a middle of the night cluster of seizures, but it can also represent a dramatic shift in perspective. In their scholarship, *disruptive* is meant to promote a postconventional stance regarding disability and read as an opportunity to “trouble, reshape, re-fashion liberal citizenship” and normalcy (Goodley et al., p. 3). However, I feel that it is important to note that *disruptive* can and does represent both possible meanings in the lives of those within the disability community. Disability is complicated, unexpected, painful, and difficult, but disability is also beautiful, transformative, and full of so much possibility and becoming. This plurality is the heart of postconventional understandings of disability, and, as highlighted in this one conversation had by Jenny, Michael, and Narise, the perspectives and, ultimately, the ideologies of disability had by a majority of the Smith family.

In the second familial conversation explored above in Event 6, comments like Riley’s “Sick” and “She’s so full of attitude” and Jenny’s “Little Miss Missy” are examples of Riley and Jenny’s joint decisions to speak about Narise as though she is not a part of the conversation, despite Narise’s continual multimodal participation in their collective exchange. With their discursive decisions, they are engaging in *everyday* or *minor ableism*. Everyday ableism can take shape in a variety of ways, including “talking to a person with a disability like they are child, talking about them instead of directly to them, or speaking for them” (Eisenmenger, 2019, n. p.). As signified by the descriptor *everyday*, most often, individuals are not even aware they are participating in everyday ableism, because it is woven into the fabric of their day to day lives. Riley and Jenny, too, may be unaware they are engaging in this damaging practice, as it is such a routine part of their familial discourse. Their ideologies of disability inherently inform their participation in everyday ableism and reflect underlying deficit lenses, whether intentional or not.

The prominence of the deficit views of disability held by the medical model is inescapable in the lives of those within the disability community. This influence is not only apparent in the Smith's lives. Bhattacharya (2019) also references similar practices within research focused on girls with Rett Syndrome that includes overwhelming negligence of the girls' cognitive abilities. Like those with Rett syndrome, Narise does not communicate using extensive verbal speech. She instead expresses herself through a variety of modes of expressive language, including single words, gesture, adaptive sign language, and AAC. However, these means of expression are often not acknowledged or accepted outside of familial or educational spaces where individuals may be more familiar with AAC use. Even when considering families within the disability community, it may seem easier to communicate without employing these forms of communication, particularly when discussing topics that directly impact the disabled individual, as shown in the event above. When so many aspects of life, including consistent care and medical needs, are incredibly difficult, communicating in one mode may seem like one decision that doesn't have to be time consuming and thoroughly thought out. Meleo-Erwin (2012) explains, "bodies of disabled people elicit great anxiety through the disruption of norms about how bodies are supposed to look and how they are supposed to function" (p. 394).

It is important to highlight that it is those *without* disabilities who exclude the disabled by choosing not to extend invitations to participate in multimodal conversations. As Bhattacharya further (2019) explores, citing Lindberg (2006), "part of their handicap is caused by those of us who form their outer world. We are not used to conscious and varied analysis and interpretation of nonverbal signals (p. 64)" (p. 91). Again, in Event 6, analyzed here, and in other instances of everyday ableism, normalcy dictates how and when the disabled can exist and communicate. While this view may seem totalizing and dire, postconventional models of disability, bolstered by postmodernism, support the rejection of grand narratives and the questioning of aspects of society that seek to uphold the exclusion of disabled people (Goodley, 2014).

The Smith family's perspectives, expressed through their familial conversations, are often infused with postconventional ideas concerning disability, including expanding their participatory and communicative frameworks, participating in advocacy efforts, and promoting a sense of shared humanity. These progressive perspectives of disability exist alongside instances of everyday ableism and ideologies of disability informed by medicalized perspectives. Thus, this analysis of the Smiths' perspectives presents contrasting ideologies of disability, particularly ideologies centered around shared humanity and exclusion. These differing perspectives highlight the idea that ideologies are not fixed and do not occupy just one view; they are continually shifting and often at odds with other ideologies.

As explored in the Smiths' familial conversations, their ideologies of disability shift in response to different activities or roles. Family members learn and unlearn concepts surrounding disability through self-guided research, like the extensive amount of work completed by Jenny following Narise's diagnosis. Individuals also change their perspectives while talking with one another, based on context, as shown in the conversations had between Michael, Jenny, and Narise in Event 7 and Jenny, Riley, and Narise in Event 6. Together and separately, the Smiths employ cultural resources to make sense of their understandings of disability and form their own ideologies and constitute others'.

One major cultural resource in the lives of individuals within the disability community is the educational system, as they navigate multiple legislative decisions, required assessments, and dense documentation and advocate for needed accommodations and modifications, including those concerning environment, support, and the tools needed to succeed. The following section explores the perspectives of Mrs. Tammy, the select educational stakeholder included in this study, and the ideologies that are bound within the different aspects of the educational system that inform her perspectives.

Educational Ideologies of Disability

Conway (2012) writes, “It is easy to find statistics on children with disabilities in special education, since from day one they are identified, branded with the scarlet ‘S,’ and put to work” (p. 3). This statement, albeit harsh, is true in many ways, as evidenced by the extensive amount of data collected and shared by National Center for Education Statistics and the Department of Education and featured within legislation like the Individuals with Disabilities Education Act (IDEA). These annual reports and shared information, ultimately, determine how and where additional resources are provided to schools, so the determination of disability status is complex and under the regulation of state and local agencies. These statistics often fail to take into consideration the nuanced, lived experiences of students with disabilities and their families. This section of the findings seeks to explore the unique educational experiences of one family within the disability community, the Smiths. Specifically, I illuminate the ideologies of disability that circulate within the events and artifacts that comprise the Smiths’ experiences with their local educational system alongside the perspectives of Narise’s teacher, Mrs. Tammy.

The customized analytic framework, informed by Saldaña (2021) and Vanover et al. (2021), also assisted in the process of determining the themes that are explored in this section. Within this section, I explicate the second theme: *Through shared experiences with data, assessment, accommodations and modifications, and support services, educational stakeholders’* *perspectives constitute others' ideologies of disability.* This section is also separated into smaller subsections, based on the initial categories that informed the creation of the overarching theme. These categories include the following: *Data and Assessment* and *Accommodations and Support Services*.

Data and Assessment

The Smith family shared a total of 14 separate pieces of educational documentation with me for inclusion in this study, and the documentation shared within this study is only a fraction of the artifacts they have collected. Table 4 in Appendix J, as discussed in Chapter 3, includes additional information regarding each piece of documentation, including who created and then provided each document and a brief explanation of the purpose of each document. Every document included in the analysis underwent five cycles of coding, and, in Cycle 4, I identified representative data that responds to my posed research questions, and the documents that are explored in this section are a part of this representative data. Throughout each of the 14 documents, I began to take note of Mrs. Tammy's perspectives of disability, particularly related to Narise's academic progression and skill development.

Most noticeably, Mrs. Tammy's perspectives are apparent in the results of Narise's IED-II and within Narise's IEP. These perspectives are made evident in the discourses that Mrs. Tammy, among other evaluators, uses to document Narise's skills and the corresponding measured developmental age range for a particular skill. For instance, within the IED-II, Mrs. Tammy has documented that Narise's current skill level in "Pre-Handwriting" is equivalent to a developmental age of 2.0, and her skills are described as follows: "[Narise's] pre-handwriting skills are characterized by her ability to demonstrate such skills as: attempts scribble but strokes are not controlled and most go off the paper" (2020, p. 2).

In Narise's IEP, her academic skills are also assessed. However, academic skills are not the sole focus, as her social and emotional development are measured, too. Narise's current developmental age in this area is listed as "1 year and 0 months." Specifically, within this same larger section, her "Relationship with Adults" is assessed as the developmental age "2 years and 0 months," with the following detailed description. This excerpt, as included in Narise's IEP, is also featured in Appendix L as Figure 4.8.:

> [Narise's] general social and emotional development can be characterized by her ability to demonstrate such skills as; Looks attentively at a human face; visually follows a moving person; responds with a smile; likes to sit with others who are playing or working; smiles or vocalizes as a means of getting attention (IEP, 2020, p. 7).

Within Narise's IEP, the concept of developmental age is also present and used as a measure of Narise's abilities. In addition to this quantitative measure, Mrs. Tammy provides a qualitative explanation of Narise's social interaction with adults. The excerpt above reveals that Narise engages with adults in meaningful ways, and her support team values different forms of expressive language, including facial expressions, eye contact, and vocalizations, as valid means of communication and social interaction.

Normative Frameworks and Literate Citizenship

To explore Mrs. Tammy's perspectives in these two pieces of educational documentation (IED-II and IEP), the concept of *developmental age* in relation to Narise's diagnosis of multiple disabilities and the connection between developmental age and normative discourse must be first unpacked and untangled, followed by an exploration of the discourses Mrs. Tammy employs. This initial untangling is complex because developmental age is difficult to define. Definitions of developmental age vary based on context and the intended use of the measure. When diagnosing a developmental disorder or disability, developmental age is determined when "a child's characteristics can be compared with relevant norms" (Dyck et al., 2003, p. 979). However, *relevant norms* are either measured by a child's own intelligence or with the child's peers, dependent on disability (Dyck, 2003). For example, when diagnosing Learning Disorders, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM V), asserts that achievement in a particular ability must be substantially below what is expected based on IQ (APA, 2013).

No matter the measure, developmental age, as a concept, is embroiled in medicalized understandings of disability, as both intelligence quotients (IQ) and predictions of development are based upon eugenic ideals and position those "who were deemed to have *less* intelligence… as possessing an objective and measurable disconnectedness from valued citizenship and full humanness" (Kliewer et al., 2015, p. 5). Employing the concept of development age, the IED-II provides Narise's family and educators information on how she is performing in five standardized development areas (Community-University Partnership for the Study of Children, Youth, and Families, 2011). Narise's skills and behavior are compared to a predetermined standard, specifically the performance of her peers that have been labeled *normal* or whose development has been deemed normal.

Understandings of developmental age, particularly those featured in the IED-II, are informed by *cognitive ableism*. Goodley (2014) defines cognitive ableism as "an attitude of bias in favor of the interests of individuals who possess certain cognitive abilities (or the *potential* for them) against those who are not believed to possess them" (p. 30; emphasis in original). As seen in the IED-II, the assessment of Narise's pre-handwriting skills is infused with cognitive ableism, as Narise's skills are measured against individuals who supposedly do possess pre-handwriting skills or have the *potential* for future handwriting skills. These individuals make up the norming sample for the IED-II that includes 1,171 children across 24 states and is intended to represent the population of the United States in terms of ethnicity, income level, level of parent education, and area of residence (Community-University Partnership for the Study of Children, Youth, and Families, 2011).

The discourse featured in this portion of the IED-II is infused with perspectives of disability that are normative and static. However, these often deficit-based perspectives are not Mrs. Tammy's alone. The creators of the IED-II have also inserted their own perspectives within the content and design of the assessment, particularly in the way student data is collected. For instance, the context in which the IED-II is administered is not the same as Mrs. Tammy and Narise's classroom environment where they participate in engaging learning labs that are designed to strengthen handwriting skills and build off of the children's books they read together each day (Individual Interview, 2021). As a part of the IED-II, the documentation of students' performance must follow extremely detailed procedures for administration, scoring, and interpretation (Community-University Partnership for the Study of Children, Youth, and Families, 2011). Therefore, Mrs. Tammy's determinations within the IED-II may not represent her perspectives. Instead, the data Mrs. Tammy reports is dictated by the required assessment protocols and accompanying discourse.

These strict guidelines leave very little room to provide authentic reasons for communication and for varied interpretations of the different modes of communication that Narise engages with and in. As Dhont et al. (2020) explain, children with multiple disabilities often are not able to express themselves using written text or verbal speech. Instead, their communicative skills are "described as pre- or protosymbolic, including many idiosyncratic and subtle behaviors.” (Dhont et al., p. 530). Aligning with Dhont et al.’s work, Narise also communicates in subtle but intentional ways that are and cannot be measured with the IED-II, an extremely regulated assessment that values handwriting and other traditional modes of communication above other multimodal means of expression. By highlighting the intricacies of the implementation of the IED-II, I am identifying the systems of power that inform Mrs. Tammy’s perspectives and pedagogical decisions.

Additionally, it is important to reiterate that Mrs. Tammy is an experienced educator with a background and specialized training in special education. In her individual interview, she shared the following about her decision to pursue a degree in special education:

> …this is [what] I grew up around, because my mom was a special ed teacher, so I grew up around this. I don’t have any family members with, um, disabilities. I have a few friends with children with disabilities, but no family members. Um, so it was just something that I fell into (2021).

Watching her own mother’s journey as a special educator and spending hours in her mother’s classroom before and after school, Mrs. Tammy has been entrenched in the discourses, ideologies, and concepts that comprise special education. Special education, as a field, is notoriously known to promote understandings of disability and competence that are heavily informed by the medical model of disability.

With the medical model, special education classrooms are seen as sites of rehabilitation aimed at “fixing individuals” rather than aiming to change society (Haegele & Hodge, 2016, p. 202). Often with a disability diagnosis or special education referral, a “singular discourse of educational, sociocultural, and intellectual incompetence and perpetual disconnectedness” is perpetuated for individuals with disabilities (Kliewer et al., 2015, p. 2). This singular discourse is rampant throughout the educational system and assessments that typically focus "on individual deficits and the educational structures and practices that disable children" (Connor et al., 2012, p. 10). These structures and practices can be seen in the narrow ways that Narise's handwriting is assessed by the IED-II.

While similar discourse is also present in Narise's (2020) IEP, it isn't the singular discourse featured in the IED-II. The multiple discourses housed within Narise's IEP is partly due to the highly individualized nature of an IEP, as it designed with one student in mind by multiple stakeholders. Within Narise's IEP, discourse informed by the medical model of disability is also coupled with more progressive perspectives of disability. These perspectives are highlighted by the ways Mrs. Tammy describes the possibilities of Narise's multimodal communication and the ways Narise displays pride and self-confidence, emotions that aren't associated with a medicalized view of disability. Most noticeably, these perspectives align with the social model of disability. The social model of disability considers individuals' social environments and material conditions (Ginsberg & Rapp, 2013). This inclusion is a departure from the singular perspectives featured in the IED-II and marks a move toward literate citizenship for Narise. As explored in Chapter 2, literate citizenship "present[s] an intersectionality of themes related to perceptions of human competence, value, and citizenship" regarding participation in literacy-based activities that ultimately lead to participation in much of society (Kliewer et al., 2006, p. 165). By expanding and valuing multiple modes of communication within her IEP, Mrs. Tammy and Narise's educational support team advocate for a reconsideration of who may be literate and, in turn, who can engage in forming social and emotional connections with others. This connection is vital for Narise and other students with disabilities who have historically been and still routinely are devalued and understood as disconnected with society at large (Kliewer, 2006).

Narise's modifications and support services have begun to change this damaging pattern of exclusion but not without difficulty. The following section details Mrs. Tammy's perspectives that are informed by these needed and welcome changes. Additionally, the ideologies of disability that have informed the design and implementation of Narise's modifications and support services are explored.

Modifications and Support Services

Not to be confused with *reasonable accommodations* that are employed to allow a student to learn the same material as peers in a general education setting, *reasonable modifications* are changes "in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity" (U. S. Department of Education, 2020). Reasonable modifications are required under Title II of the Americans with Disabilities Act (ADA), and, specifically addressing elementary and secondary school contexts, Section 504 ensures free appropriate public education (FAPE). The history of FAPE is bound within repeatedly amended legislation led by the U. S. Department of Education and the Office of Civil Rights, and it is quite easy to get lost in the jargon and overwhelming number of acronyms used. However, the goal of FAPE is intended to be simple and guarantees that reasonable modifications are given through "the provision of regular or special education and related aids and services designed to meet the student's individual educational needs as adequately as the needs of nondisabled students are met" (U. S. Department of Education, 2020). Narise's IEP details that she receives modifications, as she is enrolled in a Special Day Class (SDC) or self-contained program special education program. Through this program, Narise engages in a curriculum that differs from general education and focuses on occupational skills alongside modified academic content.

Promised by FAPE, the provision of modifications for Narise through adapted special education curriculum and individualized aids and services is evident throughout the educational documentation and across individual interviews with the Smith family and Mrs. Tammy. One significant modification is the one-on-one aide that is provided for Narise each day she is present at school. Before exploring the very specified support that Narise receives from the one-on-one aide, it is important to note that this resource is not guaranteed to all students with significant and multiple disabilities. Many families must continually fight and advocate for the barest of provisions and modifications for their children. Schoorman et al. (2011) highlight the marginalization of parents in the decision-making processes that occur during special education referrals, and this marginalization does not end once the referral has been completed (Bicard & Heward, 2019). Throughout students' educational journeys, there is often an unequal "balance of power between professionals, who have traditionally wielded power, and families, who have felt they could not affect their children's education" (Heward & Cavanaugh, 2001, p. 311).

The process of ensuring this aide permanently wasn't particularly difficult for the Smith family, and their case is extremely unique. One of the many purposes of undertaking a case study is to explore this uniqueness and the particularity of the Smiths' experiences and to offer insights into events specific to their lives (Simons, 2009). The ease they experienced may have been due to various factors, as Jenny details in the following excerpt:

> I think for the most part it's been very positive, but I don't know if that's because I'm a teacher, so I knew how to advocate. I don't know if it would have been different if I knew

> nothing about the educational system. And, um, I, there was, it was having an issue at first with the one-on-one, because I wanted it to be a permanent position, and the district wasn't wanting to do it at first or whatever, but they, they managed to do it without me having to do any kind of fight or anything about it (Individual Interview, 2021).

Jenny, as an experienced educator, has extensive knowledge of reasonable modifications and accommodations, as she ensures they are provided for her own students in the classes she teaches. Additionally, the knowledge she has gained through the research she routinely engages in, as detailed in a previous section, impacts the way she continuously advocates for Narise to receive the needed modifications in these settings.

As explored throughout each section of this chapter, language use serves to illuminate the perspectives of various individuals. The term *one-on-one* employed by Jenny and Mrs. Tammy throughout their individual interviews and across Narise's educational documentation represents the very specialized, differentiated attention that Narise must and does then receive throughout the day due to her disability, specifically her seizure disorder. Mrs. Tammy details this continuous support when she shares the following:

> …she comes with a one-on-one so that, you know, adds that additional body into the classroom… You know, she's able to transition, follow the schedule. She knows the routine, all those things. It's just the one-on-one is there, too, for any time that she might have a seizure that she is there, too, to monitor that (Individual Interview, 2021).

The discourse Mrs. Tammy chooses to use in the above excerpt provides insight into her perspectives. Mrs. Tammy details what she believes Narise can do and what specific support the one-on-one aid provides. For instance, Mrs. Tammy explains the attention Narise is given by the one-on-one aide at recess. She recounts:

> …when she's out at recess, she, you know, she interacts and does, I mean, she doesn't talk to the other kids, but she like, you know, kind of follows or whatever. Um, the only modification really for her is just that you know, she has an adult within three feet of her at all times, you know, because we don't know when, if and when you know that seizure is going to come on (Individual Interview, 2021).

Mrs. Tammy highlights that Narise does engage with other children, and she stresses that Narise's one-on-one aide is only there to ensure to Narise's safety. The aide is not needed for any other purposes, including socialization or behavior management.

Across the data, other modifications that are implemented in both educational and familial spaces were featured. Within Jenny and Mrs. Tammy's individual interviews and throughout the observations, I noted the practice of *hand over hand*. Webster (2019) describes hand over hand as a prompting strategy that "often involves performing an activity with a student" (n. p.). Also known as "full physical prompting," hand over hand requires the person teaching a skill to place their hand over a child's hand and direct the child's hand with their own (Webster, n. p.). This modification can be used when instructing children how to perform tasks that require often difficult to grasp fine motor skills, such as writing their name or cutting with scissors. Figure 4.9 below serves as an example of Jenny and Narise engaging in the practice of hand over hand at home. In this moment, Jenny is helping Narise connect two base ten blocks.

Figure 4.9: Narise and Jenny engage with base ten blocks and use the hand over hand modification.

After noticing this practice in observations, I asked both Jenny and Mrs. Tammy about hand over hand and how they use the modification in both educational and home contexts, and I was able to learn more about their decisions to employ this method. Jenny shares:

> I think it more started with, um, [Mrs. Tammy] expressing to us, because I just thought, "Oh, okay. Well, she can't write or do this." You know, when we would go to IEPs or we would go to a Back-to-School Night or something and they were like, "No, she can do this. Look. This was her work." And I was like, "Well, I didn't know that." And they were like, "Well, hand over hand." I was like, "Okay."

Initially, Jenny was unaware that such a practice existed, and she assumed that Narise was incapable of doing particular tasks. However, Mrs. Tammy and other educators shared they were able to get Narise to engage with activities that she typically wouldn't attempt by using the technique hand-over-hand.

Power Struggles and Powerful Practices

Both modifications featured in this section reflect Mrs. Tammy’s perspectives, and, in turn, these perspectives constitute familial ideologies of disability in powerful ways. In the data collected, the ideologies of Jenny, as the family member who “handles schooling” (Individual Interview, 2021), are most prevalent. Specifically, Jenny’s ideologies of disability and the ways these ideologies are shaped by educators’ perspectives were infused in her explanation of Narise’s one-on-one aide and the process she underwent to ensure this modification was and is continually provided. As she recounted the struggle, she acknowledges how her knowledge of the educational system impacted the outcome of the provision of Narise’ one-on-one aide.

With this knowledge, Jenny has access to the various discourses that are employed within the educational system, and she can use these discourses when advocating for Narise. These discourses are coupled with power, because, as Bové (1995) asserts, discourse serves as a vital link between knowledge and power. Jenny then can alter the power imbalance that is frequently experienced by so many families within the disability community (Heward & Cavanaugh, 2001). The power that is exerted throughout interactions between family members and educational stakeholders while seeking appropriate modifications is in continual circulation, as seen in the ways that the position for Narise’s one-on-one support was not initially deemed a permanent need by the local school district. However, the district later changed its decision, further illustrating the ongoing flow of power through one entity and into the next. Detailing the constant shifting of power and roles within society at large, Foucault (1977) writes, “this machine is one in which everyone is caught, those who exercise this power as well as those who are subjected to it” (p. 156).

The practice of hand over hand, similarly, plays a role in the constitution of individuals' ideologies of disability. The perspectives of the individuals who engage in this practice with Narise, including Jenny and Mrs. Tammy, inform this constitution. Regarding hand over hand, Mrs. Tammy's perspectives and ideologies were largely asset-based. In her individual interview, Mrs. Tammy explains that she always presumes that families can and do engage in important educational and literacy practices when children are not at school. Further, she shares the many different ways she works to strengthen the needed relationships between herself and parents. Too often, families are excluded from conversations about the education of their children, rather than playing a role as a "conversation partner" that co-constructs curriculum alongside educators (Whitehouse & Colvin, 2001). By engaging in hand over hand, Mrs. Tammy, is also *presuming competence* in Narise. Kleekamp (2020) defines presuming competence as "the inherent belief that students bring many competencies into classrooms regardless of their accompanying dis/ability labels" (p. 116). Presuming competence in students further entails confronting one's own deficit ideologies and moving one's thinking from certitude of students' inability toward a mindset of possibility and exploration (Kliewer et al., 2015).

These positive beliefs are woven throughout Mrs. Tammy's dialogue about her students when describing the benefits of hand over hand and highlights her "presuming competence stance" (Kleekamp, 2020, p. 116). Mrs. Tammy further shares:

> I'm like, no, you might not be able to do this, but we're going to do hand over hand, figure it out. And then eventually, you know, build to be able to do it yourself. But a lot of times, you know… You have the ability to learn just like everyone else. It just might take us a bit longer (Individual Interview, 2021).

Mrs. Tammy, through the use of hand over hand, has created new ways for students to participate in classroom activities. With this modification, some students with disabilities can participate in activities that others may have originally thought they couldn't or wouldn't participate in and push against deficit views of disability (Kleekamp, 2020). Additionally, Jenny experienced a shift in understanding about Narise's capabilities after Mrs. Tammy shared the possibilities associated with the modification of hand over hand. In this way, Mrs. Tammy positively informed Jenny's perspectives of modifications and, thus, her ideologies of disability. Along with these possibilities, it is important to note that hand over hand is not recommended for all students with disabilities, and its implementation is not always met with approval. I explore this division in the paragraph below.

Webster (2019) writes, "Hand over hand prompting is the most invasive of all prompting strategies as it requires a teacher to physically manipulate a child's body" (n. p.). As an invasive strategy, hand over hand should be used sparingly and alongside many other modifications, as evidenced in the myriad modifications included in Narise's IEP, discussed in individual interviews, and displayed in observations. Critics of invasive strategies like hand over hand assert that that a child's body shouldn't be forced to change or move in ways that a child doesn't wish. This use of power and force echoes Foucault's concept of *biopower*, briefly introduced the previous section explore familial routine. Biopower upholds views of the body "as an object to be manipulated" and the production of a "human being who could be treated as a 'docile body'" (Dreyfus & Rabinow, 1983, pp. 134-135). However, students with disabilities are not "docile bodies" that need to or should be manipulated to meet particular academic goals.

The incorporation and implementation of hand over hand, with its varying supporters and critics, serves as a salient example of the ways that ideologies of disability widely differ and are always shifting and changing. As Leonardo (2003) writes, “Ideology never stands on its own, but it is involved in relations with other ideologies. It is never complete but instead is evolving and modifying itself” (p. 209). For instance, the frequent alignment between Narise’s modifications and the medical model of disability seen throughout this section is unsurprising, as her need for support often derives from her medically diagnosed multiple disabilities. However, the differences between the intentionality and the outcomes of Narise’s need modifications are jarring. Initially, all reasonable modifications are positioned in opposition to the medical model of disability that upholds erasure and cure as *solutions* to the *problem* of disability (Siebers, 2017). As a field, Disability Studies in Education (DSE), informed heavily by CDS, promotes inclusive education for all students, and modifications are one such way to ensure the inclusion of students with disabilities (Gomez & McKee, 2020).

Unfortunately, the perspectives of educators and the implementation of modifications are not always aligned, and, moreover, the modifications are often not implemented with the goals of DSE and CDS in mind, further damaging ideologies of disability. These issues can be traced from the ideologies that serve as the foundation of our educational system, which is both a political and social institution. Fueled by neoliberalism, Leonardo (2000) explains that educational ideologies are reproduced in a manner similar to factories through countless “hierarchical rituals” (p. 210). These rituals are the outdated and often deficit-based assessments and practices explored in this section. Poststructuralists, particularly those who work in the field of CDS, critique the view that neoliberalism is all encompassing and its effect on bodies is inescapable (Goodley, 2014). This goal is accomplished by disrupting and dismantling “norms of embodiment” and “the apparent stability of distinct and bounded categories” (Shildrick, 2012, p.

40). As subjects who are produced and produce in this neoliberalist system, students, families, and educators within the disability community can take up the postconventional call for critique.

In order to accomplish the needed deconstruction of norms and deficit categories, a community of support comprised of both educators and family members must be built. When formed, these communities powerfully shape ideologies of disability and build discourses of disability that are authentic and based on lived experiences (Whitehouse & Colvin, 2001). This influence on ideologies of disability is explored in the section below that looks specifically at the intersections of familial and educational ideologies and how these intersections take shape within the Smiths and Mrs. Tammy's lives.

Intersections of Familial and Educational Ideologies

As seen throughout the above two sections, familial and educational ideologies often intersect, as the disability community, comprised of disabled individuals, their family members, and educational stakeholders, works together. These points of intersection illuminate important power relations that exist between the different members of the disability community. Drawing from scholarship in the field of language ideologies, I continue to investigate the perspectives of the Smith family and Mrs. Tammy, highlighted by their specific language use. Specifically, I look at how the language they use is infused with political, social, and historical values at these key points of intersection (Cavanaugh, 2020). To illuminate these discourses, I discuss the various means of communication that the Smiths and Mrs. Tammy engage with and in, as communication served as a primary example of the intersections of familial and educational ideologies of disability.

Specifically, within this section, I explore the ways that communication has and continues to evolve within the context of the Smith familial spaces. First, I highlight the many different ways that the Smith family and Narise’s school community can and ultimately choose to communicate in and across familial spaces, including through the use of adaptive sign language, Augmentative and Alternative Communication (AAC), expressive language, print text, and technology. Then, I present the varying perspectives had by the Smiths and Mrs. Tammy and analyze their discourses that highlight these unique perspectives. Finally, I discuss how these perspectives inform their often-intersecting ideologies of disability.

Communication

While researching the language practices and ideologies of families within the Deaf community, Pizer et al. (2012) assert that families are “likely to develop language practices guided by a system of beliefs and attitudes concerning the language and communities in question and by the family members’ judgments concerning appropriate linguistic behavior in the home” (p. 75). Within the context of the Smith family’s home, their language practices vary, and the judgements placed on these linguistic behaviors similarly diverge. Most noticeably, in-school and home language practices heavily influence the other, and each sphere affects individual perspectives of linguistic behaviors by the continual introduction of new and different ways to communicate.

Narise primarily communicates with those around her through the use of adaptive sign language, a form of communication that has been created communally by Narise and her family. Explaining their creative process, Jenny’s shares:

> The teacher signs, and she [Narise] always makes them up how she wants to, um, we use to do this for drink [mimes holding a cup up to her mouth] and then it turned into this [places her hand over her mouth]. And now for some reason she does it with her eyes [places her hand over her eyes]. So, whenever she goes like this [places her hand over her

> eyes], we know she's thirsty. So we've just learned her signs… Um so we try to teach her, like I was working on colors, and she can kind of do with this with her hands [shakes her hands loosely], but she can't really make the letters in order to do most signs [makes different signs for letters of the alphabet in American Sign Language]… So it's just been, we just learn with her, I guess we teach her and then she just makes it up herself (Individual Interview, 2021).

In this excerpt, Jenny reveals the ways that Narise, her family, and Mrs. Tammy have collaborated to create Narise's system of adaptive sign language. Further, Jenny describes how Narise has controlled these efforts by ultimately determining the signs she chooses to use. In their attempts to teach Narise, Narise ends up teaching them.

Evidence of Narise's use of adaptive sign language was included in every virtual observation. In particular, Event 3 highlights the ways that Narise interacts with her family by employing signs she has connected to specific concepts, in tandem with her use of verbal speech and gesture. This example is included below and featured in Figure 4.10:

> Jenny: You're holding out your hand. What do you want? Yeah, you're pointing there. What do you want? Do you want to read?
>
> Narise: Uh huh.
>
> Jenny: Yeah. You want to read? We can read (Event 3).

Figure 4.10: Narise points to the bookshelf and, then, a book to indicate she would like to read.

In this event, Narise first holds out her hand, her adaptive sign that she has a request. Then, Narise points to the bookshelf and, later, a specific book that sits on top of the bookshelf. Jenny is interpreting Narise's collective use of adaptive sign language, gesture, and verbal speech to understand what activity she would like to do next. Narise doesn't limit her communication to one singular mode and uses the linguistic resources available to her to let Jenny know she would like to read. Then, Jenny, comprehending this multimodal request, responds to her wishes, and they read a book together. Together, Narise and Jenny are communicating across modes.

Narise also lets her needs and wants to be known using a core board, another form of communication supported in educational contexts and employed within familial spaces. The construction of Narise's core board was detailed in Chapter 3. Two salient examples of family members and educators' perspectives surrounding Narise's use of her core board are found in Mrs. Tammy's individual interview and in Observation 7. First, Mrs. Tammy shares Narise's support team's goal for her use of the core board and Narise's strong desire to communicate with others. She says:

> We're working on using a core board, which will help eventually, um, graduate her to an AAC device, which I know that she'll do amazing with, because she wants to communicate. And that's like, I think that's one of the biggest parts of her disability is not being able to verbally, you know, express her wants and needs (Individual Interview, 2021).

Mrs. Tammy speaks to the collaborative efforts of Narise's educational support team and the goals they have for Narise's communicative abilities. She explains that Narise's core board created from paper and Velcro strips serves as an introductory device that will prepare her to use a more technologically advanced AAC tablet device in the future. Mrs. Tammy additionally alludes to Narise's desires to communicate using verbal speech. However, with this statement, Mrs. Tammy is privileging verbal language over other modes of communication and insinuating that Narise doesn't already communicate, despite Narise's use of adaptive sign language and other multimodal means of communication. Mrs. Tammy's complex perspectives are further explored below, alongside her relationships with her students' families.

Similar to Narise's use of adaptive sign language, her choice board also gives her the means to communicate with those around her. For instance, in virtual observations, Narise used her core board to select her next activity. No selected events feature Narise's use of the core board. However, my field notes and journals contain extensive notes regarding a particular segment of Observation 7, because the negotiation fostered by the core board that occurred between Jenny and Narise was striking. The following excerpt, featured in Figure 4.11, is a display of Narise's agency, as she is determined to serve an active role in determining her daily schedule:

> Jenny: Okay. Hey, hey. I know, I know we need to update this choice [core] board, but do you want to see, what do you want to play with on your choice board? Let me see.
>
> Narise: [Looks at the many pictures on the core board, selects the printed picture of books by tearing off the Velcroed picture of books from the choice board, and hands the picture to Jenny.]
>
> Jenny: So, books. Do you want to read?
>
> Narise: [Selects the printed picture of fruits and vegetables by tearing off the Velcroed picture of fruits and vegetables and hands the picture to Jenny.]
>
> Jenny: Look, we just did your fruit and vegetables. We did your food. Yeah. Oh well.
>
> Narise: [Selects the printed picture of a guitar by tearing off the Velcroed picture of the guitar and hands the picture of Jenny]
>
> Jenny: And your guitar is broken. That's why I said we have to update the board. The string is messed up on your guitar, so we don't have that, but we do have the dog one. But do you want do books? (Observation 7)

Figure 4.11: Narise selects the picture of books on her core board.

In this exchange, Jenny and Narise are determining if they should read a book, roleplay with wooden fruits and vegetables, or play the guitar. As previously mentioned, the core board Narise has at home is made up of cardboard, printed photographs, and Velcro. This construction has created a static artifact that cannot be quickly modified to reflect the Smiths' rapidly changing lives and resources. For example, Narise is unable to play the guitar as she would like, because it is broken. Additionally, as someone who will also engage in the activity, Jenny is able to share her thoughts and preferences, and she does not want to play with the wooden fruits and vegetables once again. Together, Narise and Jenny are both participants in the conversation, avoiding a one-sided conversation that so often occurs when disabled individuals, particularly those with communicative challenges, navigate life and their own care.

Responsive Caregiving and Collaboration

These means of communication, including Narise's adaptive sign language and use of her customized core board, are unique to the Smith family and their context. However, many of the Smiths' and Mrs. Tammy's perspectives and subsequent actions are common within the disability community. For example, in the exchange documented in Event 3, Jenny is engaging in *responsive caregiving*. Keilty and Galvin (2006) describe responsive caregiving as the process during which "an adult tailors her or his interactions by accurately reading and responding to the child's unique communicative cues, [as] a type of social adaptation" (p. 220). Jenny's responsive caregiving and Narise's own social adaptation featured in Event 3 speak to the merits of the social model of disability that heavily inform CDS, including the notion that problems surrounding access, support, community participation and acceptance are due to a society that does not welcome those who are different (Goodley, 2014). Both Jenny and Narise, through their desire and need to communicate with and, in turn, understand and support one another, are actively combating a disabling society that seeks to exclude Narise by adapting the ways they communicate with one another.

In addition to responsive caregiving, Jenny combats exclusionary practices in other ways. During her individual interview, Jenny details the collaborative and, at times, difficult experiences she has had with Narise's speech therapist to ensure Narise is able to communicate using adaptive sign language in and out of school spaces:

> So, yeah, her adaptive sign language is everything that she has made up on her own. Um, and actually through IEPs, one time I was wanting to have more sign language, and I'd want to say that it was more the speech therapist maybe. I don't remember exactly what was said, but she said not everyone knows sign language. And I said, yeah, well, not everybody knows her core board or her PEC system either, so she's really never going to be around somebody that can communicate and talk to her (Individual Interview, 2021).

This exchange between Jenny and Narise's speech therapist is significant, as is the speech therapist's hesitation to incorporate more sign language into Narise's linguistic repertoire and the linguistic repertoire of those around her. Jenny isn't easily discouraged by the disagreement and insists that the use of sign language in educational contexts be expanded. Jenny's insistence reveals that not all the suggested methods of communication are practical and simple to implement both outside and within familial spaces. Individuals with disability and their families and communities adapt and alter suggestions of medical and educational practitioners to meet their unique needs. This adaptation, or need to continually change modes of communication based on context and need, aligns with the constantly changing social construction and discourses of disability. Adaptation, in relation to the social model of disability, was featured in the discussion above regarding Observation 7, when detailing Narise and Jenny's communication with one another. However, outside of the familial context, adaptations can also work to change understandings of disability held by individuals that don't have a disability or experience disability in deeply personal and intimate ways (Waldschmidt, 2017).

Collaboration fosters these needed changes in understanding, as seen in the ways that Jenny wishes to work with Narise's educational support team to bolster the use of adaptive sign language. Through this collaboration, they can work together to create inclusive environments for Narise at school, home, and in other public spaces. Pizer et al. (2013) assert that this shared sense of responsibility has the potential to break down communication barriers, but it can only be possible if members of a community, despite their diverse ideologies surrounding language and disability, find a unifying thread and common goal. In this context, Narise's family and educators' common goal is Narise's success which involves Narise connecting with others and, ultimately, participating more fully as a literate citizen (Kliewer et al., 2006). This goal wouldn't be possible without Jenny's advocacy, as seen in the above excerpt from her individual interview.

Not only does Jenny advocate for Narise, but Narise also advocates for herself through her use of adaptive sign language and her core board. Communication assisted by AAC devices is the subject of much research, particularly regarding the possibilities it provides individuals with disabilities. As seen in both Bhattacharya (2019) and Kafer (2017), the use of AAC provides users with multiple or significant disabilities with the means necessary to communicate, despite many "experts" underestimating their cognitive abilities and categorizing them as "nonverbal" or even "speechless." This case highlights Narise's communicative ability and potential, alongside Bhattacharya (2019) and Kafer's (2017) powerful scholarship and raises the question of whether "noncommunicative status is permanent or complete" (Kafer, 2017, p. 297).

In Narise’s case, her communicative status is not permanent or complete, despite Mrs. Tammy’s limited view of communication revealed in her individual interview that focuses solely on verbal language. Narise’s family educational support team has welcomed multiple and varied ways for her to share with others and, more specifically, advocate for herself. Her choice board is simply one of these ways and is envisioned by Mrs. Tammy as a scaffold that can help Narise eventually communicate using a digital AAC device that has an extensive vocabulary for her to employ.

Bhattacharya et al. (2022) detail similar circumstances of self-advocacy but within medical settings. In their work, Bhattacharya et al. (2022) detail the innovative ways an AAC device can become a tool when asking for assistance and obtaining consent. With the use of her core board, Narise sits in opposition to understandings of a “docile body,” as she fights against “disciplinary power” that has been created by the historical, technical, and political forces in our society to discipline or oppress individuals who aren’t seen as “productive” in a capitalist society (Dreyfus & Rabinow, 1983, pp. 134). Drawing from previously explored Foucauldian concepts, disciplinary power circulates primarily in factories, schools, and other state-sanctioned offices, places where so many within the disability community are continually silenced (Dreyfus & Rabinow, 1983). With its widespread reach, disciplinary power also seeps into homes, as disabled individuals are often considered too “significantly impaired” to communicate and, thus, discuss their plan of care (Kafer, 2017, p. 293). Narise, often a subject of disciplinary power, uses her core board to oppose these damaging, disciplinary discourses surrounding disability that routinely infantilize disabled people, deny them literate citizenship, and participation in society more broadly (Kafer, 2017; Kliewer et al., 2006). Chapter 5 reviews these findings regarding disability, power, discourse, and ideology and shares additional implications for researchers, teachers, teacher educators, and family and future directions for research.

CHAPTER 5

DISCUSSION, CONCLUSIONS, IMPLICATIONS, AND DIRECTIONS FOR FUTURE RESEARCH

The purpose of this study was to explore the multiple ideologies of disability that exist within one family and the myriad ways these ideologies are laden with power and constituted through interactions with other family members, select educational stakeholders, and the documents used. This dissertation describes a digital case study I conducted alongside a family in the disability community, the Smiths, and a select educational stakeholder, Mrs. Tammy, to explore the following research question: *In what ways do family members and educational stakeholders constitute one another's ideologies of disability in and across familial spaces?* Through the analysis of various sources of data, including virtual interviews, observations and documents exchanged between participants, I saw how the Smiths' and Mrs. Tammy's ideologies of disability were shaped by others' ideologies and powerful societal forces. Many of these collective and individual ideologies sat in opposition of one another, while some aligned, stemming from a variety of factors. These instances of divergence and alliance were surprising to me and helped to illuminate the complexity of both disability and the continual constitution of the Smiths' and Mrs. Tammy's ideologies.

Critical Disability Studies (CDS) served as the theoretical foundation of this exploration of ideologies of disability. In particular, I drew from postconventional models of disability, including postmodern and poststructural models of disability, to analyze both the epistemological and discursive forces that inform individuals' perspectives and experiences of disability and, thus, shape their ideologies. Additionally, concepts from language ideologies allowed me to clearly articulate the intricate relations between language, power, and social, cultural, and historical contexts. Together, CDS and language ideologies helped me to understand how ideologies of disability operate in the lives of families within the disability.

Grounded in my theoretical framework and guided by my customized analytic framework inspired by Saldaña (2021) and Vanover et al. (2021), I completed five cycles of coding. Each of these cycles informed and built upon the other, and the boundaries of these separate cycles were not always linear or fixed. I moved through and between these cycles, and I often returned to earlier cycles based on new understandings as I immersed myself deeper in the data and my theoretical framework. Throughout the five cycles, I identified patterns across the data and developed themes. These themes illuminated the varied ways that family members and educational stakeholders constitute one another's ideologies of disability in and across familial spaces, the intersections of these same familial and educational ideologies, and how these intersections manifested in the lives of the Smiths and Mrs. Tammy.

In Chapter 4, I discussed the interrelated nature of these findings and how each separate theme represents a vital element of the disability experience that informs individuals' perspectives and, thus, their ideologies. In the following sections, I revisit these findings and describe how they are situated within previously published research. I then present the implications of these findings for teachers and researchers within the field of language and literacy education and how this research can be expanded and continued in the future.

(In)Conclusion: Continual Constitution

Within this section, I discuss the key findings of this study, separated into three sections, mirroring the organization of Chapter 4: *Familial Ideologies of Disability*, *Educational*

Ideologies of Disability, and *Intersections of Familial and Educational Ideologies*. This organization allows me to highlight familial and educational ideologies separately and then elucidate how intertwined and interdependent these two types of ideologies truly are, particularly within the context of the disability community. Additionally, this initial separation helps to illustrate the power infused in both familial and educational ideologies through the specific discourses employed by the Smith family and Mrs. Tammy.

Familial Ideologies of Disability

My findings concerning familial ideologies of disability highlight the interconnected nature of familial roles, support systems, routines, and conversations in the constitution of ideologies of disability. Working alongside the Smith family, I determined that familial ideologies of disability are informed by familial roles, support systems, routines, and conversations. These findings expand upon preexisting scholarship but focus more closely on the economic, political, cultural, and historical conditions that shape individual experiences of disability for families within the disability community by employing the theoretical frameworks of CDS and language ideologies. Both CDS and language ideologies allow me to specifically unpack the discursive choices of the Smiths and the broader societal influences that have shaped these choices. By employing various models of disability and particular concepts from the field of applied linguistics, I can better understand the influences and implications of Smith's language use. Further, I continually try to include and center the experiences of individuals with disabilities, an often-forgotten consideration in previous studies published in the larger field of Disability Studies (Kerschbaum & Price, 2017).

Familial Roles and Support Systems

Previous research highlights how disability has the potential to impact parents’ and siblings’ lives through changes in physical and mental health, occupation, financial security, and relationships (Davis & Carter, 2008; Gilson et al., 2018; Perenc & Peczkowski, 2018; Resch et al., 2012; Shivers & Dykens, 2017; Singer, 2006; Tomeny et al., 2017). Additionally, individuals with disabilities have extensively shared the cultural and material effects of living with a disability (Ferri; 2011; Finger, 2006; Linton, 2007; McBryde Johnson, 2017; Mintz, 2007; Sherry, 2005; Wong; 2020). While these impacts are featured in this dissertation, the findings presented delve into the ideologies of disability that are associated with these major life changes. In particular, the Smith family’s ideologies of disability were shaped by their familial roles and support system. Informed by their individual roles and the support given and received, these familial ideologies of disability were centered around the concepts of shared humanity, comparison, and inclusion.

Jenny, as the mother and matriarch of the Smith family, admitted that she spends the most time with Narise, and this close relationship obviously affects her ideologies of disability. When Jenny engages with Narise at home, she often employs an asset-based stance by praising Narise and using People-First Language (PFL). This discursive choice highlights Jenny’s ideologies of disability that are centered around the concept of a “shared humanity to which impairment is a modification” (Garland-Thomson, 2019, p. 92). However, in different contexts, Jenny uses different language, specifically the term *special needs,* to describe Narise’s disability to others. This shift is noteworthy and speaks to the contextual and fluid nature of Jenny’s relationship to disability. Jenny’s language use doesn’t follow predetermined conventions (Ladau, 2021; Shidrick, 2021).

Jenny has created her own understandings of disability using the cultural resources available to her, just as the mothers featured in Skinner et al.'s (1999) study did. Skinner et al. (1999) also unpack the experiences of mothers within the disability community, but use narrative as a way to explore individual understandings of disability. By supporting a view of disability that incorporates social and cultural experiences and identities, Skinner et al. (1999) emphasize mothers' creation of purposeful words to explain their experiences. The emphasis of Skinner et al.'s research similarly speaks to power of language and the ways that language informs ideologies, as similarly evidenced in this case study.

Familial roles and support systems also shape the ideologies of disability held by other members of the Smith family. Both Michael and Riley employ comparisons to make sense of Narise's disability and to share their thoughts and experiences with others. Michael extensively discussed his *always on* theory, a perspective that acknowledges the ways that disability impacts every aspect of his life. His comparison derives from his experience having a child with a disability and a child without a disability. Riley, too, uses comparison to distinguish her own relationship to Narise with other sibling relationships she observes. As a father and as a sibling, two distinctly different roles, Michael and Riley use the same resources as nondisabled individuals to conceptualize their experiences and their understandings of disability. These commonalities speak to how comparison shapes many of our perspectives of disability (Goodley, 2014). Although not focusing on a single individual, Whitehouse and Colvin (2001) detail the experiences of families that, as a whole, are compared to "normative or 'ideal' versions of 'advantaged families'" further illustrating the dominance of normalcy (p. 212). Within Whitehouse and Colvin's (2001) work, this comparison is referred to as being "read" or "reading" families.

As an individual with a disability, Narise obviously experiences disability much differently than others within her family. However, without being able to communicate with Narise individually, I was unable to learn more about these experiences. Instead, I focused on how Narise's familial roles and the accompanying interactions with her family inherently shaped others' ideologies of disability. As a vital part of the Smiths' familial structure, Narise often supports various family members in decision-making processes. With this role as a decision-maker, Narise continually asserts her autonomy. Her enaction of relational autonomy, supported by her multimodal communication, informs her family's perspectives of disability and, ultimately, shapes their ideologies of disability.

Studies within the field of language and literacy education have similarly explored the significance of familial routines in the lives of families within the disability community (Cohen et al., 2015; Holloway et al., 2014; Keilty & Galvin, 2006; Robinson et al., 2019). In particular, this body of research identifies the learning opportunities for multimodal communication development and language acquisition that are embedded in routine activities like mealtime, familial conversations, book reading, and play (Keilty & Galvin, 2006). In addition to bolstering participation in both familial activities and society, these activities have the potential to shape individual perspectives and ideologies of disability, as seen with the Smiths.

Familial Routines

Featured across the interviews, observations, and documentation, the Smiths' familial routines and experiences with disability are impacted by disability. These routines ultimately shape familial ideologies of disability, and, as informed by their own familial routines, the Smiths' ideologies of disability are grounded in ideas of advocacy, acceptance, and engagement. Specifically, medically oriented events, including traveling to various medical appointments, meetings, and tests, are often apart of their schedules. In addition to these events, the medical discourse that is woven into their daily discourse highlights the ways disability has continually shaped their routines. Jenny's participation in self-guided research and the compilation of all of Narise's medical documentation serves as two examples of these impacted routines. As she engages in these routines, Jenny takes extensive notes and details her own perspectives of disability. Through this process, Jenny is exercising her ability to participate in medical discourses surrounding disability, and she sees participation in these types of discourses as opportunities to advocate for Narise in medical settings. Additionally, the knowledge that Jenny has gained has given her new perspectives of disability. Her ideologies of disability have evolved into an ideology of a "shared humanity" (Garland Thomson, 2019, p. 92) as explored in the section above, away from deficient and medicalized understandings of disability. Holloway et al. (2014) similarly found that mothers had higher engagement in interactions with medical professionals. Focusing specifically on Latino families within the disability community, Holloway et al. (2014) explored the economic pressures experienced and cultural preferences of these families and noted that family members were responsive to others' involvement in family routines.

Michael and Riley's perspectives have also shifted in response to their engagement in familial routines, particularly as they care for and spend time with Narise. They both view disability as an almost indistinguishable part of their routines. It is a common occurrence to alter a family activity to accommodate Narise's needs, as seen when Michael and Narise must pause their storytime for Narise to take her daily seizure medication or when Riley details Narise's adapted participation in their family's game nights. However, Riley also acknowledged disability's presence in their routines is not always easy, when she shared the difficult conversations that her family has about their future and who will one day care for Narise.

Michael and Riley's individual perspectives inform the ways they respond to disability's integration into their routines, and ultimately their ideologies of disability. Further, it is important to note the dialogic relationship between routines and ideologies of disability. As individual perspectives of disability inform familial routines, familial routines also inform ideologies of disability. Responses to disability, like those had by Michael and Riley, are a critical element of the constitution of ideologies of disability, as evidenced in Kabuto's (2016) work that examines how language facilitated the construction of the concept of disability for a mother and son. Kabuto extends the social model of disability to explore how disabilities are socially constructed, particularly by family members' own interpretations, intricately bound within their own separate histories and experiences. These individual perspectives shape the ways that individuals with disability view disability and themselves. Within the context of the Smith family, disability is often viewed as a site of possibility and transformation that presents new ways of being (Shildrick, 2021).

Narise participates in familial routines by communicating multimodally through the use of expressive language, including gesture, facial expression, and single word utterances, and adaptive sign language. In their research on the positive impacts of reading, Robinson et al. (2019) also considered the multimodal and multisensory communicative practices of children with disabilities, particularly when children wished to express their thoughts on their wellbeing. Further, Robinson et al. encourage families within the disability community to support and validate multimodal communication and activities as meaningful social exchanges. In the context of this study, the Smiths have taken on Robinson et al.'s (2019) call by continually encouraging and recognizing Narise's multimodal communication and collectively engaging in multimodal activities as a family. In this way, Narise has informed her family's ideologies of disability through her participation in familial routines.

Familial Conversations

For the Smith family, many conversations concern disability, as noted above through the influence and presence of disability in their familial roles and routines. These conversations surrounding disability serve difference purposes, as the participants in these same conversations have different reasons to discuss disability, based on their varied perspectives and ideologies of disability. These conversations then, too, shape their ideologies of disability, and the Smiths' ideologies of disability, highlighted through their familial conversations, were influenced by disruptive moves and everyday ablism.

With their familial conversations, the Smiths' participatory frameworks were often expanded and reconsidered. In these instances, Narise does not employ the use of extensive verbal speech. She instead actively contributes to conversations multimodally through adaptive sign language and expressive language. This broadened understanding of literacy, as seen with the Smiths' communicative practices, serves as the foundation of *inclusive literacy practices*. As Flewitt et al. (2009) shares, inclusive literacy practices push again traditional notions of literacy that seek to exclude children with disabilities and instead value all literacy experiences. Both Flewitt et al. (2009) and Kliewer et al. (2006) examine the social and institutional barriers faced by children with disabilities and their access to full participation in literacy practices. Inclusive literacy practices, then, present a means for children, families, and educators to push against and break past these barriers and advocate for full participation in society, more broadly.

This full participation in society is not an easy journey, even within familial spaces, as social and institutional barriers are imbedded deep within family's lives. For instance, Narise's family often acknowledges and responds to her multimodal participation in their conversations, but, at times, her involvement is not considered. One such example was observed during an exchange with Narise, Jenny, and Riley where Jenny and Riley engaged in *everyday* or *minor ableism* (Eisenmenger, 2019). Often, individuals do not even know they are participating in everyday ableism. Despite their intentions, participation in everyday ableism serves as a reflection of underlying deficit views of disability. Many well-intentioned family members also possess these same deficit views and fail to presume competence in children with disabilities, particularly in regard to their potential engagement in literacy-based activities (Kabuto, 2016; Kliewer et al., 2006; Ricci, 2011; Robinson et al., 2019). Kliewer et al. (2006) link this routine denial of participation to "historic practices of general human devaluation" (p. 165).

These damaging views of disability that inform acts of everyday ableism are based within the medical model of disability. While many new models of disability critique and contest the negative perceptions associated with the medical model of disability, the medical model is still prevalent within our society (Haegele & Hodge, 2016). Bhattacharya (2019) presents a review of research conducted with girls with RS that reveals how these girls have historically been ignored in education research due to their perceived cognitive abilities. This exclusion is caused by assessments that focus solely on verbal speech and fail to properly measure the ways that girls with RS can and do communicate. As Bhattacharya (2019) shares, "people with limited speech due to multiple disabilities, including RS, are thus debilitated in a speech-oriented society" (p.

91). Jenny and Riley's actions have similarly been influenced by the dominance of verbal speech within society.

Considering the vast differences between the conversations that include Narise and encourage her participations and the events that exclude her, the Smiths individually and collectively possess varying ideologies of disability. These findings highlight that ideologies of disability are not fixed. Instead, they are in flux and, at times, seemingly in opposition with other ideologies of disability. The Smiths employ various cultural resources across contexts in response to different familial conversations and roles to make meaning from their experiences with disability. This meaning making process shapes their ideologies of disability.

Educational Ideologies of Disability

Collaborating alongside the Smiths and Mrs. Tammy, I determined that through shared experiences with data, assessment, accommodations and modifications, and support services, educational stakeholders' perspectives shape others' ideologies of disability. These findings are situated within previous scholarship focused on students within the disability community published within the field of language and literacy education. However, this study was specifically inspired by research that explores inclusive literacy practices. This criterion helped facilitate an in-depth exploration into the various ways that students with disability are positioned within inclusive contexts. Further, the alignment with inclusive literacy practices helps illustrate the possibilities inherent in a framework grounded in CDS that fosters both critical inquiry into the material construction of disability within society and the linkage of theory with action (Meekosha & Shuttleworth, 2009). In this way, a focus on inclusive spaces serves as an additional lens to examine the political, social, cultural, economic, and historical barriers experienced by students with disabilities when accessing classrooms and schools (Milton 2017b).

Data and Assessment

By analyzing the educational documentation shared by the Smiths, I became aware of Mrs. Tammy's perspectives of disability specifically regarding Narise's academic progression and skill development. Mrs. Tammy's perspectives, then, shaped her ideologies of disability, and these ideologies were often focused on normative frameworks and the concept of literate citizenship. Throughout both Narise's IED-II and IEP, the concept of developmental age was featured. As Dyck et al. (2003) shares, developmental age is determined when "a child's characteristics can be compared with relevant norms" (p. 979). This comparison was similarly evident in familial ideologies of disability, as seen in both Riley and Michael's perspectives and experiences. The prevalence of these perspectives across familial and educational spaces highlights the dominance of medicalized understandings of disability within society. Kliewer et al. (2015) speak to the implications of these perspectives for children with disabilities. In their research that investigates the social construction of intellectual disability, Kliewer et al. (2015) assert that employing developmental age as a measure positions children who fail to meet predetermined standards as "hav[ing] *less* intelligence" and "possessing an objective and measurable disconnectedness from valued citizenship and full humanness" (p. 5; emphasis in original).

Within the classroom, teachers can perpetuate these attitudes and dispositions toward students with disabilities (Valtierra & Siegel, 2019). However, through the incorporation of inclusive literacy practices coupled with critical literacy, educators can "ensure students with disabilities and struggling readers are not only included in rich literacy experiences but are also empowered to contribute to social progress" (Valtierra & Siegel, 2019, p. 119). In order to accomplish these goals, Valtierra and Siegel posit that teacher preparation programs must design methods courses that include critical literacy that features examples involving individuals with disabilities. These pedagogical suggestions are explored further in the section entitled, "Implications for Teaching, Learning, and Literacy Research."

In the context of this study, many of Mrs. Tammy's ideologies are informed by assessment practices, particularly those required by the IED-II. This assessment requires specific procedures for administration, scoring, and interpretation (Community-University Partnerships for the Study of Children, Youth, and Families, 2001). These strict guidelines don't provide the space for educators to provide authentic reasons for communication and for students to engage in the different modes of communication they engage with and in. Dhondt et al. (2020) speak to the need for those who communicate with children with disabilities to "use contextual information and prior knowledge to interpret their communicative utterances" (p. 530). This case study extends Dhondt et al.'s consideration for those who communicate with children to those who design and proctor assessments for children with disabilities. Assessments need to expand the ways that communication is interpreted to incorporate multimodal inclusive literacy practices, as seen in the rich and vast ways that Narise was shown to communicate outside of assessment data.

Intertwined with medicalized views of disability, Narise' educational documentation also featured a variety of asset-based discourses and perspectives. Many of these discourses expand traditional notions of literacy and align with the social model of disability. With the social model of disability, literacy is positioned as a set of sociocultural practices (Flewitt et al., 2009). With this interpretation of literacy, *presuming competence* and *literate citizenship* both serve as means to oppose the social impositions that stand in the way of children with disabilities to fully participate in literacy practices (Kliewer et al., 2006).

Within Narise' IEP, Mrs. Tammy and Narise's support team presume competence in Narise's communicative abilities and help Narise work toward achieving full literate citizenship by valuing her multimodal means of communication. In contrast to Narise's experiences, Kliewer et al. (2006) cite several cases where literate citizenship has been denied to students with disabilities. Understanding Narise's experiences alongside others' presents a wide-angled view of the ways that students with disabilities have historically been "outside the circles of educational privilege" (Kliewer et al., 2006, p. 165). This view also highlights actions that can be taken to end this cycle of exclusion and challenges educators to continually reconceptualize literacy, disability, who may be literature, and, ultimately, who can engage in forming social and emotional connections with others. Accommodations, modifications, and support services attempt to alter these damaging patterns. Similar to the design and implementation of educational assessments and the creation of educational documentation, these adaptations are informed by various educational stakeholders' ideologies of disability.

Modifications and Support Services

The provisions of accommodations, modifications, and various support services is often a difficult process for families within the disability community. In their research, Schoorman et al. (2011) speak to this difficulty, particularly the marginalization and discrimination experienced by immigrant parents during the decision-making processes that are a part of special education referrals. The Smiths did not encounter this difficulty, and their experiences may be due to various factors including Jenny's career as an educator and her extensive experience in education. These unique experiences based on power struggles and powerful pedagogical practices regarding modifications and support services, ultimately, informed their ideologies of disability.

Within this case, Narise receives customized modifications and support services that have been designed with her specifically in mind. Two examples of modifications that were featured across Narise's educational documentation and within observations are the *one-on-one* aide that is paired with Narise throughout her school day and the practice of *hand over hand*. Both modifications help illuminate the interplay the between power and discourse in the constitution of the Smiths and Mrs. Tammy's ideologies of disability. In particular, Mrs. Tammy's perspectives regarding each modification helped to unearth how these modifications inform the ideologies of disability of multiple stakeholders, including both educators and family members.

Narise's one-on-one aide, through both the discourse associated with and the goals of the position, aligns with medicalized views of disability. Siebers (2017), when describing the complex politics associated with disability identity, details the ways that the medical model of disability views an individual with a disability "as an individual patient whose distinct pathology requires a treatment designed specifically for it" (p. 199). In this view, Narise's one-on-one aide is seen as a *treatment* especially designed for Narise to *cure* the results of her impairment (Haegele & Hodge, 2016).

However, not all of Narise's modifications are informed by a medicalized stance. For instance, the practice of hand over hand is situated within an asset-based framework. Through the enactment and promotion of hand over hand, Mrs. Tammy is presuming competence for both her students and their families. In her work that explores the potential of teachers presuming competence in the unique ways students with disabilities engage in texts, Kleekamp (2020) states that presuming competence entails teachers opening up their classrooms, changing their teaching practices, and believing “that students bring many competencies into classrooms regardless of their accompanying disability labels” (p. 116). Mrs. Tammy’s perspectives and teaching practices follow Kleekamps’s (2020) understanding of presuming competence, as she firmly believes that students can and will participate in tasks by engaging with hand over hand. Further, in addition to Jenny’s own educational experience and extensive knowledge of disability from her self-guided research, Mrs. Tammy’s asset-based perspectives of hand over hand positively informed Jenny’s perspectives of various modifications and her ideologies of disability.

Through the promotion of hand over hand, Mrs. Tammy presumes competence in students’ families by acknowledging that families can and do participate in rich literacy practices when children are not at school. Hand over hand is simply one way parents can facilitate these practices. By sharing how and why families and students should engage in modifications like hand over hand in familial spaces, Mrs. Tammy invites families to occupy the role of a “conversation partner” that co-constructs curriculum alongside educators, a role that families within the disability community often do not occupy (Whitehouse & Colvin, 2001). Adaptations supported by educators and employed by families is featured heavily in much of the published research on inclusive literacy practices (Hunter et al., 2017; Keilty & Galvin, 2006; Ricci, 2011; Robinson et al., 2019). Collaborations, such as those featured in preexisting scholarship, work to enact the needed deconstruction of norms and deficit categories that are woven throughout educational ideologies of disability. When formed, strong relationships between educators and families within the disability community can shape ideologies of disability through discursive choices that are authentic and based on lived experiences of disability (Whitehouse & Colvin, 2001).

Intersections of Familial and Educational Ideologies

Throughout the data, I saw the myriad ways that familial and educational ideologies often intersect, as Narise, her family, and Mrs. Tammy worked together. These points of intersection represent the contingent power relations that exist between members of the disability community. In particular, communication served as a primary point of convergence within the context of this study. Collectively, the findings show that family members and educational stakeholders' perspectives, informed by the various means of communication they engage in, constitute one another's intersecting ideologies of disability. By exploring the many means that the Smiths and Narise's school community use to communicate with one another in and across familial spaces, I continued to see how individual perspectives informed ideologies of disability. Specifically, the Smiths' and Mrs. Tammy's ideologies of disability were shaped by the concept of responsive caregiving and their engagement in collaboration with one another.

The members of the Smith family and Mrs. Tammy all had varying language practices that they employed in different contexts, and, further, their judgements of these same practices differed. Pizer et al. (2012) noted similar patterns in their study of language practices and ideologies of families within the Deaf community. Pizer et al. assert that families who potentially experience communication barriers often "develop language practices guided by a system of beliefs and attitudes concerning the languages and communities in question and by family members' judgements concerning appropriate linguistic behavior in the home" (p. 75). In regard to the Smith family, in-school and home language practices heavily influenced the other, and familial and educational ideologies also affected individual perspectives of linguistic behaviors by the continual introduction of new and different ways to communicate.

Within her home and at school, Narise used adaptive sign language and a customized core board. While these modes of communication are both unique to Narise, as she has created or assisted in the creation of both, the perspectives had by the Smiths and Mrs. Tammy surrounding Narise's use of these means of communication are common within the disability community and the literature published on family literacy practices within the disability community. For example, many caregivers engage in *responsive caregiving*, just as Jenny does when she interprets and responds to Narise's collective use of adaptive sign language, gesture, and verbal speech to communicate her wants and needs. Keilty and Galvin (2006) define responsive caregiving as the process when "an adult tailors his or her interactions by accurately reading and responding to the child's unique communicative cues" (p. 220) and cites several examples of responsive caregiving in their work. Throughout five holistic case studies, Keity and Galvin (2006) further note that responsive caregiving is ultimately contingent on three components: child-directed initiation of communication; caregivers' continued engagement; and caregivers' sensitivity toward children's needs. Thus, as evident in this case and Keilty and Gavin's (2006) research, responsive caregiving is dependent on the perspectives of all involved, as ideologies of disability impact both the initiation and response to multimodal communicative practices.

Using her core board, Narise was also able to convey her thoughts. Narise's use of her core board was supported at home and at school, and she was often asked to share her preferences. While Jenny and Mrs. Tammy have differing perspectives of Narise' core board, they both have a common goal: Narise's success. This goal involves Narise communicating and connecting with others and, ultimately, participating as a literate citizen within society more broadly (Kliewer et al., 2006). The use of AAC devices, such as core boards, and the possibilities they provide has also been the subject of research with children and families within the disability community (Bhattacharya et al., 2022; Kafer, 2017; Koppenhaver et al., 2001). Both Bhattacharya et al. (2022) and Kafer (2017) detail how AAC devices give users with multiple or significant disabilities the tools necessary to express themselves and, further, push past preconceived notions regarding their cognitive and communicative abilities. The use of AAC devices also challenges educators and researchers alike to reconsider what it means to speak and to participate in literacy activities (Bhattacharya et al., 2022). As these findings highlight, perceptions surrounding speech and literacy continually evolve. These changing perceptions, in turn, shape ideologies of disability.

Implications for Teaching, Learning, and Literacy Research

As a member of the disability community, I related to many of the experiences shared by Narise, Jenny, Michael, Riley, and Mrs. Tammy and seen within the Smiths' home, because my family and I had also experienced similar events. However, their experiences also facilitated new understandings of disability, as I encountered so many aspects of the disability experience I had never before considered. Alongside my role as a sibling, my role as a researcher also led to new understandings. As Bhattacharya (2017) states, case studies can lead to "new relationships, concepts, and understandings inductively rather than deductively" (p. 109). Through my personal history, in addition to all I've learned throughout this study, I contemplated the benefits of the implications of this study. These varied implications for researchers, teachers, teacher educators, and families are explored in the following sections.

Researchers

Many of the implications for qualitative researchers stem from the inclusive research practices that informed much of the design and implementation of my study, as these practices should be considerations for all researchers, particularly those that work alongside the disability community. As Goethals et al. (2015) assert, *inclusive research* is often “a term that encompasses a range of research approaches that have been traditionally termed ‘participatory’ or ‘emancipatory’” (p. 80). However, inclusive research does not have to fall into these particular paradigms or conform to a specific label. Instead, inclusive research entails that individuals with disabilities are active participants and that analysis is grounded in the lived experiences of the participants (Goethals et al., 2015; Kerschbaum & Price, 2017). Simply put, inclusive research practices involve the engagement of individuals with disabilities in every stage of the research process. This inclusion then creates spaces to explore new theory, methods, and social change (Goethals et al., 2015).

In addition to employing inclusive research methods, employing CDS as a theoretical framework has expansive potential for qualitative research (Schalk, 2017). As Schalk (2017) posits, CDS can be understood “as a method, an approach, a theoretical framework—not (exclusively) a study of disabled people” (p. 5). CDS allows researchers to understand that their analysis is situated within a society that materially and discursively constructs the concept of disability. Further, CDS fosters the critique of these same constructions. The criticality associated with CDS can push researchers to look more deeply at qualitative methods and practices and rethink the ways that disability in positioned in their work. Kerschbaum and Price (2017) similarly challenge researchers to “unsettle” their assumptions about qualitative research and have participants’ needs guide their design and the methods they ultimately employ (p. 98).

As I came to know the Smiths and Mrs. Tammy and continued this study, I had to question my own beliefs surrounding qualitative research, disability, literacy, and inclusive research practices, and the theories and models associated with CDS served as an invaluable guide during this process. I edited and expanded the data collection methods due to safety precautions set in place after the start of the COVID-19 pandemic and responding to the Smiths' needs. I pushed against my own deficit understandings of disability and communicative practices and learned more about AAC devices and their transformative role in the lives of those within the disability community. I reconceptualized my own definitions of literacy and literacy practices and investigated the dominance of verbal and written speech within our society. I was consistently reminded of my own reliance on verbal and written speech. Often, within the data, I missed so many instances of multimodal communication, particularly Narise and her family's use of adaptive sign language and expressive language. I had to repeatedly rewatch recorded observations and interviews to understand the nuanced ways that the Smiths communicate with one another, ways that seemed so different to me but were a part of their ever-expanding repertoires. Engaging in this study as a teacher and teacher educator, I urge all educators across fields to similarly challenge their beliefs concerning these complex concepts.

Teachers

As with qualitative research, the incorporation of CDS within educational spaces has widespread implications. In particular, the Smith family's collaboration with Mrs. Tammy and the other members of Narise's educational support team highlights how educators become vital members and extensions of the disability community. Often, educators are the individuals that families turn to for support, whether looking for recommendations of texts, educational opportunities and training, or the formation of community (Lampp Berglund, 2021). With this large role in the lives of families within the disability community, educators, then, are responsible for making educational spaces more inclusive and accessible sites where students with disabilities and their families can participate more fully.

As Sandoval Gomez and McKee (2020) share, CDS can help educators “understand the ‘why’ of inclusive education and equality” and help them determine how to move forward and take action (p. 2). The actions that teachers can take vary based on a number of contextual factors, including grade level, administrative support, and the resources available. However, practical applications of incorporating CDS into one’s pedagogical practices and teaching philosophy include, first, promoting CDS to our colleagues and students through workshops and curriculum. These opportunities can prompt deep, communal and individual reflections on our own biases about disability and what larger social, cultural, political, economic, and historical forces have shaped these understandings (Schalk, 2017; Ware & Hatz, 2016). Second, teachers can presume competence in their students and their families. By presuming competence, teachers can push against deficient views of students with disabilities and broaden the scope of how students and their families participate in classroom communities and society more broadly (Kleekamp, 2020; Kliewer et al., 2006; Valtieraa & Siegel, 2019).

In addition to these applications of CDS, teachers can also listen to and center the voices of the disability community in their classroom materials and beyond through humanizing and accurate portrayals (Wong, 2020). However, as Wong (2020) asserts, “And yet while representation is exciting and important, it is not enough... *We all should expect more. We all deserve more*” (p. xxi; emphasis in original). While inclusion in materials is important, inclusion is physical spaces is paramount, but inclusion in regard to educational placement cannot be accomplished without the support of school leaders (Sandoval Gomez & McKee, 2020). School leaders must engage in perspectives grounded in CDS and Disability Studies in Education (DSE). With these perspectives, school leaders and teachers then see educational placements as a civil right, rather than a privilege. In order to promote these perspectives, school leaders need to cultivate a collaborative community of learners. This community is formed through “building the learning capacity of their educators to teach all students” (Sandoval Gomez & McKee, 2020, p. 4). Professional development, including the workshops mentioned above, can work to build this capacity. However, to make this lasting change in P-12 education, perspectives in teacher education must first be shifted.

Teacher Educators

While the work that takes place in teacher preparation programs lays the foundation for the powerful pedagogical practices and leadership skills that are featured above, many of the suggestions for teachers are similarly applicable for teacher educators. Most importantly, incorporating a CDS lens when mapping curriculum and designing courses in teacher preparation programs can facilitate these needed changes. Understanding the lived experiences of individuals within the disability community informs how disability is discussed in teacher preparation programs. This reframing involves promoting an asset-based curriculum and positioning disability as multifaceted concept, rather than a deficient categorization. Specifically, acknowledging the complexity of the disability experience can transform both undergraduate and graduate level courses in teacher education. These courses, among so many others, can promote providing an inclusive and equitable environment for students with disabilities, their families, and their larger community.

Van Hove et al. (2012) have begun this needed work and conceptualized “a pedagogy of hope” graduate level courses in education grounded in DSE. This pedagogical approach supports “a way of thinking and working in which problems, solutions, and roles are defined differently from the traditional models of disability” (Van Hove et al., 2012, p. 45). In order to take up this approach, teacher educators must foster the continued participation of all students. Participation, in this sense, means much more than being present. Participation means belonging and active involvement in whatever may be happening, whether that means listening, providing support, or joining in advocacy efforts. By instilling these tenets of a pedagogy of hope throughout courses in teacher education, pre-service teachers can become reflective, critical, and transformative educators who promote these same values with their own students.

Families

As evidenced in this study and previously published research, family participation deeply impacts students' educational experiences, specifically in the disability community, as family members and educational stakeholders continually collaborate to ensure the best educational outcomes are achieved. Often, these outcomes are achieved due to advocacy efforts led by family members. Gardland-Thomson (2017) presents the concept of *academic activism* within the field of CDS. Academic activism is "the activism of integrating education" and creating inclusive learning environments for students with disabilities (p. 377). This concept is supported by the belief that "scholars and teachers shape the communal knowledge and the archive that is disseminated from kindergarten to the university," and educational stakeholders serve as the grassroots movement working toward equitable education for students within the disability community (Garland-Thomson, 2017, p. 377). I contend that family members are integral members of this community that shapes our collective knowledge, as they also do the cultural work of exposing oppression and offering counter narratives for different ways of being and knowing in educational spaces (Garland-Thomson, 2017). Through academic activism, family members can work to break down the cultural, social, economic, and historical barriers that students face when attempting to participate more fully in their classrooms and society, as highlighted in this study.

Increased participation of families within educational spaces can take many shapes, particularly when conceptualizing the participation of families within the disability community. However, before this participation can be facilitated, families must first “revalue themselves as knowledgeable” contributors within classroom and educational communities (Kabuto, 2016, p. 302). In order to accomplish this revaluation, families need to examine their individual and collective ideologies surrounding disability. As seen in the Smiths’ experiences, familial ideologies of disability can become entangled in educational ideologies, as families experiences the “emotional, social, and cultural impacts of school-based labels” (Kabuto, 2016, p. 302). By first becoming aware of these influences, families can then work to dismantle damaging effects and become active participants in children’s educational experiences.

Directions for Future Research

This research specifically explores the multiple ideologies of disability that exist within one family and the varied ways these ideologies are laden with power and constituted through interactions with other family members and select educational stakeholders and the documents exchanged. While the focus of this study was on one family, this research could be extended to consider multiple families’ perspectives. This extension would highlight the commonalities and differences of the experiences of families within the disability community. As Turnbull and Turnbull (2001) share, “Every family is such a mixture of characteristics that it is probably safe to say that every family is idiosyncratic” (p. 86). Understanding these idiosyncrasies can serve as a way to understand how to change research practices and instructional methods to better suit the needs of an increasingly diverse student population.

In addition to expanding the number of families that are considered, additional elements could be incorporated as sources of data. While interviews, observations, and documents served as the sources of data within this case, case study, as a method, presents the opportunity for researchers to collect multiple and varied sources of data. These sources can include but are not limited to documentation, archival records, interviews, direct observations, participants-observations, and physical artifacts (Yin, 2018). Having more data sources collected in this study can provide an even wider scope of a case and assist in conducting in-depth and relevant research based on each family's particular context. Specifically, I hope to use an observational survey of children's literature that was conducted with the Smith family as an additional source of data to deepen my analysis and continue my research.

Alongside the possibilities of featuring more sources of data to provide insight into the variability and multifaceted nature of the disability experience, I also acknowledge the importance of exploring intersectionality in future research. Past research on disability "assign[ed] prominence to disability and use[d] an additive approach which entails looking at various variables as isolated and dichotomous rather than interactive and mutually dependent" (Goethals et al., 2015, p. 75). Only recently, CDS scholars have begun to engage in research that features an examination of "multiple axes of differences" (Goethals et al., p. 75). In future research, attention should be given to other identity categories held by those within the disability community, including but not limited to race, gender, and socioeconomic status. This inclusion will promote "an understanding of the complexities of people's lives" (Goethals, et al., p. 75) that is vital to inclusive and transformative research that is conducted alongside the disability community. However, it is important to note that employing an intersectionality lens does not mean that future research should focus solely on varying identity categories. Instead, intersectionality also presents the opportunity to analyze structures of inequality, because "intersectionality is inextricably linked to analyses of power" (Cho et al., 2013, p. 797). In this way, the framework and methodology of intersectionality can assist in a deeper exploration of the varied ways ideologies of disability are laden with power and continually constituted.

Employing an intersectional lens, I hope to further explore the concept of literate citizenship (Kliewer, 2006) and the power bound within varying understandings of citizenship. As Ramanathan (2013) explains, citizenship goes beyond "the passport one holds or one's immigration or visa status" and "needs to be understood in terms of *being able to participate fully*" (p. 162; emphasis added). Moreover, Ramanathan (2013) asserts that citizenship should be viewed "as a process amidst tensions, fluid contexts, and diverse meanings" (p. 162). This expansion of the notion of citizenship also involves acknowledging the related concept of *dis-citizenship* which occurs when a citizen's rights are denied (Bhattacharya & Jiang, 2021; Pothier & Devlin, 2007). Within CDS, dis-citizenship is experienced within "a system of deep structural economic, social, political, legal, and cultural inequality in which persons with disabilities experience unequal citizenship" (Pothier & Devlin, 2007, p. 1). Recently, researchers within the field of language and literacy education have sought to address the myriad ways that pedagogical practices and institutional discourses foster conditions in which the process of dis-citizenship occurs for individuals within the disability community (Bhattacharya & Jiang, 2021; Ramanathan, 2013). Joining these efforts and building off the foundational work of Kliewer (2006), Pothier and Delvin (2007), Ramanathan (2013), and Bhattacharya and Jiang (2021) in future research endeavors, I plan to continually reflect on the complexity of citizenship and, more specifically, the concept of literate citizenship and the ways that Narise's multiple identity categories collectively impact the ways she can and does "participate more fully" in educational and literacy-based activities.

Lastly, extending this research into classroom spaces would further illuminate family members and educational stakeholders' ideologies of disability. The COVID-19 pandemic, safety guidelines, and the corresponding required research protocols impeded my wishes to also conduct research in schools. However, as guidelines ease, this extension could help researchers and educators see how disability is positioned in educational spaces by examining the discourses employed daily by educational stakeholders and students and the curriculum and resources used. Having this perspective could provide an expansive view of the lives of those within the disability community, as these lives are not only lived within familial spaces. In order to make the needed changes within our educational system and society, we must first more fully understand the current reality of students with disabilities, including their experiences within educational spaces. While the data produced within familial spaces provides insight into educational experiences, as educational and familial spaces often overlap within the disability community (Engel, 2020), many discontinuities exist. With this knowledge of differing environments, resources, and the specialized training of educators, educational spaces, too, must be explored.

Throughout the study, in both familial and educational settings, multiple participants shared the following statement about Narise: "She's writing her own book." This study explored just one small section of Narise's book. As she continues to experience disability, she will go on to fill even more pages of her book with her own unique perspectives, and, as educators, researchers, and scholars, we have so much to learn from her and other students within the disability community. Through research, teaching, and advocacy, we will never stop learning, as disability and our ideologies of disability continually shift and evolve.

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Children's Literature

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Appendix A

Recruitment Flyer

(DIS)ABILITY COMMUNITY MEMBERS NEEDED

I am conducting a research study about the different ways family members navigate their understandings of (dis)ability and what resources they use.

WHAT IS INVOLVED?

Family members will be asked to do the following activities virtually:

- An initial family interview (to share background information, establish norms, and create a schedule) that will last 1 hour max
- One individual interview with each family member that will last 1 hour max
- Twice weekly hour-long observations for three months during April, May, and June (up to 24 total)
- Bi-monthly check-ins (up to 6 total)
- Survey of children's books in your home using a method of your choice.

WHO CAN PARTICIPATE?

Families which include at least one child with a (dis)ability.

INTERESTED?

Please contact Alex Berglund at 478-231-1198 or alampp@uga.edu. The faculty advisors associated with this project are Dr. Jennifer Graff (jgraff@uga.edu) and Dr. Usree Bhattacharya (ubhattacharya@uga.edu)

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Appendix B

Table 1

Timeline for Research Process

Timeline	**Step in Research Process**
April	IRB Approval
May	Recruitment of Participant Family **Collection of Data** *Interviews*: • Initial Interview with Jenny *Fieldnotes/Journal Entries* Data Analysis (Ongoing)
June - August	**Collection of Data** *Interviews*: • Individual Interviews with Participants (Jenny, Michael, Riley, and Mrs. Tammy) • Follow-Up Interviews – 1 Total Interview • Spontaneous Conversations (as they occurred) *Observations*: • 1 Hour (as scheduled) – 12 Total Observations *Document Analysis* *Fieldnotes/Journal Entries* *Survey of Children's Literature* Data Analysis (Ongoing)
September - December	Fieldnotes/Journal Entries Data Analysis (Ongoing)

Appendix C

Initial Interview with Parent Protocol

Thank you for participating in this study focused on ideologies, disability, and family, and thank you for meeting with me today. I am so excited for the work that we are all going to do together, and I cannot wait to get started. However, before we begin, I want to share a little more about myself. As I may have mentioned, my brother was diagnosed with a disability, autism, when we were both children. His diagnosis, and the way my family navigated that diagnosis and still continues to, inspired my desire to work in education and, more specifically, to conduct research with families within the disability community. I care deeply about the work that I do, and I have worked to understand these concepts in my own personal life. Now, I hope to explore how other families work to understand these same concepts.

During this initial interview, we need to establish the ways that we will engage in this research together by reviewing research protocols and discussing any other people who you think would be important to include in the study (e.g., other family members, select educational stakeholders, etc.). To help us in this process, I've created a few guiding questions. If you have any additional questions, please let me know. This is a collaborative process, and I value your input in every step of this study.

Topic Domain: Family

Lead Off Question: I know family is a complex concept and one that changes continually throughout our lives as we experience loss in different forms and also joyful events. At this time, who do you consider your immediate family and why?

Possible Follow-Up Questions:

- Who, within your immediate family, would you like to participate in the study and why?
- Who, within your extended family, would you like to participate in the study and why?
- Are there any exceptions to any familial participation in any stage of the study?

Topic Domain: Disability

Lead Off Question: You initially included this in the recruitment survey, but would you mind speaking briefly about ___________'s disability diagnosis (e.g., age of diagnosis, process, etc.)? Is there anything specific about their diagnosis that you would like to share?

Topic Domain: Research Methods

Lead Off Question: Again, I would like to confirm that what you included in the recruitment survey is still accurate and that your preference has not changed. Would you mind sharing your current preference for future in-person or virtual interviews and observations? During in-person interactions, I would wear appropriate PPE and follow the CDC guidelines and local laws and regulations regarding COVID protocols. During virtual interactions, we would use Zoom or another video communication platform.

Possible Follow-Up Questions:

- What life routines would you like featured in twice-weekly observations? These could include a variety of activities such as family storytime, independent reading time, homework completion, play time, etc.
- What times of day and days of the week would be best to observe these routines? These may vary each week, and that is okay.
- Who would typically be present during these routines?

- I would like to schedule bi-monthly check-ins to create a space for us to share any details, concerns, or questions that we may have that we don’t get to discuss during our interviews and observations. These should last no longer than an hour. What dates and times would work best for you and your family?

Lead Off Question: What documents would you feel comfortable sharing with me? These documents would be communication or resources that are exchanged between you and your family members and/or educational stakeholders. Examples of documents include brief handwritten messages, emails, Individual Education Plans (IEPs), artwork, school/class flyers and newsletters, etc.

Lead Off Question: How would you like to share the children’s books that you have in your home? You can share photographs of book covers, I can visit (with proper PPE) to make a list, or you can create the list. What do you prefer/feel comfortable with, at this time?

Appendix D

Table 2

All Data Sources Featured in the Study

Data Source	**Date**	**Length (In Minutes)**	**Participants**
Initial Interview	6.1.2021	24.56	Jenny; Narise
Individual Interview	6.22.2021	51.10	Jenny; Narise
Individual Interview	6.23.2021	28.18	Michael; Narise
Individual Interview	6.25.2021	33.41	Riley
Individual Interview	7.21.21	54.10	Mrs. Tammy
Follow-Up Interview	8.11.2021	36.32	Jenny
Observation 1	6.11.2021	60.00	Jenny; Narise
Observation 2	6.21.2021	57.21	Jenny; Narise
Observation 3	6.24.2021	63.36	Jenny; Michael; Narise
Observation 4	7.6.2021	59.31	Jenny; Narise
Observation 5	7.8.2021	62.24	Jenny; Narise
Observation 6	7.9.2021	60.36	Jenny; Narise
Observation 7	7.19.2021	63.36	Jenny; Narise
Observation 8	7.20.2021	61.48	Jenny; Michael; Narise
Observation 9	7.22.2021	61.12	Jenny; Narise; Family Friends
Observation 10	7.26.2021	61.12	Jenny; Michael; Riley; Narise
Observation 11	7.28.2021	58.07	Jenny; Michael; Riley; Narise
Observation 12	7.29.2021	53.55	Michael; Narise

Appendix E

Individual Interview Protocol:

Parents

First, I would like to thank you for meeting with me today. After establishing norms in our initial conversation, I'm grateful to have this time with you, to gain your insight, and to hear more about you and your individual understandings of disability, family, and so much more. To help guide us in our conversation on these concepts, I've created a few questions to get us started, but, if you want to discuss anything other topics or ask any questions during our time together, please do so.

Topic Doman: Family

Lead Off Question: Could you tell me a more about yourself, your family (e.g., children, living arrangements, etc.), and your child with a disability (e.g., age, sex, type of(disability, etc.)?

Possible Follow-Up Questions:

- What kinds of things do you like to do for fun with your family?
- What is your role in the family?
- What are the roles of other family members?
- Can you share more about the relationships between your child with a disability and their sibling(s)?
- Can you share more about the relationships between your child with a disability and other family members?

Topic Domain: Disability

Lead Off Question: How would you define disability?

Possible Follow-Up Questions:

- How do you think __________’s disability has influenced/changed your family, if it has?
- How do you think others view your child with a disability?
- What are the different resources you receive or have received for your child with a disability? Where do you get extra support for your child, their siblings, and yourself?

Topic Domain: Children’s Literature

Lead Off Question: When we first met, you shared that you and your child(ren) read children’s literature together. What types of children’s books do you typically read with your child(ren)?

Possible Follow-Up Questions:

- What children’s books has _________ enjoyed the most?
- How do you find and choose books to read with/for ___________?
- How do you see disability represented in the children’s books you read together, if at all??

Topic Doman: Education

Lead Off Question: Earlier, you mentioned that __________ received support services with/from _________. As a parent of a child with a disability, could you share some of your experiences within the larger school system?

Possible Follow-Up Questions:

- Could you describe your relationship with various educational stakeholders that work to support ___________ and your family?
- How do you communicate with your child’s teachers and other educational stakeholders?

Appendix F

Individual Interview Protocol:

Sibling of Child with a Disability

First, I want to thank you for meeting with me today. I am so excited to speak with you and learn more about you. Before we start, I'd like to tell you a little bit about myself. My name is Alex, and I am a student at the University of Georgia. I also want to share that my brother has a disability. His experiences, in addition to my own and my parents' experiences, around disability led me to this project where I get to talk to you and your family about your own experiences, thoughts, and feelings around and about disability. I know that you and I both have so much to share with one another and that we can work to build new knowledge together. Additionally, please know that what you share with me stays between us. I will not share any of our conversation with your parents, unless the information concerns your safety. To help guide us in our conversation, I've written a few questions to get us started, but, at any time, if have any questions or any other topics you would like to discuss, please let me know.

Topic Doman: Family

Lead Off Question: Could you tell me a little about yourself (e.g., hobbies, school, etc.) and your family (e.g., parents, siblings, etc.)?

Possible Follow-Up Questions:

- What kind of things do you and your family like to do for fun?

- What life routines do you think would be important for me to observe to get to know you and your family better? These could include different activities, such as family storytime, independent reading time, homework completion, play time, etc.
- Can you share more about other family members that you see often?
- Can you share more about your relationship with your brother/sister?

Topic Doman: Disability

Lead Off Question: Can you tell me more about your sibling's disability?

Possible Follow-Up Questions:

- How do you and your family talk about your sibling's disability, if you do? How do your friends talk about your sibling's disability, if they do?
- Could you tell me more about when you first learned about your sibling's disability?

Topic Doman: Children's Literature

Lead Off Questions: What are your favorite books to read with your family? What are your favorite books to read by yourself?

Possible Follow-Up Questions:

- How do you choose the books that you read?
- Can you tell me more about the characters that you see/read about in the books that you choose?

Topic Doman: Education

Lead Off Question: Can you tell me a little more about your school/your teacher/your (virtual) classroom?

Possible Follow-Up Questions:

How does your family participate in your classroom, if they do?

Appendix G

Individual Interview Protocol:

Educational Stakeholder

First, I would like to thank you for meeting with me today. I'm grateful to have your insight and hear more about you and your understandings of disability, education, children's literature and so much more. However, before we begin, I want to share a little more about myself. As I may have mentioned previously, my brother was diagnosed with a disability, autism, when we were both children. His diagnosis, and the way my family navigated that diagnosis and still continues to, inspired my desire to work in education. I was a preschool teacher for three years before pursuing a PhD in Language and Literacy Education full-time. For my dissertation, I am conducting research with families within the disability community. I care deeply about the work that I do, and I have worked to understand these concepts in my own personal and professional lives. To help initially guide us in our conversation on these concepts, I've created a few questions to get us started, but, if you want to discuss anything else during our time together, please do so.

Topic Doman: Disability

Lead Off Question: Could you share a little about _________'s disability?

Possible Follow-Up Questions:

- How would you define disability?
- How do you think ___________'s disability has influenced/changed your classroom, if it has?

- How do you think other students view ___________’s disability?

Topic Doman: Children’s Literature

Lead Off Question: What types of children’s books do you typically read with your students, if you do?

Possible Follow-Up Questions:

- How do you find the time and space to read children’s books with your students, if you do?
- What children’s books have your students enjoyed the most?
- How do you find and choose books to read with your students?
- How do you see disability represented in the children’s books that you read with your students?

Topic Doman: Education

Lead Off Question:

Could you share more about your experiences working with ______________ and their family this year?

Possible Follow-Up Questions:

- What accommodations does _____________ receive, if any?
- What modifications have you set in place for ______________, if any?
- Who are other educators or support staff that you work with?
- Could you share more about your collaborations with other educational stakeholders? How do you and other stakeholders work together to create an inclusive environment for _____________?

Appendix H

Follow-Up Interview Protocol

First, I would like to thank you for meeting with me today and for your continued participation in and collaboration with this study. I'm so grateful to you and your family for your openness, flexibility, and kindness. Today, I'd like to discuss some of the things I've noticed during our time together and in the documents that you've shared. I've created different questions to help guide this discussion. However, if at any point, you would like to discuss any other topics or ask any questions, please do so.

Topic Domain: Family Literacy Practices

Dissertation

- In your dissertation, you share that Naris and your experience as a mother of a child with multiple disabilities inspired you to pursue your chosen topic. How did various other family members play a role or inform the writing process or journey, if they did?
- In your dissertation, you include that you've saved all the documentation from Narise's medical appointments and educational meetings. What function does this collection of documents serve for you and your family?
- Throughout your dissertation, you discuss Narise's love of books and that you weren't exactly sure what sparked this love. However, could you share more about the time when you noticed when this love first began?
    - In our interview and observations, we discussed and I saw you and Narise read some of her favorite books (*Madeline and the Bad Hat*, *Mr. Brown Can Moo. Can*

You?, I Love You, Stinky Face, etc.). What do you think draws Narise to these particular books?

- In your narrative, you described the different ways that Narise has learned to communicate with everyone around her (gesture, speech sounds, adapted sign language, PECS, etc.). How have these different communication systems affected the ways that your entire family communicates with one another, if it has?

Topic Domain: Disability and Race

- Throughout the observations and interviews with you, your family and Narise's teacher, Narise's seizure disorder was repeatedly mentioned. Could you share more about Narisee's seizure disorder (frequency, intensity, aftereffects)? How do you think Narise's seizures impact your family and your daily routine?
- In your dissertation, you briefly mentioned how race determined which cognitive assessments Narise was able to receive. Are there other ways that you see race affecting how your family has navigated the disability experience? If so, could you share some examples?

Topic Domain: Education

- Narise's teacher shared that she uses a parent communication app, Bloomz, to share messages with parents throughout the year. What has been your experience communicating with Narise's teacher in the Bloomz app?
- In our interview, Narise's teacher mentioned the practice of hand-over-hand, where the educator, parent, or therapist places their hand(s) over the child's hand(s) to guide them during an activity. This practice is something I've noticed you and Narise doing at home

during our observations. Can you share more about how you learned to do or started to do this process?

Topic Domain: Research Methods

- How would you describe the experience of participating in the observations that have been a part of this study? How did your experience change as the study progressed?
- How do you think the presence of the tablet influenced Narise's behavior, if it did?

Appendix I

Table 3

Observation Events

Observation	**Date Collected**	**Event**	**Details**	**Length**
1	6.11.2021	1	First observed storytime with Jenny and Narise reading *I Love You to the Moon and Back* (Hepworth, 2015)	3.90
3	6.21.2021	2	Storytime with Michael and Narise; Jenny gives Narise her medicine as storytime is beginning	6.00
7	7.19.2021	3	Storytime with American Sign Language (ASL); receptive identification; and dialogic reading practices	4.55
9	7.22.2021	4	Storytime reading *The Wonky Donkey* (Smith, 2010)	4.00
9	7.22.2021	5	Storytime with Jenny and Narise; Narise selects her favorite story from *Mad About Madeline: The Complete Tales* (Bemelmans, 2001)	5.00
10	7.26.2021	6	Familial conversation with Michael, Jenny, and Narise	5.00
11	7.28.2021	7	Familial conversation with Jenny, Riley, and Narise	5.00

Appendix J

Table 4

Documentation Included in Study

Document	Description	Created By	Shared By
Annual Goal 1 (2020-2021) – Math	Annual goals and objectives progress report in a particular subject area	Mrs. Tammy	The Smiths
Annual Goal 2 (2020-2021) – English	Annual goals and objectives progress report in a particular subject area	Mrs. Tammy	The Smiths
Annual Goal 3 (2020-2021) – Self Help	Annual goals and objectives progress report in a particular subject area	Mrs. Tammy	The Smiths
Annual Goal 4 (2020-2021) – Language Development	Annual goals and objectives progress report in a particular subject area	Mrs. Tammy	The Smiths
Annual Goal 5 (2020-2021) – Language Development - Math	Annual goals and objectives progress report in a particular subject area	Mrs. Tammy	The Smiths
Annual Goal 6 (2020-2021) – Handwriting	Annual goals and objectives progress report in a particular subject area	Mrs. Tammy	The Smiths
Speech Goal 1 (2020)	Annual goals and objectives progress report in speech	Speech Therapist	The Smiths
Speech Goal 2 (2021)	Annual goals and objectives progress report in speech	Speech Therapist	The Smiths
Brigance Diagnostic Inventory of Early Development II (IED-II)	Inventory of early development that measures skills alongside assessed developmental age	Mrs. Tammy	The Smiths

Individual Education Plan (IEP)	Inventory of performance, strengths, goals, accommodations, and any other needs to required services	Educational Support Team; The Smiths	The Smiths
Individual Program Plan (IPP)	Inventory of goals, services, and supports needed to increase participation in community	Service Coordinator (Local Support Center for Individuals with Disabilities)	The Smiths
Psycho-Educational Report	Assessment renewal of special education services; Contains review of records, observations of behavior, interview, and health and development survey	Educational Support Team; The Smiths	The Smiths
Seizure Action Plan	Detailed health and medical information that provides guidelines on how to respond in a medical emergency	Narise's Doctor	The Smiths
Speech and Language Evaluation Report	Inventory of records, medical information, assessment results, and service recommendations to include in IEP	Speech Therapist	The Smiths

Appendix K

Table 5

Coding Cycles

Cycle	**Analysis**	**Coding**	**Memo**	**Product**
1	Inductive	Descriptive Coding	Record thoughts on data collection and potential analysis process	Organized data
2	Deductive	Topical Categories (Aligned with research questions)	Record initial impressions	Organized, relevant data
3	Inductive/ Deductive	Open Coding	Develop code definitions Identify key ideas in relation to the research questions	Inductive codes; Codebook
4	Inductive	Pattern Coding; Theme Development	Respond to research questions; Identify representative data; Develop case summaries; Catalog changes	Findings
5	Inductive/ Deductive	Theoretical Coding: - Critical Disability Studies (CDS)	Respond to the analytic questions in relation to existing research and theoretical framework; Develop explanation of findings	Theory-based explanation of the findings

Theory: Critical Disability Studies

Appendix L

Table 6

Example of Coding Cycles

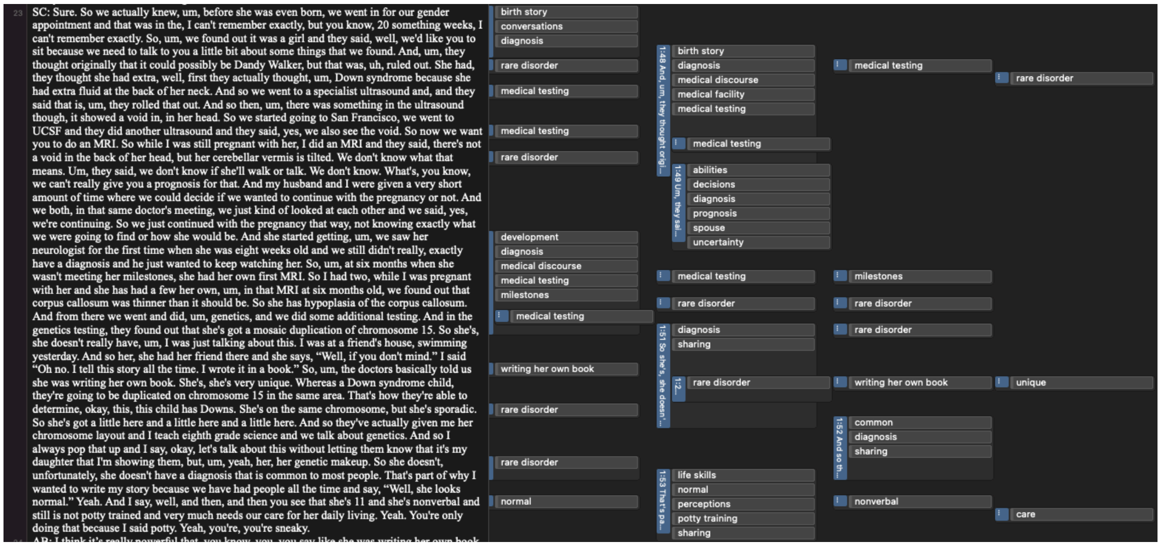
Data Excerpt: Individual Interview 1

Coding Cycles:

Cycle	Analysis	Coding	Product
1	Inductive	Descriptive Coding	**Descriptive Codes Used for Individual Interview** (See Figure 3.3 below): Abilities; Birth Story; Conversations; Decisions; Development; Diagnosis; Rare Disorder; Medical Discourse; Medical Facility; Medical Testing; Milestone; Prognosis; Sharing; Spouse; Rare Disorder; Uncertainty
2	Deductive	Topical Categories (Aligned with research questions)	**Categories Created** (See Figure 3.4 below): Communication; Disability Discourse; Family
3	Inductive/ Deductive	Open Coding	**Inductive Codes Used for Individual Interview** (See Figure 3.4 below): Diagnosis; Medical Discourse; Medical Testing; Uncertainty
4	Inductive	Pattern Coding; Theme Development	**Theme**: Familial ideologies of disability are informed by familial roles, support systems, routines, and conversations. **Findings Statement**: The presence of medical discourse is seamlessly woven into the Smiths' daily discourse.

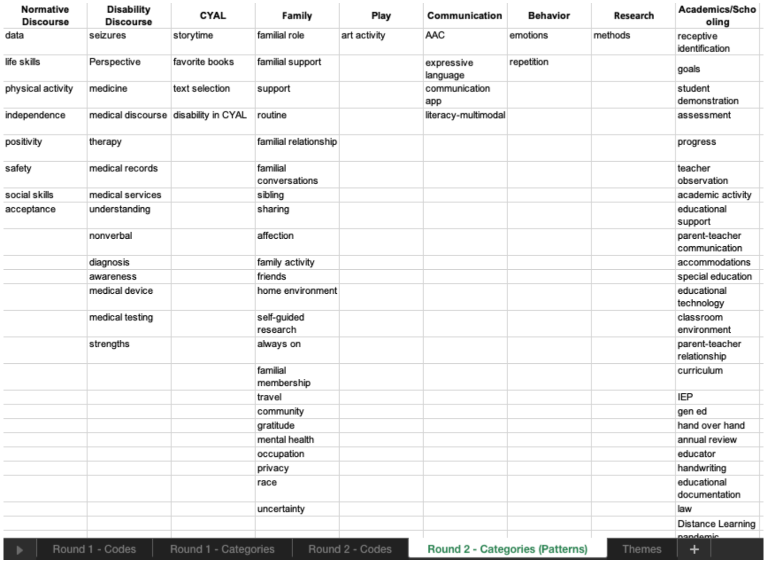
Theory: Critical Disability Studies

5	Inductive/ Deductive	Theoretical Coding: Critical Disability Studies (CDS)	**Explanation of Findings**: Jenny effortlessly infuses medical discourse into her daily discourse. Further, she affirmatively participates in medical discourses surrounding disability, discourses that are traditionally authoritative and limiting (Haegele & Hodge, 2016).



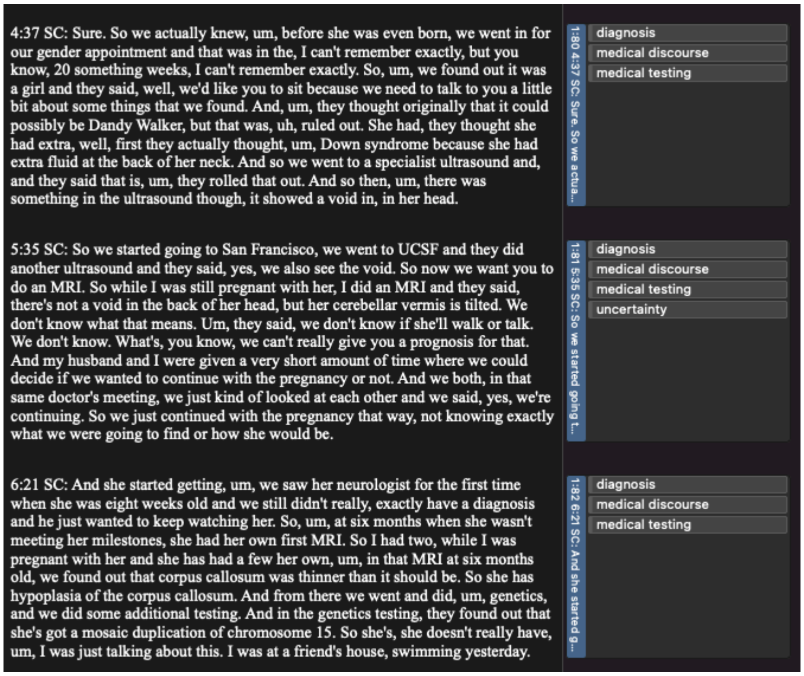
SC: Sure. So we actually knew, um, before she was even born, we went in for our gender appointment and that was in the, I can't remember exactly, but you know, 20 something weeks, I can't remember exactly. So, um, we found out it was a girl and they said, well, we'd like you to sit because we need to talk to you a little bit about some things that we found. And, um, they thought originally that it could possibly be Dandy Walker, but that was, uh, ruled out. She had, they thought she had extra, well, first they actually thought, um, Down syndrome because she had extra fluid at the back of her neck. And so we went to a specialist ultrasound and, and they said that is, um, they rolled that out. And so then, um, there was something in the ultrasound though, it showed a void in, in her head. So we started going to San Francisco, we went to UCSF and they did another ultrasound and they said, yes, we also see the void. So now we want you to do an MRI. So while I was still pregnant with her, I did an MRI and they said, there's not a void in the back of her head, but her cerebellar vermis is tilted. We don't know what that means. Um, they said, we don't know if she'll walk or talk. We don't know. What's, you know, we can't really give you a prognosis for that. And my husband and I were given a very short amount of time where we could decide if we wanted to continue with the pregnancy or not. And we both, in that same doctor's meeting, we just kind of looked at each other and we said, yes, we're continuing. So we just continued with the pregnancy that way, not knowing exactly what we were going to find or how she would be. And she started getting, um, we saw her neurologist for the first time when she was eight weeks old and we still didn't really, exactly have a diagnosis and he just wanted to keep watching her. So, um, at six months when she wasn't meeting her milestones, she had her own first MRI. So I had two, while I was pregnant with her and she has had a few her own, um, in that MRI at six months old, we found out that corpus callosum was thinner than it should be. So she has hypoplasia of the corpus callosum. And from there we went and did, um, genetics, and we did some additional testing. And in the genetics testing, they found out that she's got a mosaic duplication of chromosome 15. So she's, she doesn't really have, um, I was just talking about this. I was at a friend's house, swimming yesterday. And so her, she had her friend there and she says, "Well, if you don't mind." I said "Oh no. I tell this story all the time. I wrote it in a book." So, um, the doctors basically told us she was writing her own book. She's, she's very unique. Whereas a Down syndrome child, they're going to be duplicated on chromosome 15 in the same area. That's how they're able to determine, okay, this, this child has Downs. She's on the same chromosome, but she's sporadic. So she's got a little here and a little here and a little here. And so they've actually given me her chromosome layout and I teach eighth grade science and we talk about genetics. And so I always pop that up and I say, okay, let's talk about this without letting them know that it's my daughter that I'm showing them, but, um, yeah, her, her genetic makeup. So she doesn't, unfortunately, she doesn't have a diagnosis that is common to most people. That's part of why I wanted to write my story because we have had people all the time and say, "Well, she looks normal." Yeah. And I say, well, and then, and then you see that she's 11 and she's nonverbal and still is not potty trained and very much needs our care for her daily living. Yeah. You're only doing that because I said potty. Yeah, you're, you're sneaky.

Figure 3.3: Cycle 1 Coding for Individual Interview 1



Normative Discourse	Disability Discourse	CYAL	Family	Play	Communication	Behavior	Research	Academics/Schooling
data	seizures	storytime	familial role	art activity	AAC	emotions	methods	receptive identification
life skills	Perspective	favorite books	familial support		expressive language	repetition		goals
physical activity	medicine	text selection	support		communication app			student demonstration
independence	medical discourse	disability in CYAL	routine		literacy-multimodal			assessment
positivity	therapy		familial relationship					progress
safety	medical records		familial conversations					teacher observation
social skills	medical services		sibling					academic activity
acceptance	understanding		sharing					educational support
	nonverbal		affection					parent-teacher communication
	diagnosis		family activity					accommodations
	awareness		friends					special education
	medical device		home environment					educational technology
	medical testing		self-guided research					classroom environment
	strengths		always on					parent-teacher relationship
			familial membership					curriculum
			travel					IEP
			community					gen ed
			gratitude					hand over hand
			mental health					annual review
			occupation					educator
			privacy					handwriting
			race					educational documentation
			uncertainty					law
								Distance Learning

Figure 3.4: Cycle 2 Coding for Interview 1



4:37 SC: Sure. So we actually knew, um, before she was even born, we went in for our gender appointment and that was in the, I can't remember exactly, but you know, 20 something weeks, I can't remember exactly. So, um, we found out it was a girl and they said, well, we'd like you to sit because we need to talk to you a little bit about some things that we found. And, um, they thought originally that it could possibly be Dandy Walker, but that was, uh, ruled out. She had, they thought she had extra, well, first they actually thought, um, Down syndrome because she had extra fluid at the back of her neck. And so we went to a specialist ultrasound and, and they said that is, um, they rolled that out. And so then, um, there was something in the ultrasound though, it showed a void in, in her head.

5:35 SC: So we started going to San Francisco, we went to UCSF and they did another ultrasound and they said, yes, we also see the void. So now we want you to do an MRI. So while I was still pregnant with her, I did an MRI and they said, there's not a void in the back of her head, but her cerebellar vermis is tilted. We don't know what that means. Um, they said, we don't know if she'll walk or talk. We don't know. What's, you know, we can't really give you a prognosis for that. And my husband and I were given a very short amount of time where we could decide if we wanted to continue with the pregnancy or not. And we both, in that same doctor's meeting, we just kind of looked at each other and we said, yes, we're continuing. So we just continued with the pregnancy that way, not knowing exactly what we were going to find or how she would be.

6:21 SC: And she started getting, um, we saw her neurologist for the first time when she was eight weeks old and we still didn't really, exactly have a diagnosis and he just wanted to keep watching her. So, um, at six months when she wasn't meeting her milestones, she had her own first MRI. So I had two, while I was pregnant with her and she has had a few her own, um, in that MRI at six months old, we found out that corpus callosum was thinner than it should be. So she has hypoplasia of the corpus callosum. And from there we went and did, um, genetics, and we did some additional testing. And in the genetics testing, they found out that she's got a mosaic duplication of chromosome 15. So she's, she doesn't really have, um, I was just talking about this. I was at a friend's house, swimming yesterday.

Figure 3.5: Cycle 3 Coding for Individual Interview 1

Appendix M

Figure 4.8: Excerpt from Narise's IEP for the 2020-2021 School Year

instruction. Present Levels Data may include, but are not limited to, the following: progress on goals, report card information, informal assessment data, formal assessment data, district, curriculum or site-based assessments, teacher-made assessments, as well as distance learning activities.

Social and Emotional Development
Current Level: 1 year 0 months

H-1 Relationships with Adults: 2.0
[redacted]*'s general social and emotional development can be characterized by his/hers ability to demonstrate such skills as; Looks attentively at human face; visually follows moving person; responds with smile; likes to sit with others who are playing or working; smiles or vocalizes as a means of getting attention; is shy with strangers; plays peek-a-boo; shows attraction to care takers, and maybe afraid of strangers; gives affection to family members; shows an interest in activities of others; imitates actions of others, such as putting blocks into a box; show pride and pleasure in new accomplishments; explores environment and returns to care taker as a secure base; watches the faces of other people for clues to their emotions or feelings; is warmly responsive to adults; engages with an adult by doing an activity for five minutes or more, Responds appropriately to directions from adults*

H-2 Play Skill and Behavior: 1.0
[redacted]*'s play and behavior skills are characterized by her ability to demonstrate such skills as; Gets excited when a toy is presented; shakes rattle or other object when placed in hand; likes to reach for objects and grab it; engages in a simple game with others such as rolling a ball back and forth; watches other children play, plays alone in the presence of other children (parallel play).*

H-3 Motivation and Self-Confidence: 2.0
[redacted] *motivation and self-confidence skills are characterized by her ability to demonstrate such skills as; searches for hidden (covered) object; shows determination by going for a toy out of reach; expresses emotions such as joy, fear, anger, and surprise; explores environment with curiosity, shows a sense of self as evidence by wanting less service and dependence, shows pride in new accomplishments, begins to be aware of good and bad behavior is self and others, reacts appropriately to change, maintains a positive attitude, transitions appropriately from one activity to another activity.*

Vocational
Due to emergency conditions, present-level data is being reported based on information gathered during distance learning and in- person instruction. Present Levels Data may include, but are not limited to, the following: progress on goals, report card information, informal assessment data, formal assessment data, district, curriculum or site-based assessments, teacher-made assessments, as well as distance learning activities.

[redacted] *is able to follow one to two step verbal direction. She is able to participate in simple classroom chores, such as stacking chairs, picking up trash, etc.*

Adaptive/Daily Living Skills
Due to emergency conditions, present-level data is being reported based on information gathered during distance learning and in- person instruction. Present Levels Data may include, but are not limited to, the following: progress on goals, report card information, informal assessment data, formal assessment data, district, curriculum or site-based assessments, teacher-made assessments, as well as distance learning activities.

Daily Living
Current Level: 2 years 0 months

G-1 Feeding: 3.0
[redacted]*'s feeding skills are characterized by her ability to demonstrate such skills as:*
manipulates spoon to "scoop" food; takes spoon from plate to mouth, with some spilling; uses straw to drink; drinks from a cup or glass held in one hand without assistance; chews with ease and rotary motion; inserts spoon in mouth without turning it upside down, moderate spilling; uses a fork for eating; uses napkin when prompted. During breakfast and lunch [redacted] *will select her breakfast and lunch from the lunch counter.*

G-2 Undressing: 2.0
[redacted]*'s undressing skills are characterized by her ability to demonstrate such skills as: cooperates in undressing; removes socks; assists in undressing; removes shoes; removes coat.*[redacted] *needs help with pulling her pants down during toileting.*

G-3 Dressing 2.0
[redacted]*'s dressing skills are characterized by her ability to demonstrate such skills as: cooperates in dressing; assists in dressing; puts on front-opening sleeved garment with assistance in positioning the garment so that the arms can be placed in the correct sleeves; puts on front-opening "pull up" garment with assistance in positioning the garment so that the feet can be placed in the correct legs of the garment.*