Caregiver Experiences With The Dyslexia Identification Process In A Borderland Community In Texas

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CAREGIVER EXPERIENCES WITH THE DYSLEXIA
IDENTIFICATION PROCESS IN A BORDERLAND
COMMUNITY IN TEXAS

ANGELA VICTORIA ENRIQUETA OWENS
Doctoral Program in Teaching, Learning and Culture

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by

Angela Victoria Enriqueta Owens
DEDICATION

This dissertation is dedicated to my daughter, Bailey. I have had the most wonderful experience learning to be your caregiver. I will appreciate all of the moments we shared together throughout your childhood as you now begin to transition into young womanhood. I hope that every single aspiration you ever dream up is realized; here is to hoping this quarantine is over soon! You are the most genuine, sarcastic, artistic, humble, honest and sincere little person I have ever known. The world is yours girl… go after your dreams!

This dissertation is also dedicated to children who have different learning abilities and learn to navigate the school systems they are placed in. It is also dedicated to all of the caregivers who have ever cared and loved for a child, whether biological or not. As a child who was adopted when I was just four days old, I feel an immense appreciation toward caregivers and the communities who take on the tremendous responsibility of nurturing a child. Thank you to the caregivers who adopt or foster children and make this loving and selfless commitment.
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IDENTIFICATION PROCESS IN A BORDERLAND
COMMUNITY IN TEXAS

by

ANGELA VICTORIA ENRIQUETA OWENS, M.Ed., M.Ed., B.I.S.

Presented to the Faculty of the Graduate School of
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of the Requirements
for the Degree of

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There are many people whose help, guidance and kind words were instrumental in completing this dissertation. First and foremost, I would like to thank the caregivers who volunteered their time and shared details about their lives with me. I was honored to hear your stories. Your examples of advocacy and resilience in the face of so many adversarial moments were inspirational. Similarly, I will be forever amazed with the work that is done by the volunteers at the Borderland Disability Coalition, thank you for the work you do in teaching caregivers about their rights and how to navigate these processes.

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ABSTRACT

This phenomenological study (Moustakas, 1994; Peoples, 2020) uses critical disability theory (Devlin & Pothier, 2006) and intersectionality (Crenshaw, 1989) as a lens for investigating the experiences of caregivers in a borderland community in Texas during their child’s dyslexia identification process. I used Interpretive Phenomenological Analysis (IPA) which has roots in hermeneutic phenomenology (Heidegger, 1971) as a research method to answer the research question, *How do caregivers from minoritized backgrounds in a Texas Borderland community experience the Dyslexia identification process in public schools.* The three caregivers in this study were able to participate through face-to-face and virtual formats, due to the global pandemic that began during data collection for this study. Participants were given the option of expressing their experiences in Spanish, English, or through translanguaging (García & Kleyn, 2016). This study responds to a gap in the literature (Silverstein, 2015), which thus far had not captured the experiences of caregivers from various socio-economic statuses (SES) who are from mixed race and ethnic and racial groups in Texas.
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CHAPTER I: INTRODUCTION

In a recent four-part series called Denied in the Houston Chronicle, Carroll (2016) captured the anger and frustration that Maricruz Cantu, a mother in Texas, had when attempting to get services for her daughter, who had characteristics of dyslexia. This caregiver\(^1\) stated that, “It was killing her,” referring to her daughter’s inability to read and further stating that her daughter would hit herself on the head and cry at night. After three months, the school tested her daughter and determined that she qualified as a student with dyslexia characteristics. Soon after that diagnosis, she came to find out there was not any funding in the district for her daughter to get intervention services, even though she had just qualified for services. This ambiguous process forces caregivers to come to terms with the fact that their child may struggle in school for a majority of their school career due to the challenges with reading associated with the Specific Learning Difference (SLD) of dyslexia, along with the difficulty of obtaining needed services.

**Statement of the Problem**

The impact that the misidentification, late identification, or failure to identify an individual with dyslexia, has been documented as having significant effects on an individual. Previous research on the strain that is placed on caregivers to support and advocate for their child

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\(^1\) I have used the term caregiver throughout this work, to represent the adults in a child’s life that serves as their primary caretaker and advocate. Depending on a child’s circumstances their caregiver may be their natural biological parents, adopted parents, their parents who identify as a part of the LGBTQ community, grandparents, foster parents or family and/or friends that are charged with the responsibility of providing for, and raising a child. This definition is meant to be as inclusive as (Hanson & Lynch, 1992) define which allows for a family to be defined in a variety of ways however “members of the unit see themselves as a family, are affiliated with one another, and are committed to caring for one another” (p. 285).
who is struggling to learn has been captured in studies that will be shared in the upcoming chapter. Existing challenges that caregivers face during the identification process include familial stress and advocacy for their child within public school systems. Specific learning disabilities (SLD) are defined by the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) as “a disorder in one or more of the basic psychological processes involved in understanding or using language… which manifests itself in the imperfect ability to listen, think, read, write, spell or do mathematical calculations…” (IDEIA, 34 C. F. R. 300.8). I am using the term SLD interchangeably and prefer Specific Learning Difference to represent the nuances of neurodiversity that each individual may have. Although there are assessments used to determine if a person is exhibiting characteristics of the Specific Learning Difference (SLD) of dyslexia in medical as well as educational settings, caregivers are also an integral component of the identification of SLD’s. This is due to the fact that caregivers may notice some of the challenges that their child is having with reading when they are in the home environment.

**Purpose of the Study**

The purpose of this study is to explore the experiences that caregivers in a borderland community in Texas have had with school systems and the identification process for the SLD of dyslexia. More specifically, this study will consider the experiences that caregivers have with school systems as they seek to find support for their child who presented reading challenges at home due to dyslexia, which is not a visible disability.

In his 2003 study, McNulty documented the adversities related to dyslexia by using *life stories* to understand how dyslexia impacted adult males who had been identified with dyslexia as a young child in Illinois. The study found that misunderstandings of unexplained struggles with adversities related to hidden learning disabilities such as dyslexia have a significant impact
on a child at a young age and the caregivers that support them. This study is a response to the limitations of a similar study (Silverstein, 2015), and examines the experiences of minoritized caregivers who were not included in the study’s sample group, which was predominately female, White, well-educated caregivers from a high SES. The purpose of this study will be to capture the variances in specific experiences that caregivers of diverse SES and racial backgrounds in a borderland community have experienced. Borderland communities are complex and represent spaces of multiple intersections amongst diversity, language, and culture (Anzaldúa, 1987; Delgado-Bernal, 2001; González, 2006). Since this is in response to a similar study that did not incorporate the experiences of a variety of caregivers I planned to understand the experiences of caregivers from varied SES, ethnic, racial and linguistic backgrounds. For example, before I became an elementary administrator, I worked as a dyslexia interventionist and had been trained in dyslexia identification and intervention. As an administrator I worked in a school with approximately one thousand students. One of the reasons that I am passionate about this research is that the head administrator told a teacher who was concerned about a student’s academic progress that she “thought every student in her class was dyslexic and did not need to worry about having this student assessed for the SLD since we did not have any more room for students who needed this service anyway.” After this scenario occurred, the student was moved along to the next grade without being identified and without any supports to help him learn how to navigate new patterns of language in the following grade level; however, he finally was assessed after three months of schooling the following year, and ended up qualifying as dyslexic and began the intervention program that our school district used, the Wilson Language Program. This lapse in assessment and identification sometimes means that some children are retained in the same grade level and not assessed for the SLD of dyslexia, or, in other cases such as this one, the
child gets moved up to the next grade level because of adequate progress in areas other than reading.

The process of dyslexia identification can be complex and varies greatly depending on local school policy and on teacher knowledge of dyslexia characteristics. This study aims to capture the multifaceted experiences that minoritized caregivers have had with the identification process and may integrate how differences in language and culture also impact the identification process.

**Research Significance**

Caregiver’s reactions may differ when they realize that their child has a disability. This response may differ according to the age of the child, and the caregiver may go through Kübler-Ross' (2014) stages of adjusting to loss, such as grief, bargaining with the diagnosis, or denial of the disability (Ray, Pewitt-Kinder & George, 2009). The ways that parents cope with the identification of a disability are individual, but are often supported by the communities, networks of support and the specialized personnel that surround them. Caregivers may observe some of the characteristics of reading difficulties and/or dyslexia in the home setting, and this often occurs during homework time. The challenge becomes that there are myths associated with dyslexia and it makes it difficult to identify. According to Shaywitz (1996) common myths of dyslexia characteristics include the following:

1. Reversals and backward writing are associated with dyslexia however writing backwards or mirror writing are typical for non-dyslexic and dyslexic children alike in the beginning stages of writing.

2. Boys are not more likely to have dyslexia than girls. The prevalence of the learning difference of dyslexia is approximately similar between both genders.
3. Although individuals with dyslexia can learn to read with accuracy, dyslexia does not ever go away and cannot be outgrown.

4. Intelligence is not related to phonological processing meaning that individuals with dyslexia can be brilliant and very successful. Some examples of these individuals with dyslexia who are successful in spite of the learning difference are Charles Schwab, Steven Spielberg, and Whoopi Goldberg.

Mineral research attention has been focused on the experiences that caregivers have as they seek to find support for their child who is struggling with reading due to the SLD of dyslexia and studies have stated that further research in this area is warranted (Cook, 2017; McNulty, 2003; Silverstein, 2015).

Learners with dyslexia are able to lead successful independent lives once they have learned the skills to cope with their learning difference. This study is an opportunity for myself as an outsider to understand the challenges that caregivers from minoritized groups experience during the dyslexia identification process.

As Crenshaw (1989) states, “When they enter, we all enter” (pg. 167). This means that as outsiders to this experience, once we all understand the challenges caregivers face, as educators and policymakers, we can better recognize what needs to be considered in order to help all students find success and aid them in their efforts to find success as readers. Harry (2008) asserts that “an understanding of parents’ views of and roles in the placement process should be an integral aspect of professional preparation and professional practice” (p. 372). This study will explore the phenomenon of the lived experiences that caregivers have had with the public school system as they advocate for the initial identification and support services for their child(ren) who have dyslexia. This study may help to inform the systems that are created by policy makers and
teachers who can intervene when students begin to show characteristics of dyslexia.

Research Question

For purposes of this study, the guiding research question is:

How do families from minoritized\(^2\) ethnicities in a borderland community in Texas experience the dyslexia identification process?

This study will use Interpretive Phenomenological Analysis (IPA) which has roots in hermeneutic phenomenology (Heidegger, 1971) as a research method. A primary goal of this work is to understand the ways that caregivers describe their experience with the phenomenon of the dyslexia identification process in a borderland community in Texas. Phenomenology is an approach that is appropriate for this study, as it allows me to interpret and have a new understanding of caregivers’ perceptions of the process of SLD identification. Three caregivers participated in semi-structured interviews. I ultimately sought to recognize the relationship between the ways that caregivers explain their experiences and the phenomenon of SLD identification in school settings. This study provides examples of the varied perspectives of caregivers who have encountered the policies for the identification of the SLD of dyslexia as mandated by the public school system in Texas.

Definition of Terms

Caregiver: The term caregiver is used in this study to represent the adults in a child’s life that serve as their primary caretaker and advocate. This definition is meant to be as inclusive as possible to represent the various adults that may serve in this role for a child.

\(^2\) I have used the term minoritized to reflect the way that power and political function have impacted racial, religious and ethnic groups as subordinate without regard to the size of the group (Paniagua, 2015). Since previous studies in the United States have only considered the perspectives of families from White households, I am focusing on understanding and sharing the experiences that families of Color have had during the identification process.
Dyslexia: Dyslexia is a specific language-based learning difference that is neurobiological in origin, and is associated with specific cognitive variances in basic reading skills (International Dyslexia Association, 2017; Lyon, Shaywitz, & Shaywitz, 2003; Moats & Dakin, 2008).

Section 504: A civil rights law created in 1973 that ensures that children are not discriminated due to their disability and have equal access to the same education that other students are receiving (Understood, 2018). This law can also protect students who do not qualify for services under the special education law.

Special Education: The Individuals with Disabilities Education Act (IDEA) is legislation that requires that children with a disability be provided a free and appropriate public education (FAPE) that is designed to meet their individual needs (McGinley & Alexander, 2018). In order for a child to be eligible for special education, they must have a disability and need special education and related services.

Specific Learning Disability (SLD): A general term that describes a heterogeneous group of disorders that are manifested by challenges with abilities in acquiring listening, writing, speaking, reasoning, or mathematics (National Joint Committee on Learning Disabilities, 1991). These disorders are intrinsic and can occur throughout the course of an individual’s life.

In the first chapter, I have provided an overview of the context and scope of the proposed study. This qualitative study analyzed diverse caregivers’ experiences during the identification process in public school settings. I discuss further scholarly and practice-based implications in the conclusion of the dissertation. I hope to contribute to the literature on how school systems can provide support for caregivers who are seeking to have interventions in place for their child who is showing challenges with reading based off of similar studies conducted in Massachusetts (Woodcock, 2020), New York (Cook, 2017) and California (Silverstein, 2015).
Chapter II: LITERATURE REVIEW

In this review of the extant literature, I explore and synthesize the literature on caregiver experiences during the dyslexia identification process, as well as the literature on how dyslexia identification impacts caregivers as they interact with the public education system during the dyslexia identification process. The second category of literature considers how the public education system has implemented the federal and local policies for dyslexia identification, alongside caregivers. The third category of literature investigates the impact that dyslexia identification has had on social and family dynamics in public school contexts, and the literature that explores the impact that dyslexia identification has on family dynamics. I identify a gap in the literature which is that at the national level in the United States experiences that caregivers have had with the dyslexia identification process have rarely been captured. Silverstein (2015) identified a gap in the literature and recommended that future studies examine the experiences that caregivers have with dyslexia, specifically, caregivers who do not identify as white and upper class. The specific gap identified was a lack of research on the “experiences of fathers, minority parents, and low-income families” (p 219) in relation to their experiences with dyslexia identification in public schools in Texas. Furthermore, there have not been any studies on this topic conducted in the state of Texas. This signifies a need for further research.

I begin by providing an overview of the theoretical framework of Critical Disability Theory (CDT) and a discussion about how intersectionality will be applied to this study. I then describe what literacy is and how it is taught, specifically in regards to typical learners. I follow this discussion by looking at learning differences when it comes to reading, and the ways that literacy is taught to atypical learners, specifically those with dyslexia. Then I explain in more depth what dyslexia is, and I outline the identification process for students once they enter
school, along with the processes in place for caregivers to have their child identified with dyslexia. I follow that with an outline of the processes for dyslexia identification, and then I delve into the three bodies of literature I mentioned above: as it affects caregivers, dyslexia identification in schools, and the effects of dyslexia identification on family dynamics.

**Dyslexia via the Theoretical Lens of Critical Disability Theory and Intersectionality**

In the medical model, disability is seen as abnormal and something that must be corrected via medical intervention (McCord, 1983). The social model of disability is one that views disability as something which is socially constructed and further separates impairment (non-existence or defect of a part of a body) from the disability (a form of disadvantage placed on an individual from society because of their impairment) and considers oppression faced by individuals with disabilities (Oliver, 1990; Reddy, 2011; Shildrick, 2013; Union of Physically Impaired Against Segregation, 1976). The social model includes critiques and analysis of current disability models and provides perspectives of disability that integrate the use of various theories to include queer theory (McRuer, 2006) multi-dimensional intersections of both internal and physical impairments (Garland Thomson, 1997), and the integration of feminist and critical race theory to consider the perceptions of individuals who have been oppressed as to aid in assisting those who have experienced forms of discrimination due to their disabilities (Asch, 2017). “What CDS (critical disability studies) intends is to unsettle entrenched ways of thinking on both sides of the putative divide between disabled and non-disabled, and to offer an analysis of how and why certain definitions are constructed and maintained” (Shildrick, 2013, p. 35). Various subsets of disability studies and rhetoric include disability inquiry or disability studies in education (DSE) which is field that focuses on the social phenomenon, construct and culture using a minority group model to understand the experiences of people with disabilities in educational
settings. It is geared toward the inclusion of children with disabilities in schools and includes the ways that educational leaders, teachers, and caregivers experience disabilities as a social construct (Mertens, 1998). For purposes of the theoretical lens used in my dissertation, CDT and intersectionality will be investigated as it relates to the experiences that caregivers have had during the identification process of the SLD of dyslexia. I will begin with an analysis of the evolution of disability models and then will describe intersectionality.

**Medical model of disability.** The medical model of disability is based upon tenets that only consider the limitations that an impairment presents for a person. This model considers an individual’s physical or mental trait, impairment as a disadvantage and does not consider how that impairment is impacted by the environment around them (Samaha, 2007); furthermore, it requires a customized medical solution (Johnson, 2003). In this version of disability model, only the impairment itself is viewed as something that is disabling (Oliver, 1996). The impairment is viewed as the limitations that a person must overcome because of their disability. Another key tenet of this model rests upon the idea of what is considered to live in a society that identifies the normative views of what it means to be normal or to be ‘right’ and appealing which evolves from a recognition that handicapped people are perceived as deviants (McCord, 1983). This belief of normalization eliminates the idea that there are natural differences in each person regardless of ability that do not necessarily need to be remedied by medical professionals.

The medicalization of disabilities suggests that human variation is a deviance from what is normal and has influenced conventional understandings of disabilities, separating people based on a biomedical category using diagnostic categories (Reddy, 2011). If an individual with a disability has differences that are below the average ability, the differences are viewed as having a deficit that needs to be corrected by a medical professional in this model of disability. The
norm pins down that majority of the population that falls under the arch of the standard bell-shaped curve (Davis, 2006, p. 6). Once a person who has a disability is recognized as having a difference, the individual then becomes an object that should be fixed. Medical professionals have seen the body as an object and diagnosed differences and deficiencies as being phenomena that are dangerous to society (Barnes & Mercer, 2003). The problem with solely considering differences as a danger to society is that at some stage in a person’s life, each of us will will have a disability (Fenton, 2016). Also, viewing the body as an object eliminates the other aspects of having a disability such as the impact that an environment may have around a person who has a disability. Furthermore, the medical model does not consider intersections of a person’s identity that occur when considering what it means to be disabled.

Limitations of the medical model of disability. The medical model of disability relies on contributions from medical professionals regarding how individuals with disabilities can be cured or fixed to conform to a society of individuals without disabilities (Simmons, Blackmore & Bayliss, 2008). This reliance on medical professionals excludes the inclusion of individuals with disabilities in society, separates them as members of society who all have the same needs medically and educationally. These binaries of disabled versus non-disabled eliminate the individuality of persons who have different abilities.

Social model of disability. “The social model of disability suggests that society view disability as a disadvantage caused by the confluence of two factors: a person’s physical or mental traits (impairment) and the surrounding environment which is at least partly constructed by others (disability)” (Samaha, 2007, p. 1251). This model evolved from the medical model of disability which only considered an individual’s disability rather than a separation of the disability from the impairment. According to Slee (2010) “the sociological analysis therefore
becomes a means for identifying the multiplicity of oppressions in everyday life for disabled people and building cultures and practices that dismantle barriers” (p. 568). In everyday settings oppressions occur towards persons with disabilities, however in this model, cultural, social, and medical practices are each considered in order to reduce or eliminate obstacles.

The social model of disability came to be because disability-rights advocates and persons with disabilities felt there was a need to separate impairment from disability. The social model defines impairment as the lack of or defect of a limb, and disability as a form of disadvantage that is imposed by society as an outcome of social barriers and relations (Union of the Physically Impaired Against Segregation, 1976). Also, the social model of disability presents a positive disability identity where society considers the separation of impairment from disability (Oliver, 1990). This distinction is imperative since the medicalized model before it intertwined impairment and disability. Impairments are considered a disadvantage only because of an individual’s interaction with a social setting, meaning that abilities can be heightened/lessened depending on social environment. To provide an example that is directly related to my study’s focus, Cosier & Pearson (2016) noted what the social model perspective of disability would look like in a school setting for a child with dyslexia. A learner with the impairment of dyslexia would be able to read with ease if provided an audio text that removes the barrier in their environment of printed text.

Limitations of the social model of disability. However, some critics of the social model argue that complete separation of impairment from disability ignores aspects of a disability and an individual’s identity and further only considers physical disabilities discounting those who have learning difficulties or mental health problems (Reddy, 2011; Shakespeare, 2000). This means that individuals with dyslexia for example who have a hidden disability may not be seen
to some in society as having an impairment and may limit some of their access to services. Other scholars within the special education community have asserted that the social model limits access that some individuals with disabilities may have to medical professionals and special education educators (Anastasiou & Kauffman, 2011). Although there is critique of the social model, Gallager, Connor & Ferri (2013) state that disability studies scholars have “sought more nuanced understandings of it rather than a shift back to the traditional medical model.” (p. 1130). This means that as scholars in disability theory critique and understand disability, the meaning and understanding of terms are constantly evolving to understand new perspectives of those who have disabilities experience the world around them as well as how they experience the disability internally. Furthermore, Myers (2004) states that disability studies defines the medical discourse that surrounds disabilities as inter-subjectivity, where multiple stakeholders both inside and outside of medicine continuously come together to challenge a medicalizing discourse which continues to surround public policies created for health, welfare systems, and health insurance.

**Critical Disability Theory.** Critical Disability Theory (CDT) critiques the traditional binary models of disability, such as disabled versus non-disabled, social model versus medical model, and disability versus impairment. CDT evolves to a more thorough understanding (Meekosha & Shuttleworth, 2009) which challenges discrimination against individuals with disabilities so that assumptions are confronted regarding the invisibility of disability discrimination (Johnson, 2010). The evolution of disability theory considers the intersections of disability and the multi-faceted nature of a medical model of disability versus the rhetorical model of disability (McRuer, 2006). This field attempts to address the social phenomenon of using a minority group label and examines ideas of oppression and labeling individuals with disabilities (Goodley, 2012; Linton, 1998). Another purpose of CDT is to challenge ideas of
discrimination against and equality for individuals with disabilities (Bilken, 2000; Broderick, Mehta-Parekh & Reid, 2005; Brown, 2011; Devlin & Pothier, 2006; Dudley-Marling, 2004; Goodley, 2008; McKinney, 2010; Rioux & Valentine, 2006; Skritic, 2005). CDT considers the phenomenon that surrounds individuals with disability, challenging ideas of discrimination that occur against individuals with disabilities and questioning the ways that those with disabilities are provided equality in society.

Goodley (2014) explains that Crip Theory (McRuer, 2006) has expanded CDT in that it challenges the normative idea of what it means to be human. When I heard this term for the first time, I had to visit the body of scholarly work to understand the language used to describe disability as Crip. I learned that the use of this term is an example of groups of individuals that have reclaimed language as a matter of pride, such as the reclamation of the word queer used in queer theory (Heller, Harris, Gill & Gould, 2018). Crip theory interlinks the neoliberal idea of ableism and challenges the multiple intersections that are around in everyday life.

I decided to select CDT as a framework to understand the variances in the experiences that caregivers had during the identification process since CDT seeks to question politics and power(lessness), power over and power to those who have disabilities (Devlin & Pothier, 2006). Through this lens, I will learn about the experiences that caregivers had since this is a disability which cannot be seen such as a physical disability.

These experiences may provide insight to the interactions that caregivers had during the identification process. For example, the Texas Dyslexia Handbook (2014; 2018) states that caregivers can initiate a dyslexia assessment by providing a letter requesting that their child be assessed. If a school official does not agree with the caregiver that there is a need for assessment, then this request could potentially be denied. For this reason, I have selected CDT to understand
the marginalization that occurs when some groups are valued and others are not in regards to the
disability that they have (Devlin & Pothier, 2006; McKinney, 2010; Rocco, 2005). If a
caregiver’s request for assessment is denied, this is an example of marginalization that can occur
depending on the type of disability that is being evaluated. Depending on the type of disability
that is being evaluated, a child maybe identified more quickly or in a delayed manner. For
example, if a child with a physical disability were to enter a school for the first time in
Kindergarten, the school staff might not think twice about having the child assessed for the
needed intervention perhaps form a physical or occupational therapist.

As caregivers navigate the journey of attaining the assessment, they are advocating for
their child to be assessed and to begin receiving services that will help with the SLD. Devlin &
Pothier (2006) state that the goal of CDT is to challenge the presumptions and assumptions of
able-bodied norms. CDT as a perspective also addresses the invisible forces of ablelism by
recognizing and addressing ability microaggressions (Johnson, 2010; Rocco, 2005). Ableism is
the idea that disability is a diminished category of being human and that any
person without a
perfect body must be cured (Kumari-Campbell, 2008). The selection of this theory as a lens will
also provide context as stated in (Devlin & Pothier, 2006) providing insight “from the bottom up,
from the lived experiences of persons with disabilities, rather than from the top down, from the
disembodying ivory tower… it is a form of embodied theory” (p. 9). The perspective that CDT
provides will allow for me to learn about the ways that caregivers experienced the process of
SLD identification policy at their local school district.

**Intersectionality.** CDT aligns with intersectionality to understand the multiple ways that
caregivers experience variances in “the tension between assertions of multiple identity categories
and the ongoing necessity of group politics” (Crenshaw, 1991, p. 1296). Intersectionality is
important in disability research because it helps to consider the lived experiences that a person or group has had with ability. For example, six years ago, when I was a dyslexia specialist, I met a caregiver who had already advocated for her daughter to have an assessment completed so that she could begin receiving intervention services. This caregiver had noticed that her youngest child, one of five siblings, had not developed reading skills at the same rate as her other children. She was a trained speech therapist who was also employed in the same district where her daughter attended school, and she had noticed that although her daughter was able to make connections to complex concepts orally, she struggled when she was presented with any tasks that had to do with written letters. This had been happening since entering kindergarten. The caregiver’s frustration stemmed from the delay in assessment and intervention processes. Those processes encouraged teachers to wait until students failed to initiate the evaluation process. Upon request for formal assessment made by the caregiver two years after she had advocated for the initial request, her daughter was tested and qualified for dyslexia. As caregivers move through the journey of identification the identification process, different intersections arise, allowing others to consider the experiences and challenges they have had with systems of power and marginalization that they experience. In the example I just provided, the caregiver had to become an advocate for her daughter and go against the professional opinion of two of her daughter’s teachers and school administrators. In doing that, she challenged the systems of power in the district where she worked. Carbado, Crenshaw, Mays, & Tomlinson (2013) provide a critique of the dimensions in which intersectionality were grounded in within Critical Race Theory, not only to consider social relations of power, but also to realize the subtle forces that are hidden so that they may be transformed. Caregiver experiences with the identification process for invisible disabilities varies depending on the system that supports them and the
systems of support can differ from family members to individuals in school systems responsible for identification of these disabilities.

Since this study will employ phenomenology as a methodological approach, the intersectionality between variances described during the dyslexia identification process will also be analyzed. According to (Moustakas, 1994) “the empirical phenomenological approach involves a return to experience in order to obtain comprehensive descriptions that provide the basis for a reflective structural analysis that portrays the essences of the experience” (p. 13). The phenomenon I will be looking at the essence of the ways that caregivers experience the dyslexia identification process. I will use a research design of phenomenology which will be framed by CDT and intersectionality as described by the framework below. I decided to select phenomenology to help me understand the central meaning of the caregivers’ experiences and the essence of how my participants understand and conceptualize the phenomenon of identification. (Dilthey, 1976; Gadamer, 1984; Moustakas, 1994). For purposes of this study, I am proposing to use phenomenology, which will allow me to understand interpret the phenomena that each caregiver has experienced via the process of a hermeneutic circle where I will set my preconceived ideas about the dyslexia experience “aside and hear what the text says” (Gadamer, 1976, p. xviii). As caregivers journey through the experience of requesting dyslexia assessment for their child, there are multiple junctions where they find themselves learning how to take on the role of an advocate.

Rief & Stern (2010) state that:

Becoming familiar with children’s educational rights, learning to communicate well, and holding firm when necessary allow parents to be a significant part of the team that works to meet a child’s needs. Combining tact, knowledge, and persistence can go a long way in
creating a productive relationship with a child’s school community (p. 182).

These attributes of an advocate create moments where a caregiver may experience challenges throughout the identification process and different experiences with intersectionality. This is to say that when a caregiver becomes familiar with the processes that the public education system has in order for their child to become identified with the hidden disability of dyslexia, they in turn become an advocate for their child. Intersectionality is a term coined by Kimberlé Crenshaw in 1989 and considers the multitude of areas that overlap for an individual or group depending upon factors that intersect and contradict one another. Power relations that either legitimatize or challenge normative relationships of power in race, gender, class, sexual preference, age and ability are all examples of areas that are multidimensional and require that a critical lens be used to consider forces that dominate discrimination through power and subjectivity towards marginalized groups of people (Crenshaw, 1989). Goodley (2013) considers intersectionality as the process of varied interactions that may either oppose or validate one another across socio-cultural categories to include language, legal status, ability, gender, race and sexuality. This is different from isolating specific aspects of identity from one another and recognizing the multifaceted ways that individuals experience phenomena. The intersectionalities that caregivers of children who have a disability that is unobservable are multi-dimensional and will be discussed via empirical research that has been collected to understand the lived experiences before and during the time of identification.

Pavey, Meehan & Davis (2013) stated that “The main ways of talking about dyslexia fall within a medical-psychological (deficit-based) view and a socially constructed view” (p. 1). This means that an individual with dyslexia can be viewed as someone who has a neuro-biological condition and depending upon the environment around them, the effects of the disability are
either intensified or lessened. Furthermore, the theoretical framework of intersectionality will allow me to examine relationships between identity categories such as race, class, gender and language and interactions with others (Hancock, 2007) and systems of oppression with each one.

**What is the Process of Acquiring and Learning Literacy? Discussion of Ideological Conceptualization Models**

The process of acquiring literacy and reading skills varies among individuals with dyslexia and those who do not have this learning difference. Because the process of learning to read is different for each learner, it is important to first understand the typical process of acquiring and learning literacy.

Literacy is the act of being able to understand a message that is being conveyed in a variety of formats to include oral and written configurations. When describing the differences between oral and written literacy, Ong (2002) states that the difference between words in print and those spoken aloud has to do with personal connections to written words and meaning. In order for individuals to become literate they must learn how to make sense of the world around them; be it in oral or print modalities.

Definitions of literacy include what it means to be literate in different settings and modalities (Gee, 2004; Schleppegrell, 2004); how literacy can be taught to developing learners (Birsh, 2011; National Institute of Child Health and Human Development, 2000; Moats, 1999; Puett-Miller, 2010); how literacy is taught to atypical learners (Shaywitz, 2003; Torgeson, 2004; Vaughn & Linan-Thompson, 2003), how higher-order skills such as comprehension, inferencing and semantics develop among typical and atypical learners (Perfetti & Frishkoff, 2008); and how literacy is assessed in educational settings for typical readers (Allington, 2008; Cambridge Assessment, 2013; Hagood, Alvermann & Heron-Hrruby, 2010; Hall, Burns & Edwards, 2011);
as well as atypical readers (Nevills & Wolfe, 2009; Shaywitz, 2003). Literacy skills include knowing how to use a variety of approaches when they are needed to understand and make meaning of words across content areas and social settings, including both academic and non-academic settings (Carris, 2011; Gee, 2004; Kiili, Mäkinen, & Coiro, 2013).

In the upcoming section, I will first provide a brief overview of models of theoretical conceptualizations of reading to include the autonomous, ideological and multiple literacies. I will then will provide background on how this transfers to classroom pedagogical practices for teaching learners to acquire literacy.

**The Autonomous Model of Literacy.** Literacy in this viewpoint means explicit instruction done in a sequential, skills-based manner (Carnine, Silbert, & Kameenui, 1996; Lyon, 1998; National Institute of Child Health and Human Development, 2000) and does not account for culture or situations that occur during the learning process. This model reduces literacy to a set of basic skills, and it leads to literacy skills being seen as a marker of democratic engagement. That is, those who are nonliterate are seen as lacking the skills needed to successfully participate in a democratic society (Graff & Duffy, 2008; Street, 2003). Supporters of the autonomous model, which is seen as autonomous, or separate from society, view literacy as a binary, where an individual is either literate or not. This conceptualization makes literacy a commodity and a social norm that needs to be controlled by government agencies and those in positions of authority (Horn, 2016).

**The Ideological Model of Literacy.** The ideological model considers the development of literacy as a social practice that is learned in various social contexts, and is influenced by variables such as culture and societal situations (Hall, 1998; Stewart, 2011; Street, 2006). This model integrates the idea of learning how to read based on cultural and social settings, and it is
about the construction of meaning first and foremost. Advocates of the ideological model see learners as being able to make connections in terms of how literacy can be used in different modalities and for different purposes. Graff & Duffy (2008) note that this model is called ideological because “literacy is a product of the special circumstances of its acquisition, practice, and uses, and so reflects the ideologies that guide these” (p. 10). Additionally, this model differs from the autonomous model in that it does not assume that simply becoming literate will give you access to more economic resources or social mobility (Auerbach, 1992). This means that those who see literacy as ideological understand that being able to interpret oral language and written texts is one component of a being complex human being.

The multiple literacy model includes cultural and ideological practices that children and adolescents use; these ideas were initially integrated and considered by the New Literacy Studies (Street, 1993; Street, 2003). Literacy in this model considers literacy as a social practice rather than a set of limited tools one uses during literacy. Furthermore, this view of literacy requires that we consider the meaning-making that is constructed with the continuously changing digital technologies (Sang, 2017). Mosley (2007) explains “The New Literacy Studies is not a catchall pedagogical framework but instead is a theory of literacy as a social and cultural practice that opens spaces for teachers to draw on multiple frameworks” (p. 15). A multiple literacies approach considers the different purposes that people want to become literate for, as well as the different types of literacies themselves. Alverman (2002), for example, states that adolescents may want to learn more about interactive communication technologies (e.g. chat rooms, social media), which are types of literacy. While Kist (2000) defines the five characteristics of multiple literacies as multiple forms of representation, the integration of multiple ways to discuss problems and create solutions, explicit conversations about how symbols have been used
currently and historically, and activities that can be done individually or collaboratively, and that are engaging to the user. The idea of multiliteracies coined by the New Literacy Studies also consider the intersections of diversity and social justice that are negotiated as readers use the world around them to understand literacy (Hagood, 2000; Gee, 2004; New London Group, 1996). It seems that the ideological models of literacy are more aligned with CDT in that there are multi-faceted ways that individuals can access literacy based on their own intersectionalities. The ideological models seem to allow for the fluidity that is demanded by CDT and not only a binary as in the autonomous models.

**Instructional Approaches for Teaching Reading**

**Explicit Instruction, Whole Language or Balanced Literacy?** Debates over the definition of the best approach to teach reading have evolved over decades and have been coined “The Reading Wars.” Each of the approaches have theorists and educators alike who either defend or critique the effectiveness of a certain theory and the effectiveness a particular approach: an autonomous approach with explicit instruction of phonics (Blumenfeld, 1982; Groff, 1998; Moats, 2000; Moats & Foorman, 1997; Sweet, 1997), an ideological approach (whole-language) where learners make meaning of written texts through an integrated view of language, learning and people not solely focus on phonetic instruction (Cazden, 1972; Edelsky, 1996; Goodman, 1965; Goodman, 1970; Hall & Moats, 2006) or a multiple literacy approach that considers sociocultural and cultural meanings linked to power and ideology (Street, 1993; The New London Group 1996). The book *Why Johnny Can’t Read* (Flesch, 1955) was a bestseller in the early 1950’s, and it suggested that there was a policy emergency in terms of basic literacy that would threaten democracy, and could be solved with the phonics approach. By the late 1990’s, that sense of urgency returned, and the federal government as well as the media
claimed that the United States was in a “reading crisis” (National Institute of Child and Health and Human Development, 2000). The idea was that students in the United States were significantly behind those in other industrialized countries, and that the “cure” for the reading crisis was skills-based instruction, or the autonomous model of literacy.

The approach that teachers implement as pedagogy for instructing beginning readers is taught to them either at the university level as pre service teachers or as in service educators. The approach used to teach reading is informed by one of or a combination of the three theoretical models of literacy mentioned above. Allington (2013) mentions that as a graduate student a professor told his classmates that it takes decades for classroom pedagogy to be influenced by research findings. This is an example of the how long it takes for a theoretical ideology to transfer to classroom pedagogy. Disagreement between scholars and educators alike exist concerning whether explicit instruction, such as phonics (autonomous), whole language, or the ideological or balanced literacy are best suited to teaching someone how to read (Kim, 2008). These conflicting opinions about the best method that should be used to teach students how to read continue to be influenced by federal and state policy. Advocates of explicit instruction may support this approach as they strive to produce students who can perform well on high stakes assessments (Botzakis, Burns, & Hall, 2014) regardless of the culture or ability they bring to the classrooms. In contrast, adherents of the balanced literacy approach understand that literacy is culturally situated and involves other factors beyond just decoding text such as motivation, ability, and culture.

The necessity for educators to adhere to either explicit instruction or whole language was at the core debate of The Reading Wars. The Reading Wars as it applies to practitioners of reading was summarized by Jeanne Chall in *Learning to Read: The Great Debate* where she
states that reading instruction in early childhood can be asked with one question: “Do children learn better with a beginning method that stresses meaning or with one that stresses learning the code?” (p. 75). I believe that this question can be answered simply, regardless of the approach implemented, an educator must have a thorough understanding of how to introduce, intervene and provide extended support when a learner is learning how to systematically decode written language. I support a balanced approach that integrates both the autonomous and the ideological models, so that a child’s ability to become literate includes exposure to linguistic patterns as well as conversations that help them use their language and texts in meaningful ways (Pinnell & Fountas, 2009). Castles, Rastle, & Nation (2018) call for an end to the Reading Wars. They suggest that there has been significant scientific evidence spanning over decades proving the need for the criticality of teaching alphabetic decoding skills as a foundation of learning to read from comprehensive government evaluations to include the United States (The National Institute of Child Health and Human Development, 2000), the United Kingdom (Rose, 2009) and Australia (Rowe, 2005). However, the resistance to ending the debate has occurred for two reasons. The first is because educators have limited knowledge about the orthography, which is the written system which represents spoken language. The issue of orthographic depth will be discussed in more detail in an upcoming section. The second is that while practitioners know that there is more to reading that just teaching alphabetic skills, and that it includes advanced aspects of reading acquisition, they often find it difficult to deliver a combined balanced approach of teaching skills as an effective reading instructional practice. This is because educators are having to balance a multitude of factors when planning reading instruction that includes intertwining district mandates, intentionally planning for differentiation of delivered material based on student ability and interest levels, and environmental factors. Pressley and Allington (2015) argue that
teachers of reading should use a balanced instruction approach that combines a deep understanding of how various reading abilities are developed over time. They also assert that the balanced literacy approach to teaching reading:

“takes the research evidence on the potential of early and explicit decoding instruction and the evidence on explicit comprehension strategies instruction and blends it with research evidence on the potential of meaning-emphasis instruction for developing vocabulary, comprehension, and motivation to read” (p.19).

I personally agree with balanced literacy for typically developing learners. However, for educators who provide the supplementary instruction for learners with dyslexia, they should have an even deeper understanding of explicit instruction as suggested by the International Dyslexia Association and combine that knowledge with practices that incorporate what a child already knows. I believe that educators who teach reading have intentions of instructing their students using the most effective strategies possible. Conversely, there is also literature that opposes the way that teachers teach reading and suggest that because of their inability to teach reading, students end up being negatively affected by some reading teachers, which will be discussed in the section below.

**Dysteachia.** Dysteachia is the idea that students of all ability levels are placed at a disadvantage and do not learn how to read due to poor teaching methods, that is to say that even children without disabilities may not learn how to read due to poor instruction (Armstrong, 2000). Hennessy (2012) provides an alternative point of view to the pedagogical descriptions I have discussed above of explicit instruction or balanced literacy that are implemented in classroom settings. She states that the effects on students who are instructed by educators who do not have a deep understanding of theoretical implementation of reading skills and the practical
implementation of reading skills during classroom instruction. Hennessy (2012) describes the challenge that ensues when educators attempt to identify and offer remediation for struggling readers using haphazard approaches. These haphazard ways that educators use to provide literacy instruction can in turn create instructional confusion for learners (Learning Stewards, 2013). This confusion leads to what Lyon (2002) refers to as instructional casualties as a result of inefficient preparation of general and special education teachers who do not know how to use effective instructional approaches. When educators do not have a solid understanding of the rules that govern the patterns within the orthographic systems they are instructing their students to learn, and use haphazard ways to teach students how to read and write. As a result, they inadvertently produce students who have challenges with decoding text and those students’ behaviors may mimic or exhibit hallmark characteristics of dyslexia due to the lack of systematic teaching of the structures and functions of a language (Moats, 2009).

Hurst (2017) suggests that a new population of learners, consisting of students who do not have SLD’s and would have been able to become successful readers, suffer from dysteachia which will only be dealt with when Schools of Education adequately equip teachers with a knowledge base that integrates skills regarding the teaching of reading. Since I am a professor of early childhood and special education that also teaches reading to pre-service students, this concept of dysteachia is of grave concern as I create my reading courses. There are a multitude of reasons which contribute to barriers of creating teaching practicum experiences such as the availability of teaching supplies and materials, supervisory and administrative responsibilities associated with tutoring programs, various class sizes, and most importantly the void of teaching frameworks which support preservice teachers in initiating reading instruction (McCombes-Tollis & Spear-Swerling, 2011). In a recent
study with 48 pre-service teachers, Englert et al. (2020) examined the ways that pre-service special education teachers understood and felt prepared to teach struggling readers in early childhood settings. The authors stated that,

primary-grade special education teachers must be trained to recognize and address deficiencies in phonological awareness, word identification, decoding and phonics, and spelling. Without this multilayered and intensive approach, their students with disabilities may never catch up to their peers, and their literacy difficulties will not be ameliorated. (p. 235)

Furthermore, as someone who has taught reading to elementary students in both general and special education, I can attest to the challenges I have felt in this regard. I struggled when I taught my first groups of learners to read. I was responsible for teaching reading to. Although I had been through a traditional teacher preparation program, the theoretical approaches that I learned in the absence of having actual students to implement the theories on made it difficult for me to apply that knowledge to actual students in my classroom. While I had the best intentions when providing interventions to my struggling readers, during the time that I was in my teacher preparation program, I feel that the most impactful understandings came from my internship experience, just before I began my teaching career. The experience was before I was in a classroom and I attribute this success to the real-life classroom exposure during my last semester as a student intern. I observed a master reading teacher in a general education setting, and I attribute this experience to the connection I was able to make between theory and practice with actual students and observing a teacher in action. This success was streamlined due to the support of a campus philosophy from administration at the elementary campus that encouraged educators to observe each other in action and provide constructive and critical feedback to
improve their reading instruction. This experience prepared me to have the skills to intervene and provide instruction for students who were struggling in my general education classroom.

However, another skill that aided me in learning more about teaching reading to young learners came five years into my teaching career. That was when I received extensive training in a dyslexia intervention program and I had multiple opportunities to improve my skills with one-on-one coaching from certified language interventionists. This training required that I became self-reflective to realize that some learners may need to be taught how to read in a way that allows them to become successful, using unconventional methods. As a certified dyslexia interventionist in the multisensory education methodology, I learned about the tenets required to maintain fidelity to a framework that is required for teachers who provide intervention for students with dyslexia characteristics. The challenge, therefore, with defining the acquisition of literacy based on one model or approach is not attributed to only one factor; the process of acquiring literacy is complex and dependent upon each individual child’s sociocultural context. In the next section I will consider the process of literacy acquisition for learners with dyslexia.

**What is Dyslexia? The Reading Acquisition Process for Learners with Dyslexia**

The skill of learning to read is not a natural process such as the one that takes place when learning to speak one’s native language is (Gee, 2001; Rayner, Foorman, Perfetti, Pesetsky, & Seidenberg, 2001; Rayner, Foorman, Perfetti, Pesetsky, & Seidenberg, 2002). It does not happen without effort (Birsh, 2011). Knowing that the development of reading skills are not innate, the process of reading acquisition occurs at different times depending on a multitude of factors. These factors include the nuances of each individual person’s cognitive functioning (Snow, Burns & Griffin, 1998; Sousa, 2016), motivation and desire to learn the type of specialist variety of language being considered (Gee, 2004; Schleppergrell, 2004), and even linguistic and socio-
economic opportunities that have been experienced by the person (Corson, 1999; Gee, 2004). For example, a learner who is attempting to learn decoding skills in their native language and who also has an SLD may need multiple opportunities to apply new skills, due to the specific nuances of their learning difference.

**Dyslexia Defined.** Dyslexia is a specific language-based learning difference that is neurobiological in origin, and is associated with specific cognitive variances in basic reading skills (International Dyslexia Association, 2017; Lyon et al., 2003; Moats & Dakin, 2008). Developmental dyslexia is considered not only to be neurobiological, meaning it occurs in the brain, but it is also considered to be correlated with a first-degree relative who has dyslexia which is called familial risk (Carroll & Snowling, 2004; Eklund, Torppa, Aro, Leppanen & Lyytinen, 2015; Giménez et al., 2017; Scarborough, 1990). That is, if a child begins to show characteristics of dyslexia, educators should ask if there is a familial history of reading differences, because there is a genetic component. Dyslexia can manifest as a spectrum of characteristics, ranging in severity; however, individuals with dyslexia are able to thrive in learning environments that are purposeful in working with their strengths, rather than focusing on deficits (Rappolt-Schlichtmann, Boucher, Evans, 2018). According to Peer, Reid, and the British Dyslexia Association (2003), dyslexia typically affects the following areas:

1. Reading – individuals with dyslexia may have differences with reading. One area that may present a divergence is fluency, which has to do with accuracy, the speed of reading, and expression (in oral reading).

2. Spelling – difficulties with commonly used spelling patterns. Examples include miscues in frequently used words such as spelling the word *for* as *fro*.

3. Writing – alternate ways of expressive writing and handwriting may have to be used.
4. Memory – traditional approaches to memory retrieval may not work. Some learners may have to find ways to retain/recall information in their own particular way.

5. Coordination – gross and fine motor coordination skills may need more practice, such as using scissors to cut. However, some people with dyslexia may have exceptional abilities in the arts and sports.

6. Organizational and information processing – new information should be connected to previously learned information, so that it is applied and stored in the brain for later use.

7. Phonological tasks – learners may have to find their own specific ways to process details related to the awareness of sounds, such as remembering the rhythm/rhymes in words, and;

8. Visual processing awareness – accuracy in seeing some parts of written language. For example, they may see letters that merge together into one another, may skip lines or words when reading or see a visual misrepresentation of letters.

Each of the aforementioned characteristics can vary in levels of frequency and are seen to different degrees in various learners with dyslexia.

**Dyslexia & Orthography: Written Language Systems**

The amount of time it takes for a caregiver to realize their child is struggling to learn the written version, or orthography, of the native language they speak also depends on the type of language being learned. Some languages have written symbols, while others have logographic representation for words. The Chinese language is one that does not use an alphabetic system rather a logographic system is used with representations of a particular group comprising of lines, dots or strokes are positioned to represent a word or phrases (Anderson, Ku, Li, Chen &
Chinese children represent characters “in terms of component units corresponding to recurrent patterns of strokes” (Anderson, Ku, Li, Chen & Shu, 2013, p 55.) While languages such as English have been described by authors such as Caravolas (2005) as an alphabetic orthography which is considered to be:

the most inconsistent and irregular system [alphabetic orthography] because (a) the relationship between graphemes and phonemes is often opaque (e.g. the letter t in “listen” has no corresponding phoneme, (b) the grapheme-phoneme and phoneme-grapheme correspondences are inconsistent (e.g. the grapheme ea has different pronunciations in “head” and “heal”); and although the words “beef”, “chief” and “leaf” all contain the same vowel /i/, it is assigned a different spelling in each word), and (c) many exceptions exist to acceptable orthographic patterns (p. 4).

Depending on the type of written symbols which are being learned, the orthography can present a challenge for caregivers who suspect that their child has a learning difference which is not considered legitimate until a considerable amount of time has passed (Dyson, 1996). This requirement of a specific amount of time to allow for a learner to understand the basic principles of the orthography of their language is one of the reasons that caregivers may become frustrated during the process of identification for dyslexia. For example, there is a misconception that learners with dyslexia cannot be assessed for dyslexia characteristics until they are seven years old. This misconception has been clarified and early identification is encouraged by the TDH (Texas Education Agency, 2014; 2018) but some educators still do not know this.

Orthographic depth refers to the complexity of the written language as well as how the orthography is represented by symbols. These symbols are referred to as either being transparent
or shallow, which means that the symbol and sound are consistent, or that the language is opaque or deep (morpho-phonemic) meaning that there is a high level of irregular and inconsistent spellings in the written language as compared to how the language is spoken orally (Florit & Cain, 2011; Shaywitz, 1996; Ziegler & Goswami, 2005). These differences mean that depending on the language and written representation via symbols that a child is learning to read in, success in understanding predictable patterns in that language will vary if the language uses a transparent or opaque orthography.

Orthography is a term that is used in multiple ways and can refer to spelling conventions, awareness of common patterns that are consistent between words but may be inconsistent when writing them in a phonic process, the spelling of words, and the writing system that is associated with a spoken language (Kilpatrick, Kaufman, & Kaufman, 2015). This is to say that an orthography represents familiar spellings or written patterns within a language. Depending on the type of language being learned, early readers learn patterns to decode unfamiliar words. For example, phonological awareness is an important component of alphabetic languages where letters represent sounds, however in logosyllabic languages such as Chinese, the ability for a reader to visually memorize and process representations is more important (Goswami, 2002). Each of these differences mean that since dyslexia is a neurologically based learning difference, learners in any written language may manifest challenges with learning patterns in their written language, however they may exhibit difficulty with the written language depending on how consistently patterns are represented through print.

Examples of languages classified as transparent include Icelandic, Italian, Norwegian, Spanish, German, Dutch and Finnish. Lyytinen et al., (2004) provide an explanation of acquisition of the Finnish language, which has a transparent writing system meaning that learners
are exposed to and learn one-to-one correspondence between each letter and a single sound of the sounds (in Finnish that would be 23 letters). Once these learners are aware of the one-to-one correspondence of each letter and sound, they begin to make connections with practice so that the sounds and letters become automatic and finally they would acquire the skills to assemble the phonemes. In languages with transparent orthographies, fluency is the most appropriate measure of success. Reading fluency is “the ability to read text with sufficient speed and accuracy to support comprehension” (Moats & Dakin, 2008, p. 52). This means that if a learner is unable to decode patterns of written language in a transparent language, their struggle with reading fluently should be an indicator of potential reading difficulty.

On the other hand, languages with opaque orthographies include English, Danish and French (Landerl et al., 2013). Opaque orthographies are those in which associations between sounds and letters are not consistent and numerous exceptions are permitted within the relationships between sounds and letters (Vellutino, Fletcher, Snowling, & Scanlon 2004). In a metaanalysis of the simple view of reading and what that means for learners of opaque languages, Florit and Cain (2011) found that in the opaque language of English, decoding, accuracy, and fluency were predictors of student success in reading. Accuracy is when a reader places emphasis on on processing written parts of words or word parts. Garnett (2011) provides an explanation of what the look, sound and feel of what accuracy is on a sliding spectrum. Readers can move anywhere from effortful accuracy, reliable accuracy, then followed by the ability to read words with automaticity and ultimately gain basic reading fluency. In the effortful accuracy area this would mean that the reader reads word by word, can become tired from all of the “work” of reading and is consumed by trying to get each attempt right while using halts or choppy tones.
This means that learners of English and other languages with opaque orthographies may find success in the simple view of reading relying on both decoding and reading comprehension, however, the authors also state that this approach is not a one size fits all model that works with all learners. I agree with this because in the ideological approach to teaching reading, learners are instructed literacy skills using a variety of methods to teach them to read that incorporate their own experiences, understanding and ability therefore tailoring instruction to individual needs.

Readers who have a learning difference in the specific area of reading are able to become skilled readers once they have learned ways to cognitively process the information being learned in a way that aids them in reading. This way of learning seems to fit the description of the characteristics of the ideological model—so long as the educator knows and understands the importance of using miscues, which are responses to written text that are different from the anticipated responses, to inform reading strategies that they are using with students (Goodman, 1970). As educators analyze the miscues that children make, they can inform the next steps of instruction and ensure that students of all abilities learn how to self-regulate their learning (Cartwright, 2015). The ability for educators to understand how unanticipated responses in a miscue analysis can inform interventions that a student in their class needs is critical in making informed decisions on how to design lessons that ensure effective practice (McKenna & Picard, 2006). The authors state that in order for educators to improve their practice when instructing students, they should use miscues to aide in (1) determining the placement level of a student for instructional and independent reading purposes, (2) understanding why children have decoding skills that are inadequate, and (3) monitor how students are using cues from a combination of tools they have learned to see if what they read makes sense.

However, it is “widely agreed that the core problem of dyslexia – a difficulty in decoding
text- should be contrasted with the ultimate goal of reading – taking meaning from the written word” (Elliot & Grigorenko, 2014, p. 6). Decoding is the ability for a reader to recognize a word; “the more a reader knows about decoding, the easier it is for him or her to recognize words, but even with partial decoding, a reader can read unfamiliar words” (Carreker, 2011, p. 252). This means that even if a teacher has been trained in miscue analysis, they would also need to also understand what dyslexia is in order to be able to provide systematic intervention based on the tenets of multisensory education which improves the ability for learners with dyslexia to cope with the learning difference. Multi-sensory education (MSLE) incorporates instruction for language using a systematic, cumulative, explicit and sequential approach to show students language structure at multiple levels to include sounds, syllables, parts of words that are meaningful, and how sentences are paragraphs are structured (Eden & Moats, 2002; Farrell & Sherman, 2011). This explicit instruction links language structure in an explicit way so that students are guided to use their eyes, ears, voice and hand to improve language using the senses. MSLE requires that students participate and are exposed to language education that incorporates visual, auditory, kinesthetic and tactile responses and feedback (Birsh, 2011). In this approach to reading instruction, educators teach using structured lesson plans and continuous monitoring of student growth to document their progress in language skill acquisition.

The learning difference of dyslexia creates opportunities for learners to find alternate ways of learning to read written print. There is a difference between developmental dyslexia and acquired dyslexia. Developmental dyslexia is defined as the differences that individuals have with auditory and visual recognition of sounds as well as the way that they combine that auditory and visual input to make words and meaning within a language system (Blau, Schwalb, Zanger, & Blau, 1969; Boder, 1973; Odegard, Ring, Smith, Biggan, & Black, 2008; Shaywitz et al.,
Developmental dyslexia is what I will be understanding the varied experiences that caregivers have had once their child begins to show difficulty with the process of learning to read. Acquired dyslexia on the other hand, can happen to an individual after they are born, and is most commonly found in adults; this type of dyslexia is caused by a brain tumor or some kind of trauma resulting in a traumatic brain injury (TBI) or a stroke (Bohl & Hoult, 2016; Coslett, 2003). For purposes of this review, I will be discussing the effects of developmental dyslexia and the affects that nonidentification or delayed identification may have on school-aged learners.

**Dyslexia and Identification**

Depending on whether or not a child is assessed and identified in an educational or a medical setting, the characteristics being evaluated may differ; meaning that in both medical and educational settings, there are assessments that can identify dyslexia. This learning difference is a hidden disability, meaning that one may not know a person has dyslexia until they are put into a situation that requires skills in literacy or processing certain types of information (Reid, 2013). An evaluation is necessary to identify whether or not a learner has this hidden disability. Dyslexia is a heterogeneous concept, so we can say that no two dyslexic learners are the same (Pavey, Meehan & Davis, 2013). For these reasons, the characteristics of dyslexia have been difficult to define.

The role of the caregiver in the identification process of the hidden learning difference of dyslexia is critical (Ise et al., 2011), because caregivers may be the first to see struggles with reading at home when a child starts school. Once they notice that their child is struggling, they in turn seek assistance for further intervention from their child’s school.
What’s in a label? The role of early intervention from the educator’s perspective.

Dyslexia is a term that has a range of definitions, and is used to describe the characteristics associated with the SLD (Reid, 2013). According to Elliot and Grigorenko (2014), dyslexia offers a diagnostic label that is many times sought after, rather than shunned by caregivers and educators. Although Elliot and Grigorenko (2014) propose the term dyslexia should not be used, because it is obscure, on the contrary Reid (2013) has argued that a label can nonetheless bring forth a set of expectations associated with more informed search for resources. Educators are not able to offer a diagnosis of conditions, as this is done by medical professionals. Instead, educators use labels based on assessments given by qualified professionals such as speech and language therapists, diagnosticians, and school/education psychologists. However, there is a problem here. School entry criteria for students who show characteristics of dyslexia (Steinberg & Andrist, 2012) are not established in a consistent way. Upon formal identification in public schools in the United States, educators can initiate educational intervention services (Elliot & Grigorenko, 2014). Throughout the world, there is a challenge to create systematic guidelines for dyslexia identification and treatment (Rose, 2009). Learners with dyslexia characteristics become skilled at knowing when and where to initiate coping strategies for students who are dealing with written texts.

Dyslexia Intervention for dyslexia interventionists/teachers. In the late 1930’s, Samuel Orton and Anna Gillingham developed an approach to teach learners with dyslexia how to “break the code of print” in order to speak, read, and spell (Rief & Stern, 2010, p. 35). As mentioned above, learners with dyslexia may have difficulty when attempting to put ideas in their minds into speech, and may have challenges when reading text in print, along with spelling independently in the language that they are learning. This approach allowed individuals with
dyslexia a way to learn how to analyze the parts of language using structured, systematic, and multisensory intervention. The meaning behind the phrase “break the code” is that individuals with dyslexia are learning strategies to understand the alphabetic code of a language. Once learners have the tools to understand the alphabetic code, they are able to refine their skills that help glean meaning from the written text.

Receiving the label of dyslexia can lead to tailored intervention, so that the unfortunate experiences of shame and embarrassment can be reduced (Burden, 2008; Cooke, 2001). Some of the factors that impact ameliorating the effects of the SLD of dyslexia include motivation (Burden, 2008), varied profiles of ability for each individual, ranging from core difficulties in areas of processing to difficulties in reading, writing, and spelling (Reid, 2013). There is a misconception that as soon as a child is assessed and identified as having dyslexia, they will immediately start receiving services, and the child will begin to improve quickly. This is not always the case. As I mentioned by the introductory vignette about the Texas mother who could not get services for her daughter, the reality is that the identification process is lengthy, and resources may not be available. Additionally, during the identification process, power relationships between educators and caregivers can challenge notions of what the caregiver’s role is. Skritic (1995) found that special education laws in the United States (The Individuals With Disabilities Education Act, 2004a) have meant that caregivers of a child with a disability are granted legal rights not afforded to caregivers of children that do not have disabilities. The special education system in the United States is meant to ensure that students with disabilities and their caregivers are given access to a free and appropriate public education (FAPE). In the event that a student that has a disability is not granted FAPE, both the student and caregiver can go through a legal process called due process (Giuliani, 2012). That means special education can
be thought of as distinct from traditional schooling, in terms of the conventional relationship that
caregivers and educators have in public schools.

What’s in a Label? Seeking Early Intervention from the Caregiver Perspective

Bourdieu (1997) writes that at every stage of an individual’s school career, there are
opportunities for that student to either become a failure or a survivalist of the school system.
Although this statement was not intended to refer to experiences a child with dyslexia might
have, I am resituating Bourdieu’s insightful point to refer to the caregiver’s desire to help their
child become a survivor rather than a failure of the educational system. Due to the intense
pressure placed on students in elementary grades to read with fluency and perform successfully
on standardized assessments, caregivers may feel a sense of urgency to aid a child struggling to
read. This assistance could come once their child has been formally identified with the specific
learning difference (SLD) of dyslexia, if they have the characteristics of the condition, as defined
by a school system, and if the school has the necessary services.

Dyslexia is an SLD that affects individuals over the course of the lifespan and does not
go away. That said, reading skills can be developed and increased with early intervention and
prevention programs (Birsh, 2011). Caregivers may attempt to have their child identified with
this specific learning disability in order to ensure that their child is able to be successful with
reading in their academic career. Bohl & Hoult (2016) remark that individuals who have the
characteristics of dyslexia may exhibit behaviors such as anxiety and avoidance of situations
they find awkward, such as reading in academic settings and navigating friendships social
situations. Children with dyslexia may need explicit instruction to learn how to maintain
relationships with others due to emotional and social immaturity. To many parents and
educators, this may seem like rebellion. In reality, these behaviors are often ways to cope with
feelings of embarrassment in relation to reading. That embarrassment may escalate into high levels of anxiety and attempts to avoid situations that involve reading.

It is not uncommon for caregivers to not realize their child has a reading difference until the child reaches a school age (McGinley & Alexander, 2018). At that point, the child is likely to experience heightened responsibilities that may be more challenging that what they had initially anticipated (Winsor & Boles, 2011). When a caregiver realizes that their child is struggling to read, they may become concerned and request assessment or intervention from the school system. Steinberg and Andrist (2012) note that caregivers of children with dyslexia often experience frustration, disappointment, and anger due to a lack of understanding of what is going on with their child’s ability to learn to read. Caregivers may experience may be frustrated that educators do not understand the learning needs of their child, and there may also be frustration about the ambiguity of the criteria for dyslexia, as well as concern about what the dyslexia label does to their child socially. Frustration, disappointment, and anger can lead caregivers to become advocates for their children, since, all too often, students with dyslexia are misdiagnosed, misunderstood, or just plain ignored (Steinberg & Andrist, 2012).

In order to secure assistance for a child who is struggling to read, caregivers learn that there is a process in order for their children to gain access to systematic support (Reid, 2013), and there are both external and internal factors (McGinley & Alexander, 2018) that impact their ability to do so. Internal factors include experiencing anxiety and shock during the process of identification, since the disability was not anticipated before the child was exposed to reading (Seligman & Darling, 2007). External factors include financial strain in terms of needing to find private services, and having to learn about the legal components of the special education system, in order to become an advocate (Silverstein, 2015). As caregivers learn more about the processes
needed to have their child identified for dyslexia and to begin receiving services, they begin a journey of learning about how dyslexia can be treated. The section that follows offers background regarding interventions that caregivers may request for their child in both medical and academic settings.

**Caregivers Seeking Dyslexia Interventions: Medical and Educational Treatments**

Elliot and Grigorenko (2014) mention that the utilization and meaning of the term dyslexia varies depending upon the purpose being discussed. Either a medical diagnosis or a label is given to a child based on the setting being considered to indicate that they have dyslexia. As caregivers learn more about this learning difference, they may attempt to seek clarification from their child’s pediatrician and or a public school representative.

**Medical Approaches.** Geneticists, neuroscientists, medical practitioners, and psychologists can diagnose an individual with dyslexia, so that medical action can be taken (Elliot & Grigorenko, 2014). Further complicating the identification of this hidden disability is the challenge of identifying ways of measuring unobservable characteristics (Fletcher, Lyon, Fuchs, & Barnes, 2007. The identification and interventions provided to learners with dyslexia ultimately attempt to lessen the learning difference so that it does not impact the person negatively.

For example, Ozernov-Palchik & Gaab (2016) summarized the work that has recently been done in the medical sciences on neuroimaging, which has important implications for early identification. Neuropsychological approaches to the identification of dyslexia have evolved from a general description of what a learning disability is to a more specific understanding of the areas of the brain that are affected by certain learning differences (Fletcher, 2009.) Early identification of dyslexia characteristics can help learners cope with the challenges associated
with dyslexia. Medical interventions such as the following have attempted to remediate dyslexia characteristics:

**Perceptual-motor training.** Perceptual-motor training is an intervention that suggests learners with dyslexia can overcome dyslexia with eye-movement interventions. This is done once the learning difference has been diagnosed by a pediatrician (Manilla & de Braga, 2017). Eye-movement interventions are based on the notion that challenges that reading challenges can be remedied by training the individual to accurately perceive letters and words (Schreiber, Crawford, Fetters, Tweed, 2001; Stein, 2001). This method has proven not be effective in mitigating effects of dyslexia, as researchers have learned that the characteristics of dyslexia are neurobiological and do not have to do with eye-movement (Evans, Drasdo, & Richards, 1994; Evans, Drasdo, & Richards, 1996; Shaywitz et al., 1998). This intervention has struggled to remain a credible as research has fluctuated on its effectiveness.

Before advances in research that allowed for functional magnetic resonance imaging (fMRI), showing the exact regions of the brain that are affected by dyslexia (Shaywitz et al., 1998), learners with dyslexia were merely described in the medical literature. That is, they were understood to reverse letters, see mirror images of letters, fixate for a longer time on texts than skilled readers (Rayner, 1985a, 1985b), and to need more time than other readers to decode and comprehend individual letters and words. They were also seen to have poor comprehension of texts.

Although the effectiveness of eye-movement interventions has wavered, Manilla and de Braga (2017) propose that they have discovered an eye-movement intervention using stereoscopic eye exercises. They developed a program called the Positional Reading Arc to help children with dyslexia overcome reading challenges. This reading method for visual correction
claims that students with dyslexia who are given this intervention have immediate success. This Positional Reading Arc positions the level at which a student is presented written work by altering the degree in 30° increments which vary from the student positioning their chin toward the ground and all the way up towards their spine. This claims that students with dyslexia can learn a coping mechanism by altering the degree level that their eyes are directly positioned while reading. The researchers state that, “a pediatrician could begin the teaching of the reading method in the office and refer the student to his patient’s school teacher with appropriate communication” (p. 10). Although the intervention does improve reading ability after only five to seven days, as soon as learners stop using the intervention, the characteristics of dyslexia return immediately. For that reason, this intervention remains controversial and the effectiveness of integrating it in the classroom or the doctor’s office is debatable.

**Fatty acid interventions.** Caregivers may attempt to find alternative ways for their child with dyslexia through unconventional methods that have been supported by medical science, such as fatty acid interventions. Malacrida (2002) provides an analysis of the factors that contribute to the medicalization of hidden disabilities and the mothers who raise children with these learning differences. She discusses a doctor from the vitamin company Stordy (n.d.) who states that she began research in the area of fatty acid supplements because she noticed that in her own family there were members who had dyslexia, and that those who had been breast-fed longer were not as affected by their dyslexia characteristics as those who were not (as cited in Malacrida, 2002). Fatty acid supplementation may help a child overcome dyslexia (Baker, 1985; Richardson et al., 2000; Richardson & Puri, 2002; Richardson & Ross, 2000; Taylor, Higgins, Calvin, 2000) by eliminating fatty-acid deficiencies evidenced by dry skin and hair, brittle nails, and improvements in schoolwork.
Recent studies have found that fatty acid interventions do not improve a child’s reading ability (Cyhlarova, et al., 2007; Kairaluoma, Närhi, Ahonen, Westerholm, & Aro, 2009; Kirby, Woodward, Jackson, Wang, & Crawford, 2010). However, this treatment did improve some symptoms not related to reading.

Psychology. For children who have the learning difference of dyslexia, there have been some studies that consider the relationship between behavioral and emotional difficulties and the challenges they face with reading. Learners with dyslexia may experience lower levels of motivation to read, due to their perception of an inability to read effectively (Polychroni, Koukoura, & Anagnostou, 2006; Riddick, Sterling, Farmer, & Morgan, 1999). Negative emotions attached to reading experiences may increase the student’s anxiety and permeate other areas in their lives (Manassis, 2013; Mugnaini, Lassi, La Malfa & Albertini, 2009). Students may experience internal anxieties due to the challenges they face with reading, along with physiological responses to tasks associated with reading. Tobia et al., (2016) found that children who have dyslexia may experience skin conductance responses when reading aloud and further captured the experiences that caregivers have about their child’s difficulties when reading. This means that physical manifestations of stress related to reading are evident on a child’s skin when they read. Overall, caregivers mentioned that they recognized when their child was going to have moments of anxiety or stress due to reading and when reflecting on their own relationship to their child’s dyslexia, they too had anxiety associated with their child’s learning difference. The anxiety that caregivers sometimes experience upon identification may have to do with the perceived and actual challenges that become evident as a child progresses through formal education. For example, if caregivers have a child who has been raised at home since birth, once
the child begins formal public schooling in early childhood educational settings (3 to 4 years old) they may not have ever realized that their child is learning at a different pace than their peers.

**Educational Approaches.** In the educational field, learners who have dyslexia characteristics should receive intervention that is started early and then continued as a child matures, using reading practices that are based on programs proven to improve skills associated with dyslexia, and that include multisensory integration (Birsh, 2011; Gillingham & Stillman, 1997; Kelly & Phillips, 2011; Singleton, 2009; Towend, 2000). The programs integrated into schools typically have methods that involve teachers receiving professional development to learn how to implement the program with consistency or fidelity so that the learner improves their reading skills.

There is debate regarding whether children with dyslexia need intervention from a specialist or whether a general education teacher will suffice. Also, the question remains as to whether the intervention should happen in an inclusive setting with their peers or a separate setting isolated from their peers with a specialist. These are concerns that have been considered by educators, researchers, government agencies, and caregivers. Dyslexia specialists receive ongoing professional development in multisensory techniques as well as skills to learn how to look critically at the evidence as a student progresses through multisensory programs (Pumfrey & Reason, 1992). General education teachers may or may not have an understanding of the interventions that are needed to remediate students with dyslexia. In order to provide intervention, teachers in early grade levels must integrate intensive phonics instruction using lessons that are guided and focus on phonics and word recognition skills (Rief and Stern, 2010). Regardless of the educational systems in place that dictate if a student will receive intervention
for their dyslexia from a general education teacher or a specialist, I believe that the most important factor is that the school support the child with strategies to learn to read.

**Teacher-driver specialized interventions.** Specialized interventions such as the highly systematic instruction in the Orton-Gillingham method take place in a separate location, which removes learners from their general education setting. However, Norwich and Lewis (2005) propose that students with dyslexia should remain in the general education setting and receive instruction that is not any different that the instruction their peers receive. This idea assumes that the general education teacher is aware that students with dyslexia fall on a continuum, and that the curriculum is the same for all learners. This means that no separate intervention is needed, as a teacher should know how to tailor student instruction to each student’s ability. The issue of having students remain in their classes is that general education teachers are not prepared to work with SLDs (Giorcelli, 1999). Regardless of the model employed, learners need early intervention to become independent readers.

**Computer based software intervention.** Computer-based software interventions provide systematic instruction via a program that a learner uses. These programs can either be self-guided by the student or monitored by a teacher who decides when the student is ready to move on to another lesson in the program. In a query to see how many studies fit the requirements during a search on ProQuest using the search terms: dyslexia, computer based intervention programs, and peer reviewed, 20 studies documenting effectiveness surfaced between 1998 and 2018. This means that the interest in using computer based software intervention for students with dyslexia has gained popularity as an intervention in education.

Interventions for learners with dyslexia characteristics have been highly debated. Although caregivers do not typically give their children direct interventions and instruction to
gain coping skills in reading, many do become more knowledgeable about the different types of interventions available as they advocate for their child in different parts of the world (Ault, Bausch & Ackerman, 2018; Bohl & Hoult, 2016; Rief & Stern, 2010). Since this study will consider the experiences that caregivers have had within the state of Texas, I begin the next section with a brief discussion of the legislation that mandates special education systems in the various countries around the world. I will consider special education services internationally & nationally, noting that each country varies in the way that they identify and support students with disabilities. An awareness of the systems of support that caregivers attempt to provide to their child as they begin to show signs of struggling with reading will be discussed below.

**Empirical Research on Caregiver Experiences with Dyslexia Identification**

Due to the ambiguity of the processes by which public schools decide how to support and treat students with the specific reading difference of dyslexia, caregivers are at times forced to find the required educational support outside of public school settings, searching for private entities to provide consistent services for their child so that they can learn to read (Leitão, et al., 2017). The reaction that a school system has to a caregiver’s concern can be challenging, because the struggles the child is having can be due to a disability that is only seen when the learner is confronted with reading tasks (Fenton, 2016), compared to a physical disability. McNulty (2003) considers the misunderstandings of unexplained struggles with adversities related to hidden learning disabilities, such as dyslexia, and the impact that having a hidden disability may have on a child at a young age and the caregivers that support them. Due to the fact that dyslexia is a hidden disability, caregivers may experience various emotions and reactions related to complicated process of dyslexia identification.
It is not until the moment a child shows that they are struggling to read that families can seek support from the school system. When caregivers are attempting to prove to educators that their child is in fact, struggling with the acquisition of reading skills, they may search for answers or assistance on their own to help their child. Many caregivers search the Internet (Leko & Griffin, 2009) in hopes that they will find solutions for interventions such as the ones mentioned above in the educational and medical sciences section. Leko & Griffin (2009) discovered that 22,000,000 hits appeared after entering the search term learning disabilities in the search engine Google over six months in 2007. The plethora of Internet sites in different languages, specific to dyslexia, testify to the international interest that has been associated with challenges in this SLD (Pavey et al. 2013). This might be due in part to the emphasis that is placed on school-aged students to become successful in reading and the desire that caregivers have to provide academic assistance to their child.

In reviewing the literature on dyslexia identification and its impact on caregivers, it is necessary to first discuss legislation for dyslexia in certain countries. Then, I will review the empirical literature regarding experiences that caregivers have had during the identification process of a hidden disability to include debates on the recognition of dyslexia. The first category of literature is caregiver experiences and their interactions with the public education system during the dyslexia identification process and how the public education system has reacted to dyslexia identification, alongside caregivers, and the second category of literature will consider the impact that dyslexia identification has had on social and family dynamics. I will review and synthesize the literature regarding experiences that caregivers have as they initiate the process of dyslexia identification from an international, national and finally, a state perspective.
Legislation & Policy Considerations: Dyslexia Identification in Various Countries

Depending on the country in which caregivers live, there are different legislative considerations for the dyslexia identification process. This section will provide some background into what processes caregivers must follow in order to have their child identified with the specific learning disability of dyslexia.

**Australia.** Dyslexia is included as a learning disability in the Disability Discrimination Act (DDA) which was implemented in 1992 and revised in 2005 (Australian Government Department of Education, Skills and Employment, 2005). In 2010, recommendations were made to ensure that the Australian community at-large (not geared for those only in the education field) learned ways of how to help individuals with dyslexia in a document called *Helping People with Dyslexia: A National Agenda* (Parliamentary Secretary for Disabilities & Children’s Services, 2010). In this national action agenda, one of the recommendations made is to include the specific term dyslexia in the DDA so that education systems can receive funding to serve students with the learning disability.

**Canada.** Education in Canada is a provincial responsibility, however, school systems must consider any barrier that prevents a person with a disability from fully participating in education settings (Library of Congress: Children’s Rights, 2003). Schools for example, in Ontario, Canada are required to assess learners who may have an SLD with a formal assessment from either a school psychologist or a pediatrician (British Columbia Ministry of Education, 2002). Furthermore, there are provincial laws that require school boards to address students with special needs. Children with learning disabilities are encouraged to be identified in kindergarten or first grade, however the Ministry of Education realizes that the identification process for dyslexia may be challenging to identify and this is why educators need to have an understanding
of the characteristics of the disability to ensure success in early identification (Ontario Ministry of Education, 2003).

**Hong Kong.** In Hong Kong, there is not special education law (Poon-McBrayer, 2004). This means that even when a child may be showing characteristics of dyslexia, there is not a delineated identification process. However, caregivers with a child that shows characteristics of dyslexia have worked together to advocate and present cases to the federal government so that they can consider implementing dyslexia laws (Poon-McBrayer & McBrayer, 2014).

**Mexico.** Russo and Lozano (2015) found that in 2013, guidelines were enforced to ensure equity in education in the *General Guidelines for Special Education Services*. The authors state that the guidelines focus on the diagnosis of students with disabilities, the necessary planning for success in academics, the intentional assessment of their progress and ability to succeed in increasingly rigorous levels of education. However, special education in Mexico is seen as a complementary service (Diario Oficial de la Federación, 2011, 2012) where most children are actually excluded (Garcia-Cedillo, Romero-Contreras & Fletcher, 2014) due to insufficient services and minimal support because educators receive minimal amounts of training on how to identify and support learners who are not typically developing. Garcia-Cedillo et al. (2014) state that it is usually left to the caregivers of learners with different abilities to “seek and provide the necessary supports in order for students with disabilities to grow, develop, and benefit from the education they receive” (p. 70). This means that caregivers who have a child with dyslexia characteristics may seek intervention for their child with dyslexia in public schools but may not find teachers who have received training in intervention strategies due to lack of training and funding; therefore, caregivers who try to find support for their children would not find specialists in the area of dyslexia who work in public school settings.
**Turkey.** There are special education schools for children with special needs in Turkey, however, learners with special needs have not been commonly recognized in Turkish society and have been isolated from educational settings. In the law that was enacted in 1929, it stated that caregivers were required to raise their child with special needs and maintain education for their child (Melekoglu, Cakiroglu & Malmgren, 2009). Depending on the severity of the disability, some learners with cognitive impairments were seen as not being able to benefit from any education at all (Ozgur, 2004). Although in the past students with disabilities were completely separated from learners without disabilities, the Turkish government began a movement by encouraging schools and caregivers to increase the number of students in inclusive settings (Praisner, 2003). Furthermore, Melekoglu et al. (2009) documented that as of 2009, there were 93 centers with 440 educators that are responsible for assessing students in Turkey. This means that inclusion of students with special needs is supported by the Ministry of National Education in Turkey but depending on the caregivers access to assessment centers, their child may or may not be assessed. Learners with dyslexia cannot qualify for these schools since they have average intelligence levels. This means that children may receive the diagnosis of dyslexia but the education system is unable to provide intervention due to institutional barriers of inadequate assessments, instructional materials, training, and the stigma of having a learning difference.

**Russia.** Learners with dyslexia in Russia are identified by a medical-psychological-pedagogical committee (MPPC) that comes together to assess the child and to provide information regarding where they should be placed and how their progress should be monitored (Kornev, Rakhlin, & Grigorenko, 2010). This process begins as soon as a child enters kindergarten, as all kindergarten students in Russia are screened for speech and language impairments, and if they need interventions, the children and their family are offered placement
into a specialized kindergarten program. While this practice is offered for each child, there are not any laws about special education in the Russian Federation so after kindergarten these intervention services are not guaranteed for the child or for their family.

**Spain.** In Spain, the term learning disability has been used to describe learners who have challenges with learning since the law, *Ley Orgánica de Ordenation General del Sistema Educativo* (LOGSE) originally referenced the term in 1990 (Soriano-Ferrer & Morte-Soriano, 2017). However, this did not specify the specific area that a learner is having difficulties with rather it generalized that a child had learning difficulties (Fidalgo & Robledo, 2010). When the Education Act was re-authorized in 2006 (Ley Orgánica de Educación, LOE) there was specific mentioning of learning disabilities as its own category in Special Education. Dyslexia is a term not specifically stated but falls under the category of learning disability for learners with special education needs (SEN). At this time, depending on the region where a child lives, there are different regulations regarding the identification and interventions that are implemented for students with dyslexia. For example, Fidalgo & Robledo (2010) found that in Baleares, Spain “there is a request for the development of a protocol enabling pediatric services to diagnose dyslexia more swiftly, as well as a demand for improvements in the relevant training of education professionals” (p. 178). This means that in regards to dyslexia, sometimes the initiatives specific to dyslexia interventions offered for learners may depend on the legislation that is created which at times is initiated via pressure placed on governments by associations and organizations (Lerner & Kline, 2006) that represent fair and just treatment for children with this learning difference.

**United States.** In the United States, the guidelines that support, protect, and assist in the education of students with disabilities are delineated by the Individuals with Disabilities
Education Act (IDEA) which was originally passed in 1975 as the Education for Handicapped Children Act and was renamed and authorized most recently in 2004 as IDEA (the Individuals with Disabilities Education Act, 2004a). This law delineates that dyslexia does not have a specific category, rather that it is identified under the general category of a specific learning disability (SLD) (The Individuals with Disabilities Education 2004b; Snowling & Hulme, 2012).

In an analysis of the dyslexia laws in each state in the United States, Youman and Mather (2013, 2015) found that twenty-eight states had statewide dyslexia laws, and within those twenty-eight, fourteen have dyslexia handbooks or resource guides intended to inform educators and caregivers about the procedures for children in private and public schools. Texas and Arkansas are two of the twenty-eight states that not only have a handbook with specifically outlined laws for the identification and intervention of students with dyslexia, but they are also the only two states to have students with dyslexia served in either Section 504 or under IDEA (Phillips, Odegard, Phillips, & Odegard, 2017).

This is important in that, based on the definition, dyslexia could possibly be interpreted as a SLD as specified in Section 504 (Section 504 of the Rehabilitation Act 34 CFR §104.3, 2017). IDEA provides specific guidance under the Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA), which outline the rights of students with dyslexia and other SLDs. Specifically, IDEA ensures that any child with a disability must be provided with a Free and Appropriate Public Education (FAPE) that is aligned to the student’s specific special educational needs and prepares them for further education and independent living (The Individuals with Disabilities Education Act (2004a). Under each of these laws, individuals are legally entitled to special services to help them overcome and accommodate their unique learning needs. Such services include education programs designed to meet their needs. These
laws also protect individuals against discrimination. Although IDEA specifically provides considerations for educating students with disabilities, the law is written so that school districts and educators have some flexibility to interpret the 2004 reauthorization of the law.

Public school systems within each state in the United States have been left to interpret the laws in regards to how school districts will support students with dyslexia, depending on local resources. The flexibility to decide upon services means that schools provide accommodations either through Section 504 or through an IEP in Special Education. The differences between providing accommodations either through Section 504 or Special Education is that each state is allowed flexibility as to how they will identify dyslexia, select a therapy, and ultimately how they will accommodate students with the SLD of dyslexia. For example, there has been legislation to require dyslexia mandates for identification, assessment, intervention. Decoding Dyslexia (DD) is an example of a caregiver-led grassroots movement that advocates for policy change in schools in New Jersey. Beginning with eight caregivers, there are now local DD branches in 50 states.

**Legislation & Policy Impacts the Resources Available for Dyslexia**

Legislation also impacts the type of resources available to schools which will in turn affect the resources available to students. Depending on access to resources, failure to obtain the learning disability label of dyslexia could have adverse implications and exclude those with reading difficulties for social, economic, or political reasons (Elliot & Grigorenko, 2014). Social reasons may stem from the sentiments associated with the inability to read, which immediately stigmatizes students; misconceptions arise that the child has low intelligence, that there are inadequacies in parenting, the home environment, and/or instruction (Cook, 2017). Trimble (2001) notes that a SLD can generate internal feelings of anger, confusion, helplessness, and
sorrow in children, caregivers, and teachers.

An economic reason impacting identification of this disability is that school administrators are required to operate with smaller budgets and to have higher performance; limited budgets minimize training and resources available and may place stress on caregivers and educators trying to educate students with disabilities (Silverstein, 2015). Obtaining quality professional development and training are economic reasons that some educators may not know how to identify and then ameliorate the effects of the SLD of dyslexia (Reid, 2013). Political reasons vary depending on the country being discussed.

These economic, political, and social forces impact the ability of caregivers in attaining dyslexia services for their children.

**Dyslexia identification: Caregiver Experiences Around the World**

The following empirical studies show that across the world, caregivers are seeking assistance for their children in the area of dyslexia after a public school denies adequate services for students with dyslexia and/or suspected dyslexia. The studies are organized by the main theme that arose after the study was analyzed. Methodologies used for the studies below were overwhelmingly qualitative. However, there were some that used a mixed-methods approach, with interviews and surveys as a part of their data collection methods.

**Caregiver advocacy: Initiation of the process of dyslexia identification and the dismissal of concerns from public educators.** A common theme that is shared across each of the studies that follow is that caregivers mention that educators stated that they felt their concerns were invalid, and assessment for dyslexia was unnecessary. Some educators called caregiver responses overreactions to the struggles they suspected their children had in reading. For instance, in each study the caregivers describe their frustration with the identification
process. It seems that this sentiment captured in each of the studies is that there is anxiety associated with the SLD of dyslexia as caregivers realize that their child has a learning difference and as they attempt to secure services for their child so that they may find ways to ameliorate the impact that it has on reading ability.

For instance, Earey (2013) captures the reactions that caregivers in England had before, during, and after the assessment of dyslexia. Their reactions were discussed during in-depth interviews, and all of the participants stated that they found their way through the assessment process without the support of the schools. They noted that they had emotional reactions during the process, and one caregiver said it felt like “an uphill struggle” to have their child identified (p. 38). This was in part due to the ambiguity of when their children were assessed and when they finally qualified for dyslexia interventions. Among these caregivers, the range was from as early as seven years old to as old as fifteen. The emotional reactions that caregivers experience can be due in part to their struggle to get the school to begin the assessment (Earey, 2013). Caregivers stated that they felt that they had failed their child. They felt heartbreak, and battled to get their children identified.

Riddick (2010) captured the feelings that caregivers had in a study in the United Kingdom with 22 mothers. The participants stated that they felt that the most significant effects on their child(ren) occurred once their child was in school. Caregivers in this study mention that these effects were most impactful before their child was receiving support or had been identified with dyslexia. Similarly, in a qualitative study with parents attempting to have their child identified with dyslexia in Canadian schools, Dyson (2007, 2010) captured the experience that ten caregivers had as they were attempting to convince educators that their child had a learning difference of dyslexia. Caregivers in this study felt that the school had unrealistic expectations
for their child, and they mentioned that “They [schools] can’t possibly know what it feels like to
be learning the capital of Canada when you can’t spell and [when] you have dyslexia and you
can’t write” (p. 50). Both of these studies explored the experiences of mothers who noted that
they experienced high levels of stress associated with tumultuous interactions with school staff.
Furthermore, caregivers in the Dyson study mentioned that they felt that the schools generally
rejected their child’s needs and were not sensitive to the unique learning needs that a child with
dyslexia has. Interactions with the school were reported as negative overall and specifically
mentioned they felt that the assessments were incompetent, services were delivered in an
inconsistent manner, and expectations were unrealistic from the school.

Silverstein (2015) suggests that there is a “growing national wellspring of parent
frustration with the school system’s response to the specific learning disability of dyslexia” (p.
201) in the United States. This frustration was captured in her mixed-methods study which
highlighted families’ testimonies about experiences with dyslexia. Although this study
considered the co-morbidity of learning disabilities in general, all participants stated that
dyslexia was one of the disabilities that their child had. Families were predominately from
California but also represented in the study were caregivers from Pennsylvania, Virginia, New
York, Minnesota, Michigan, North Carolina, Texas and since a part of the survey was online- ten
caregivers from other countries completed the survey as well. The two implications for school
staff from these caregivers was that they had had experienced negative interactions with school
staff which made them feel angry and had lost any trust in educators. They mention that that
educators did not know about the processes of identification or remediation for dyslexia or
SLDs. A gap in this study mentioned was that the group represented was overwhelmingly
female, white, well educated from high economic statuses (p. 227).
The experiences of working mothers with dyslexia in the United Kingdom (Skinner & MacGill, 2015) were analyzed in a study which found that mothers who themselves had dyslexia felt anxiety before their child entered school and/or before their children were identified with dyslexia. Caregivers mentioned that they were worried about their child’s abilities and wanted to ensure that their child did not have the same negative experiences they had had. In regards to work, these caregivers experienced support via partners and family members who shared some of the care and parenting tasks related to dyslexia and stated that organizational skills and flexibility at the workplace contributed to their success as working mothers with dyslexia.

The idea that educators dismiss caregivers concerns about reading was also captured in Beck, Hazzard, McPhillips, Tiernan and Casserly (2017) study in Ireland where one participant mentioned that:

The teacher… thought she [her daughter] had no difficulty in her reading and told me that she was a level 4; 5 is excellent! I’ve been banging my head against a wall for three years... when she got the dyslexia screening it came out as severely dyslexic. (p. 153)

In this example, the educator does not recognize the same difficulties that the caregiver notices in the home setting since the assessment indicates that the child is preforming at a level 4, with level 5 being an excellent reader. Although the assessment shows that the child is able to perform at a certain level, the educator in this scenario does not realize that success in a generalized assessment does not equate to success with individual reading skills and abilities. This may be due in part to assessments that are not able to distinguish the characteristics of dyslexia.

Bringing attention to a growing national concern, Newsweek featured a story “Dyslexia and the New Science of Reading” (Kantrowitz, Underwood, & Wingert, 1999). In this featured story, caregivers’ experiences around the United States were highlighted to show the widespread
sense of urgency that is felt when children are struggling to read. In Indiana, Matthew Schafir’s caregiver was desperate to get her son effective interventions. Matthew had been struggling with reading, despite tutoring and testing offered at his school. His caregiver decided that in order for her to pay for interventions offered at a clinic seven hours from their home, they would live in a tent to save money. After six weeks of intervention at the clinic, Matthew’s reading level jumped from a second grade level to a fifth grade level. Caregivers who do not have access to cultural and financial resources are left at a disadvantage to advocate for their child who has a hidden disability and are trying to get educators to believe that they do.

When caregivers suspect that their child may have a disability related to reading, they are challenged with becoming an advocate, who has to make attempts to speak up and gain assessment and services for their child. The meetings that a caregiver has to attend to advocate for their child therefore can be stressful events. Even for caregivers who are familiar with the educational jargon used in schools, meetings assembled by caregivers wishing to advocate for their child can be intimidating. Collins (2016) finds similarities of intersectionalities as she considers her own intersections of being a scholar, teacher, single mother who is White and has a biracial child in Pennsylvania. This is important because as she tells her story, she is able to integrate a different lens that other caregivers may not be able to do which considers her own reflexivity as a scholar. She states, “I have felt overwhelmed and exhausted by every school meeting” (p. 198) regarding the tensions she felt as educators in her son’s school pushed for him to be excluded from general education classroom settings because of his high level of activity. She mentions a vignette from when her son’s classroom teacher was attempting to get him to just sit down.
The process of convincing educators to believe that a caregiver’s child is struggling with reading can lead to strong emotional reactions as they are attempting to prove to educators that they notice a learning difference.

**Educator and government response to caregiver requests for dyslexia identification.** Making the process of identification even more difficult for educators and caregivers is a finding that there are widespread instances where there is an inability for school personnel to integrate the word dyslexia into paperwork once a child has been identified (Consortium for Citizens with Disabilities, 2015; United States Congressional Dyslexia Caucus, 2015). This is due to the ambiguous nature of whether dyslexia is categorized as an SLD that should be under 504 or Special Education. Although there are many guidelines that cite both SLD and 504, the Consortium for Citizens with Disabilities and the United States Congressional Dyslexia Caucus, have written to the US Department of Education (Office of Special Education and Rehabilitative Services) to require each state to evaluate if the issue of omitting the word dyslexia, this is still a systemic problem for caregivers. Some empirical research has been conducted which considers the need for legislation and ample training opportunities for educators who serve students with dyslexia. Although caregiver experiences are not always present in the following studies, there is evidence that when caregivers begin to advocate for services for their child who is struggling with dyslexia, the government and education systems begin to consider providing services due to the increase in demand for intervention services from educators.

Aladwani and Al Shaye (2012) surveyed elementary school teachers in response to an increase in concerned calls from caregivers and educators in Kuwait. The Ministry of Education (MOE) began a dyslexia-friendly school awareness initiative in conjunction with the British Dyslexia Association that would require schools to become more aware of the special needs of
students with dyslexia (Elbeheri, 2008; Kuwait Dyslexia Association, 2002; Kuwait Dyslexia Magazine, 2007). After conducting a survey with 700 educators to evaluate their understanding of dyslexia and awareness of the early signs of dyslexia, it was determined that although teachers do want to learn more about dyslexia, issues related to limited time, and a large caseloads of students impacted their ability develop those skills. Recommendations to educate teachers more about dyslexia included: requiring a compulsory course in identifying students with this special need, continuing public awareness of dyslexia-friendly schools, and reducing the amount of administrative tasks teachers are required to do each day so that they have more time to implement new methods/technical skills needed for intervention. Although caregivers’ experiences with the school system are not documented in this study, the MOE began the dyslexia-friendly initiative based on the numerous phone calls concerning school practices. Educators in this study did want more information, but had not been afforded the opportunity to receive training regarding dyslexia.

Classroom teachers in a rural community in Pakistan were interviewed to explore how they learned about SLD identifications, as well as their experiences in SLD identification (Kazmi & Pervez, 2010). In this study, educators from 19 schools described the ways that they provided support to students with an SLD. While the researchers mentioned that parent input during the identification process may be helpful in this rural community without an LD specialist, neither parents nor educators had the resources to provide identification or intervention for students with SLD.

The early identification process for dyslexia in England was delineated as an opportunity for speech-language pathologists to provide information to caregivers about children who may be at risk of developing reading difficulties (Colenbrander, Ricketts, & Breadmore, 2018). SLPs are
able to support caregivers by facilitating the request for appropriate assessments and interventions so that the process of intervention can begin early and follow a child through the early elementary years. Due to the amount of information that these specialists have regarding a child’s case in regards to language, the SLP can also assist the child’s teacher in providing interventions. These interventions can help a child in early word abilities so that they are more successful in more challenging tasks when they are older. Early intervention via the SLP allows for students who may show signs of early risk factors who may have the specific learning disability of dyslexia to receive support from their family, their teacher, and SLP.

In another study, researchers intended to capture both the experiences that caregivers had during the dyslexia identification process as well as the impact the process had on their family dynamics. For this reason, this study will be discussed in both this section and the section below discussing family dynamics. Poon-McBrayer & McBrayer (2014) captured the experiences of 25 mothers in Hong Kong who had children with dyslexia. One caregiver stated, “My boy couldn’t even get the alphabet right and couldn’t write his Chinese name. Finally, he was diagnosed with dyslexia. I cried for a month. I didn’t know how he could face his future. He was only 6!” (p. 100). A caregiver in this study mentioned that once she found out that her child had dyslexia, she wanted to start learning more and more about the learning difference. This caregiver began to write appeal letters to seek accommodations for her child. Several caregivers also began to raise awareness of the need to have systems of support and identification in place by urging the government to create legislation that protects the rights of families affected by dyslexia. This was done to also encourage schools to implement practices that support children with the learning difference of dyslexia.
The studies mentioned above have an overwhelming theme associated with limited resources and training opportunities for the educators who work with students that have a learning difference of dyslexia. Also, the need for implementing systematic legislation surrounding dyslexia identification were themes in most of the studies. A study conducted in California, educators mentioned that they needed more training in order to identify dyslexia (Futterman, 2017). But even after the training they requested, they were unable to “say the word dyslexia,” due to lack of resources and policies that limit the amount of students that can be served in the program. One special education teacher in an urban California district mentioned that she ultimately left her role as a special education teacher after being told that in their district, they would not be identifying students and labelling them as having dyslexia. Futterman (2017) mentions that although it is known that caregivers face the issue of schools not actually using the word dyslexia in paperwork or conversations with them, at this time, there have not been any U.S. studies focusing on caregivers to understand how and why this is happening.

The impact of the dyslexia identification process: Social and family dynamics. The dyslexia identification process can also have an impact on family dynamics. This identification process challenges caregivers to seek assistance via resources that they may not be aware of. Furthermore, caregivers who attempt to find services for their children may also have to learn how to cope with their ability to support their child in an area that they may be unfamiliar with. In this final section of my literature review, I will explore the work on social and family dynamics when a child has been identified as having dyslexia. During the process of dyslexia identification, social and family dynamics are impacted in a variety of ways. This can depend upon factors such as whether the caregiver suspects that there is a disability and the types of support that are available for the caregiver. This next section will the literature on how caregivers
cope with the process of dyslexia identification and instances of how it may affect social and familial dynamics. It is necessary to mention that these experiences vary and that not all caregivers who have a child with the SLD of dyslexia will experience the impact of the identification process in the same way.

Anxiety is an emotional reaction that was identified as most common in a study conducted with 19 caregivers (Dyson, 1996). Anxiety related to devoting excessive amounts of time and energy to their child with a learning difference was reported. Other feelings related to anxiety were challenges related to behavior, academics and attempts to help their child learn how to find success in spite of their learning difference.

In a study conducted by Ginieri-Coccossis et al. (2012), the researchers identified via comparison, if there were any significant differences in terms of quality of life between caregivers who have a child with a LD and those who do not. The psychological health among caregivers of typically developing children (69 families) and those who had a child recently diagnosed with a LD (70 families) were identified. This study found that there were not any significant differences between each group of parents, which suggests that these were normal emotions. This study was an outlier, as it diverged from the other studies that discussed the negative feelings associated with having a child with a LD. However, another finding in this same study was that caregivers who had a child with a newly diagnosed LD stated that they felt that they experienced lack of social support, poor personal and sexual relationships, and dissatisfaction with their social lives, as compared to caregivers who had typically developing children. This means that although caregivers do not experience notable differences in each and every part of quality of life, ultimately there are still challenges with social and family dynamics for caregivers who have a child with a LD.
Another study that had similar findings which were not negative was a qualitative study of 32 caregivers from Israel (Heiman, 2002). The caregivers in this study reported that their relationships had improved with their partner since they had to intentionally work on communication and their relationship. This means that even though there were challenges to overcome as their children progressed through school, as long as the caregivers communicated and expressed concerns as a joint unit, they were able to advocate for their children to gain the skills needed for their SLD of dyslexia.

In a study mentioned in the first section, seven experiences of caregivers in Turkey were analyzed to consider how the dyslexia identification process impacted families in school settings and in home settings. This study was the first that had ever considered the experiences of dyslexia via the perspective of the caregivers (Yildiz, Yildirim, Ates, & Rasinski, 2012). Caregivers stated that they had emotional reactions during the identification process, such as negative attitudes towards the child with dyslexia in the form of physical violence, insults, and psychological pressure. However, another theme that arose in this study was that caregivers stated that there were problems with relationships between family members and peers. A theme that arose was that caregivers stated that their child did not want to go to school anymore because of the negative environments in their classroom. This is due to two different practices, one is that teachers have peers grade student homework and do not redirect insults that typically developing peers say to students with dyslexia. The other is that students in elementary classes are frequently grouped by ability, which creates an environment where learners with dyslexia are portrayed by their peers as low-achieving or lazy. A caregiver mentioned, “My daughter is in the lazy group. Those in the other group mock our children. This situation alienates my child from school and her class” (p. 409). This means that her daughter feels that because of her learning
difference, she is ostracized from her typically developing peers by being placed in a group that focuses on fixing her difference.

Caregivers responses in Hong Kong were captured during the identification process in this study as well as the impact that this process had on their family dynamics. A theme that arose in this study was that their emotional reactions evolved from feeling guilty and burdened towards feeling they wanted to ask for help by advocating for their child. Ultimately, many caregivers became activists and worked with their schools and other authorities change the system for caregivers and learners who have dyslexia in Hong Kong (Poon- McBrayer & McBrayer, 2014). A specific nuance of this study that differs from the other international ones is that the key virtues of Confucianism may have some conflicting impacts for both caregivers and educators on the education for individuals with disabilities.

Added complexities came from a study conducted by Yang & Wang (1994) which found that Confucian ideologies value respecting authority and maintaining harmony. It is difficult to advocate for different practices when harmony is required. When a caregiver begins to advocate for a child who is considered weak in reading, they sacrifice challenging authority which may be conflict with ideals of harmony in Confucianism. Although some caregivers became more assertive and considered themselves activists, they still maintained a cordial relationship between representatives in the school, so as to maintain harmony.

The strain that the identification process of the SLD of dyslexia in the United States was discussed in a study that asked parents about how they managed the stress of the process (Silverstein, 2015). A concern that was noted by parents was their empathy for other parents who had less access to financial resources than they did. This sentiment is evident from a vignette that a parent shared in Silverstein’s (2015) study, who stated:
I took out a second mortgage and ultimately lost my home to Fannie Mae, all trying to find tutoring for my kids. I’m out of money and out of hope. I just can’t wait for [my kids] to be done with the joke of a school system and realize that they can be great individuals on their own. (p. 95)

Lack of hope is a common thread among caregivers frustrated with their children’s lack of progress. This lack of hope strains relationships among family members as well as putting pressure on the child with dyslexia. This strain is sometimes manifested for caregivers who must stand up for their children against relatives and friends who have misconceptions of what a learning difference means.

This example from California shows the sense of urgency that caregivers feel to ensure that their child finds success in spite of a learning difference. Similar to the experiences of caregivers in other countries, it seems that classroom environments and administrator dispositions affect the dynamics of social and familial dynamics. For example, a mother remarked that she felt that although her son’s teacher was invested in making sure that he got the interventions he needed related to dyslexia, the school administrator made her feel that due to budget constraints the interventions needed to cost the least amount possible. This same mother later mentioned that when an advocate who was knowledgeable about special education law would attend meetings with her, she would have better experiences with the schools.

Woodcock (2020) recently provided a similar study understanding parent experiences using CDT as a theoretical lens to understand the experiences that she as a mother with a child with dyslexia and five other mothers had with the dyslexia identification process in Massachusetts. In her study, the caregivers were each from diverse racial, ethnic and socio-economic backgrounds and states “a primary goal in writing this paper was to tell the real stories
of real people living with dyslexia” (p. 1652). The findings addressed the two research questions (1) How are students with reading disabilities (and their parents) positioned? (2) What is the experience of parenting a child with dyslexia, and how can educators help? Her research found that the caregiver’s children resided in spaces of *in-betweenness* where there were many practitioners (educators, clinicians/medical professionals, those in higher education) needed to consider the perspectives of not only individuals with diverse abilities such as dyslexia, but also the voices of their caregivers. “We can no longer shrug off vague symptoms, or the distinguished instincts a parent often provides” (p. 1651). Most importantly, it is critical that the input of families is considered since they are the ones who have a very specific insight as to how their child is handling the immense challenges of living with a learning difference that is invisible.

Although the legal requirements vary from state to state and country to country, caregivers are interested in learning how to support their children with tools that will help them become successful with literacy skills in the way that is respectful of the learning difference and considers social and emotional development.

This section of literature provided insight into the lived experiences that caregivers encounter as they navigate the dyslexia identification process. Caregivers around the world mentioned that the impact that the learning difference had on their child in home and school settings was something unexpected that they had to learn to help their child and family navigate. Learning how to balance the unique needs of their child was something else that each study mentioned. For instance, a caregiver in Silverstein (2015) states that their child with the learning difference requires more attention that their siblings without a learning difference. Uncertainty and lack of trust that caregivers have toward professionals that are responsible for providing interventions to their child was also a theme that arose throughout each of the studies above.
Tina Skinner (2011) completed an autoethnography, sharing her own experiences of failure, and reframing the experiences she had as she went through the public school system. In this reflection, she specifies the intersections of her identity as she reflected on what it meant to be a successful student, mother, and professor. Skinner (2011) describes the anxiety she felt related to her colleagues as ridicule for inadequacy due to prejudices she experienced as she found ways to seem become a successful reader, scholar, and mother. The ridicule that might be projected toward her from researchers is due to the vulnerability of sharing her experience through the methodology of autoethnography, where the researcher has to identify their own reflexivity during the process.

In the first study of its type, seven caregiver experiences were documented in Turkish school settings (Yildiz, Yildirim, Ates, & Rasinski, 2012) to consider the identification process on family dynamics. Since this study focuses on the experiences that caregivers have during the dyslexia identification process as well as how this impacts family dynamics, it will be discussed in this section and further discussed in the social and family dynamics section as well. This study found that caregivers were frustrated with the difficult process of learning legal and assessment procedures for assessment and identification of dyslexia. Specifically, parents mentioned that assessments were made at the Consultancy and Research Centers of the Ministry of Education as well as in hospitals.

While this review will not provide a review of literature regarding the increased likelihood for students of color and/or the removal of African American students due to perceived emotional and behavioral problems, the following scenario that Collins provides suggests that her son’s teacher felt that he needed to be removed from the classroom. In this example, her son’s race impacts the preconceived ideas that his teacher has about him and places
him in a deficit as related to his abilities in his classroom. Collins’ example as a caregiver in the United States gives readers insight to the intersections that caregivers face each day when juggling the different intersections of themselves and their children with varying abilities, and we are able to consider the added layer of stress that may be added as an intersection for caregivers who are not familiar with educational jargon. Even for this caregiver who had an academic background, the dynamics of power between educational staff and caregivers made it difficult for her to advocate for her son, and this was true being armed with the language and tools of an academic. It seems that this task is all the more difficult for caregivers who do not have the background in education to advocate for their child. In Collins’ work, she further mentions that she realized that she had the privilege of social positioning to advocate for her son as he was being pushed out of place in school. She had the cultural and financial resources to seek private educational alternatives when they became necessary, but she still could not convince the school to get her son the assistance he needed.

Valle (2009) shared a collection of 15 narratives of mothers of children with learning disabilities in the northeastern and southeastern United States. Caregivers interviewed mentioned that since their children had disabilities that were unidentifiable at birth (as compared to a physical disability that is visibly seen upon birth), they themselves had not realized that something was different for their child until they began school. Furthermore, they reported that they had difficulty in knowing how to understand their children, although they noticed something different and felt as if they failed to protect their children. This left the caregivers with feelings of guilt, shame, and failure.

These examples capture some of the lived experiences of caregivers entering and journeying through the special education process, finding ways to become more informed about
the challenges that their child was facing so that they could help them find success in school and overcome the characteristics of dyslexia. More specifically, caregivers express a necessity to learn how to advocate for their child’s needs based on the legal guidelines in their nation. Navigating the special education process presented as a challenge internationally, which is a common thread for caregivers attempting to help their child United States.

These studies that looked at caregivers’ experiences provide insight into how policies affect dynamics within the household. In these studies, I was able to see how the effects of having challenges with reading impacts perceptions of a learner’s ability both in school settings and at home. As educators enter the profession, it is critical that they understand the policies in their country regarding dyslexia. For example, if a country does not yet have specific legislation for the identification of dyslexia, the suggestion for a dyslexia-friendly classroom could be implemented. A dyslexia-friendly classroom includes visual aids and multi-sensory sources of intervention available for each lesson, varied input and outcome expectations for each assignment, and plenty of opportunities for them to succeed by focusing on their strengths and abilities (Cochrane, Gregory & Saunders, 2012). The most important point in these studies is that educators must learn how to create environments where caregivers can ask questions and learn about how to support their child. presents a challenge since in some countries, there are not any guidelines for dyslexia and/or special education.

**Caregivers and Dyslexia Identification in Texas: The Gap**

**Dyslexia identification in Texas.** In Texas, dyslexia is not automatically considered an SLD, so depending on whether or not a child is placed in 504 or IDEA, they may not be under the full protections offered under IDEA. The identification process is unique to Texas, in that there is even more ambiguity for the identification process as compared to other states. This
means that in Texas, a child does not automatically qualify for services under IDEA as they are considered to qualify with dyslexia on a continuum. If a student has significant delays associated with the SLD of dyslexia and reading, they may qualify for special education services; however, if a learner only exhibits dyslexia characteristics, they may qualify for 504 services. As caregivers attempt to locate assessment and assistance for their child(ren) who struggle to read, this literature review has provided insight into the lived experiences caregivers have faced in getting their child assessed. As caregivers confront the education system and request that their child have access to FAPE that is guaranteed under IDEA in the United States, their hope is that they may help their child find success in their education. FAPE is offered without charge to the caregivers and must provide individualized programming (Yell, Drasgow, Bradley & Justesen, 2004). The problem with having dyslexia under the realm of a 504 plan is that it may not provide the individualized programming as mandated under IDEA. This means that for example, if a child has been identified with dyslexia characteristics in Texas, if the child is placed in 504, there is not any funding attached to 504 plans. Since a student who has dyslexia needs intensive intervention from a specialized educator, if they are placed in 504 there is not any funding for that teacher. Federal funding for specialized educators would fall under the special education realm of IDEA.

Furthermore, the rights of caregivers under section 504 are more limited (Richards, 2017) which may make the process of identification confusing for caregivers. Under Section 504, a child is only able to receive accommodations that change elements of the environment to help them be successful in academic and non-academic tasks. For example, a child with dyslexia that is receiving accommodations under Section 504 may be allowed the accommodation of extra time so that they can complete tasks that require reading for a specific amount of time. In this
example, the child would not be allowed to reduce the amount of reading required for their peers, they would still be required to read the same amount, however, they would have more time to read which is an accommodation not afforded to the same peers (Texas Education Agency, 2014). Also, for Section 504, caregivers are only required to be notified of the accommodations put in place for their child; they are not a required member of the 504 committee. If the child in this same example were receiving services with an IEP under the Special Education realm, the child may be required to receive additional reading support with a reading specialist as a part of their regular school day. In order for this modification to the school schedule to occur however, the caregiver would have to give authorization and provide guidance to the Special Education committee considering the change.

In order to ensure that caregivers, teachers, evaluators, and administrators understand the proper procedures for identification and service delivery for students with Dyslexia, the Texas Dyslexia Handbook (TDH) was created (Texas Education Agency, 2014) and recently updated in 2018 (Texas Education Agency, 2018). Although Texas was found to be one of three states (in 2013) and one of fourteen states (in 2015) that has a handbook for dyslexia (Youman & Mather, 2013, 2015), the process of dyslexia identification is ambiguous and confusing (Nicholson, 2016; Worthy, Svrcek, Daly-Lesch, & Tily, 2018).

The handbook is confusing because the wording in the document is technical and is not user-friendly for educators and caregivers. This confusion led to an official letter being released to address the ambiguity of either implementing a 504 plan or an IEP in the state of Texas by the U.S. Office of Special Education specific to Dyslexia Guidance in 2015 (United States Department of Education: Office of Special Education and Rehabilitative Services, 2015). This letter expressed to educators in Texas that the SLD of dyslexia can either be implemented in a
504 or an IEP plan, as long as students are offered services if they qualify. This letter still did not clarify the process enough, and students in Texas with dyslexia were not being identified consistently. Due to the inconsistency of dyslexia identification in Texas, on January 18, 2018, the United States Department of Education: Office of Special Education Programs conducted an analysis of the systems in place for the state of Texas (United States Department of Education: Office of Special Education and Rehabilitative Services, 2018). This analysis considered the guidelines in the TDH and compared them to the experiences that educators and caregivers had with the identification and intervention process for dyslexia and found that the identification processes in place for dyslexia were vague and restricted services for students even after caregivers requested assistance for a child who was struggling with reading. The processes are vague and restricted due to the bureaucracy that caregivers need to figure out before their child is granted access to begin testing. This is evident in the vignette that was mentioned in the introduction which showcased the experiences that a caregiver in Texas underwent in order to get the process of dyslexia identification started.

In a recent study specifically capturing educator’s experiences in Texas, Worthy et al. (2018) found that dyslexia specialists who help children learn how to overcome dyslexia feel that general education teachers do not know or even believe that kids have dyslexia. Not only did the study find that general education teachers do not have adequate training to identify and remediate learners with dyslexia, some participants also mention that it is a systemic concern that begins at the university level. A participant mentioned, “I’m not sure that is exactly happening at all of our universities yet. I’m not sure that some of our professors even understand that phonics and phonemic awareness might be important.” (p 373). While this recent study captures sentiments felt by dyslexia interventionists in Texas, the experiences that caregivers have with this process
has not been captured via an empirical study. In Texas, there have not been any studies that specifically consider the experiences that caregivers have with dyslexia. However, there has been legislation introduced in response to caregivers attempting to change the system so that their children can get the supports of interventions for reading. For example, in order to provide instruction for their children who had dyslexia characteristics, a Texas caregiver in the 1960’s discovered the Orton-Gillingham method (Cox, 1985). After learning more about the method, this caregiver formed a group of educators and other caregivers to begin the process of training educators in the instructional method also referred to as Alphabet Phonics. By 1975, the program was taught at the Scottish Rite Hospital in collaboration with The University of Dallas, The Dean Learning Center and East Texas State University. Each school district in Texas is required to identify students with dyslexia and also provide intervention upon their identification, however, there are still many students who are not being identified.

In a 2018 study, two participants gave examples of the fact that some students who get assessed do not qualify for dyslexia although they still exhibit characteristics of dyslexia (Worthy et al., 2018). One participant who is an educator and a parent stated that she knew that her son was dyslexic and the testing may have been inaccurate stating, “I swear he is one [dyslexic] to a T, so I don’t know how he manipulated the thing.” (p 374). This captures the same sentiment that Collins mentions in her study, that even caregivers who are educators are experiencing difficulty in having their child identified with characteristics of dyslexia.

Conclusion

The study that I hope to conduct for my dissertation research will be the first of its type that considers the specific examples of experiences with the SLD identification that caregivers in Texas have had. The issue in Texas for caregivers is that although there is a formal handbook for
dyslexia (TDH), the processes in place across the state are not clearly defined as to how a child should be identified. If students are placed in 504 or Special Education, who should provide the support, and where should the funding come from to implement programs as defined in the handbook?

In a crosssectional study, Burke & Sandman (2015) discuss the perspectives of parents in the United States, and the suggestions they proposed for the reauthorization of IDEA. A caregiver in

Burke & Sandman (2015) mentioned:

When they were diagnosed with dyslexia, the school was unable to identify specifically what was wrong with their reading patterns and they did not have the correct interventions in place to get them through the reading process at a fast enough level. So I am asking for the IDEA reauthorization to include the definition of dyslexia so all children can be screened for dyslexia. (p. 79)

This means that caregivers are requesting that when the special education law in America gets reauthorized and updated again by the United States federal government, dyslexia and its definition should be included as an SLD. Furthermore, caregivers hope that if the term is added to the law, educators might begin to be required to know how to provide interventions to students with dyslexia because it will be delineated in the law.
Chapter III: METHODOLOGY

Methodological Approach

Phenomenology can be used as a theory and/or a methodology depending on the goal of the research being conducted. In this qualitative study, I used the phenomenological approach of Interpretative Phenomenological Analysis (IPA) as a methodology to investigate the phenomenon that caregivers experienced during the process of identification for the SLD of dyslexia.

The theoretical lenses used to analyze the three caregivers lived experiences with the phenomenon of dyslexia identification in Texas were Critical Disability Theory (CDT) and Intersectionality. I selected CDT as a framework to gain an in-depth understanding the ways that caregivers experienced the identification process in Texas. I chose this theoretical framework because CDT seeks to challenge the politics and power(lessness), power over and power to those who have disabilities (Devlin & Pothier, 2006). Through this lens, I hoped to learn about the experiences that caregivers had since this is a hidden learning difference which cannot be seen at first glance, such as a physical disability. Using CDT, I sought ways to understand how each of these caregivers experienced advocating for their child and if they experienced oppression or discrimination since the school staff may not have been in agreement with their concern before the identification process began (Devlin & Pothier, 2006; Goodley, 2012; Johnson, 2010; Linton, 1998; Meekosha & Shuttleworth, 2009). Intersectionality was another theoretical framework that I considered when analyzing the caregiver’s experiences since Carbado, Crenshaw, Mays, & Tomlinson (2013) challenge us to consider the multiple dimensions in which intersectionality are present; not only social relations of power, but also realize the non-overt ways that power is used so that practices can be transformed. Broderick, Mehta & Reid (2005) assert that, “The
intersectionality of all personal and social characteristics determines how disability will be experienced” (p. 196). As I analyzed each of my participant’s stories, I ensured that I challenged my own beliefs of how each of their intersectionalities were evident as they advocated for their children. CDT considers the phenomenon that surrounds people with disabilities, and I believe it also allowed me to consider the way that their caregivers demanded equal opportunities for their children.

In order to ensure that this study aligned with the characteristics of phenomenology, I completed a review of the literature on phenomenology prior to collecting the data. IPA is derived from hermeneutic phenomenology (Heidegger, 1971) as a research method. According to Smith, Jarman & Osborn, (1999), the aim of IPA is “to explore in detail the participant’s view of the topic under investigation.” (p. 18). The IPA method requires that participants are able to speak freely so that the rich data can convey the outcomes from their own personal experiences (Flowers, Larkin & Smith, 2009).

Phenomenology falls under an interpretivist framework of inquiry (Creswell, 2007). Therefore, during the course of the collection and analysis of data, I made sure that I was revisiting and reinterpreting the data as I became more familiar with my participants’ unique lived experiences (Shinebourne, 2011). Using double hermeneutics (Smith, 2004), I moved back and forth between the parts of the experience my participants explained to a broader picture of the whole experience and then revisited each repeatedly to gain a place of sensible meaning which was free of contradictions for the present moment (Kvale, 1996). This was a process that evolved between interpretation and interaction with the participants. IPA recognizes that it is impossible to gain complete access to the precise personal world of another person, so the objective is to gain a description of the phenomenon experienced which is as near to their view
as possible (Larkin, Watts, & Clifton, 2006; Noon, 2018). The primary aim in an interpretivist framework in IPA was to understand my own conceptions as well as make sense of my participants understanding of the experience (Smith, Jarman & Osborn, 1999) via the reconstruction of their individual experience and knowledge (Laverty, 2003) with the phenomenon of dyslexia identification in Texas.

In IPA, the ontological assumption is subjectivist, meaning that the world is constructed in different ways (Lincoln and Guba, 1985). This “supports the ontological perspective of the belief in the existence of not just one reality but of multiple realities that are constructed and can be altered by the knower” (Laverty, 2003) (p. 26). In this study, I was eager to understand the realities that each of my participants had with the phenomenon and what could be learned from their experiences from a caregiver, educator and administrator perspective from their point of view.

<table>
<thead>
<tr>
<th>Goal</th>
<th>Conceptual Framework</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use CDT and Intersectionality to understand the lived experiences that three caregivers had with the phenomenon of dyslexia identification in a borderland community in Texas.</td>
<td>Literature on International Dyslexia Policy</td>
</tr>
<tr>
<td></td>
<td>Literature on Caregiver's Experiences with Dyslexia Identification Policy</td>
</tr>
<tr>
<td></td>
<td>Literature on Critical Disability Theory, Intersectionality and Phenomenology</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do caregivers from minoritized backgrounds in a Texas Borderland community experience the Dyslexia identification process in public schools?</td>
<td>Researcher Bias</td>
</tr>
<tr>
<td></td>
<td>Researcher Reactivity</td>
</tr>
</tbody>
</table>

Figure 1. An interactive model of research design. Adapted from “A Model for Qualitative Research Design,” by J. Maxwell, *Qualitative Research Design: An Interactive Approach*, p. 5. Copyright 2013 by Sage Publications, Inc.
The literature suggests the use of IPA when a study is being done that will consider the experiences of a population that is homogenous with similar demographic and socio-economic status profiles (Denovan & Macaskill, 2013; Smith & Osborn, 2003). The experience the participants had in common was having a child in their care go through a dyslexia diagnosis in a public school. I used a purposive sampling (Gay et al., 2009; Wang, 2014) to ensure that my sample comprised of individuals specifically knowledgeable with the phenomenon that I investigated (Creswell & Plano Clark, 2011). This sample also sought to intentionally include caregivers from various races, ethnicities, and socioeconomic statuses.

This methodology allowed me to understand how each participant made meaning of their experiences and the underlying dynamics that occurred in both their home and in school environments with the phenomenon. I was continuously aware using reflective interpretation (O’Brien, 2003) to understand what each caregiver explained during the process of identification. This interpretation was a process meant to gain a deeper understanding of what is hidden or unseen to the forefront of each participants’ experience (Geanellos, 1998). This reflective-interpretative process (Gadamer, 1976) “includes not only a description of the experience as it appears in consciousness but also an analysis of the underlying conditions, historically and aesthetically, that account for the experience” (Moustakas, 1994) (p. 10). Through this process I was able to understand the richness and full meaning (van Kaam, 1966) of the caregivers’ experiences with the phenomenon.

My first goal in this study was to understand the experiences and challenges that caregivers experience in terms of obtaining identification for their child. I was specifically interested in understanding the moments that arose during the identification processes among caregivers, school personnel, and family/friends who identify as belonging to a minoritized
group. While studies have been done with White middle- and upper-class participants (Cook, 2017; Silverstein, 2015) few have looked at the experiences of minoritized people, and none have specifically looked at the experiences that caregivers have with this process in Texas. It was my intention to create a research protocol which allowed caregivers the opportunity to share their lived experiences that occurred during the identification process. Secondly, I hoped to document strategies and practices that caregivers used to learn about legal processes in Texas for dyslexia identification, both those that were successful and those that were unsuccessful. In order to address these research goals, the study utilized semi-structured interviews as a data collection method. The semi-structured open-ended question interview design intended to elicit data that allowed them time to think and provide their own interpretation of their connection to the experience. Semi-structured interviews with open-ended questions in IPA are one approach that is best suited to ensure that participants’ are able to express the challenges and successes they encountered during the identification process.

**Researcher Positionality**

As the researcher, I have extensive knowledge about the dyslexia identification process in Texas. I am a certified teacher and administrator in the state of Texas, however, I no longer work in this capacity nor in the state. I have provided guidance and support for countless families seeking intervention and identification for their children. I have been a general education teacher, a special education teacher, an administrator and a project manager for the education agency for the state of Texas for families as well as elementary education. Since I have worked in education in Texas for over 16 years, I am familiar with the identification process and the nuances families are confronted with as they request services. I have been immersed in the literature about the identification process in Texas, the United States, and the world. In reviewing the results, I
believe all biases were effectively addressed and alleviated. This positionality could have possibly hindered my research interviews as my background as a general education teacher, special education teacher, dyslexia teacher, elementary campus administrator and special education administrator at the state level may have consistently impaired my ability to be objective and only consider each participants’ perspective without considering my own experiences. For this reason, I was intentional about journaling and thinking about my own experiences as I was analyzing the caregivers’ experiences. This positionality could also possibly help my research since I have experienced some of their connections in my professional life and personal life since my younger brother was identified with dyslexia when he was in elementary school. Each of the three participants knew my positionality since they had all met me in previous years at dyslexia information sessions I held and at annual dyslexia camps in the community for families and their children. I already knew each of the three participants that met the criteria from trainings and workshops I had held over the years, so when each interview began, I asked them about how their families were doing. I presented myself as someone that they were already familiar with and one of the caregivers (who was not responsive after the COVID pandemic) even forwarded my flyer and solicitation for participation email to her son’s dyslexia teacher and campus administration. The other participants who did not follow up with the preliminary email and those who did not meet the requirements to share their stories based on the study requirements were also made aware that I had previously worked for the state of Texas as an educator and administrator.

**Setting**

The setting of this research was in a borderland community in Texas. The area is among one of the ten largest cities in the state of Texas. While about 28 percent of the population speaks
English only, 69 percent of the population speaks a language other than English which is Spanish (United States Census Bureau, 2018). For this reason, I decided to conduct interviews in English, Spanish and/or in a combination of both languages to give all participants an opportunity to contribute to the study in their preferred language. Creating questions and conducting the interviews in the language of their choice were important so that I reached as many participants that I could with this demographic, since there had not been studies like this conducted with this population. All three participants elected to complete the entire interview in English; however (a) one participant, Melissa used the word pobrecita to explain the relentless tutoring and summer school her daughter attended and (b) Michelle used several dichos in Spanish to provide analogies and clarification to what she was describing in relation to her experiences.

**Sampling Method**

Participants were selected based on a purposive nonprobabilistic sampling procedure in conjunction with criterion-based selection (LeCompte & Sechensul, 2010; Merriam, 1998; Noon, 2018). Table 4.2 provides a detailed list of all participant inquiries, however, a sample of three caregivers were ultimately selected for this study based on if they meet the criteria of the study. This number was ultimately selected based upon recommendations found in the literature which suggested that between 1-15 participants be considered due to the in-depth nature of the IPA methodology (Bramley & Eatough, 2005; Smith & Osborn, 2003) and due to the limited number of participants interested in participating in interviews due to the unexpected COVID pandemic that began when I was searching for participants. The dangers of face-to-face interviews during the pandemic were considered and I notified my participants that the format for conducting interviews in person had been changed to virtual formats. I decided to switch to completely virtual formats to follow guidance from the Centers for Disease Control (CDC, 2020)
emphasized that the new virus was mainly spread in person-to-person environments and between people who are in close contact with each other (within about 6 feet), via respiratory droplets produced when an infected person coughs, sneezes, or talks, and may be spread by people who are not showing symptoms. Since these restrictions were in place during the time I was searching for and interviewing some of my participants, I changed the modality to accommodate and allow participants to share their story via the virtual modality of their choice (i.e. Zoom, Skype, phone call, FaceTime, etc.) and recorded the conversations, see Table 4.3 for details of which interviews were held in person and which were done virtually.

**Recruitment Method**

I identified participants several ways via (a) distribution of a virtual PDF and hard-copy flyer that was posted at dyslexia-connected community agencies, (b) posts used to inform caregivers of the opportunity via their organization’s social media such as Twitter, Facebook, (c) emails advertising the study from caregivers who provided their contact information at prior trainings. Caregivers were able to participate in the study if they met the criteria and were able to share their experiences before, during and after the dyslexia identification process. In order to ensure that caregivers met the criteria I had an oral survey (Appendix 6) to see if they fit the parameters of the study requirements. The following locations were selected to distribute information about the study:

a. Borderland Disability Coalition (BDC). This agency provides parent training and support groups for parents, families, and educators interested in assisting children with disabilities to find success in school and in life in both the English and Spanish languages. Participants will be given the opportunity to participate in the study after any courses offered about the topic: Dyslexia. This site has been
selected because it is a local agency for caregivers who have children identified with special needs that provide free information to caregivers of children with special needs. BDC has a grant from the United States Department of Education, Office of Special Education, to disseminate current literature, provide training, and support for caregivers who are learning to navigate the special education and 504 process.

b. Borderland Language Clinic. This site was selected because it is a clinic that provides speech and language therapy services for individuals who have dyslexia and other speech related needs.

I decided to use these locales for this research study because it ensured that I would likely find caregivers of children with dyslexia diagnoses. These two locations provide services to children and their caregivers and other families who have children who have the SLD of dyslexia.
Table 4.1. Detailed Dates of Flyer and Email Distribution for Solicitation of Possible Participants

<table>
<thead>
<tr>
<th>Action</th>
<th>Dates</th>
<th>Amount of Time Left Open</th>
<th>Possible Participants Interested &amp; Responded to Queries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Posted Flyer on BDC website &amp; social media</td>
<td>12/9/2019-01/9/2020</td>
<td>30 days</td>
<td>0</td>
</tr>
<tr>
<td>Reposted the Flyer on BDC website &amp; Social Media</td>
<td>01/09/2020-01/23/2020</td>
<td>15 days</td>
<td>0</td>
</tr>
<tr>
<td>Email: 1st attempt using prior Dyslexia Classes Emails</td>
<td>01/24/2020 – 03/17/2020</td>
<td>53 days</td>
<td>6</td>
</tr>
<tr>
<td>Email: 2nd attempt using prior Dyslexia Classes Emails</td>
<td>03/18/2020-4/18/2020</td>
<td>30 days</td>
<td>2</td>
</tr>
<tr>
<td>Email: Emailed study Flyer to caregivers on Language Clinic List-serve</td>
<td>04/15/2020</td>
<td>Sent only on that one date to all caregivers affiliated with the speech clinic</td>
<td>0</td>
</tr>
</tbody>
</table>

In phenomenological studies, a smaller sample size is encouraged so that the researcher is able to conduct an in-depth analysis avoiding superficial analysis and understanding that could occur with a larger sample size (Giorgi, 2008; Sanders, 1982; Smith, 2003). Participants were solicited for participation after the UTEP Institutional Review Board approved the study and began in the spring of 2020. Interested caregivers were given a specified window of time, three weeks, in order to initiate interest in participating in the research study. Interviews were scheduled after I had three participants that met the criteria to participate in the study. The three participants that qualified to participate showed interest after receiving direct emails from me advertising the study; this occurred after flyers and advertisements had been posted at both locations above (see Table 4.2 for details of all participant inquiries). Initially, I had let participants know they could be interviewed at a location of their personal preference for one
face-to-face interview. However, since the pandemic restrictions did not allow for face-to-face meetings, I changed this requirement so that participants could complete their interviews over the phone or another virtual format of their preference. There were some questions based on demographics that each participant was required to answer; however, the rest of the interview was unstructured so that participants answered open-ended, non-directive questions to encourage free narrative responses (Smith, 2003).

IPA’s primary focus is to understand lived experience at an individual level (Eatough & Smith, 2008; Smith & Osborn, 2008). The experiences that caregivers have had during the dyslexia identification process in Texas is unique as compared to caregiver experiences in other states in the United States because of the ambiguity of the identification process and when, where and how students receive intervention. IPA is the best suited methodology to understand how each individual experienced and made sense of their personal and social world (Smith & Osborn, 2003) during the identification process because each of their stories were analyzed to identify separate overarching themes they experienced which were then compared to the other participant’s experiences.

Research Design

This research design employed semi-structured interview questions asked in face-to-face and/or via recorded phone or virtual conversations with each caregiver. According to Smith & Osborn (2003), semi-structured interviews in IPA allow the interview protocol to be guided by the questions rather than dictated by the questions. This design is important since there “is an attempt to establish rapport with the respondent, the ordering of questions is less important, the interviewer is freer to probe interesting areas that arise, and the interview can follow the respondent’s interests or concerns” (p. 58). The modality of the interviews was dependent upon
the pandemic restrictions at the time of the interview & the preference of the caregiver being interviewed. Each participant had the opportunity to select the time that worked best to complete the first and any subsequent interviews to participate in the study. Each interview contained a few closed-ended questions that collected demographic information and the main interview had open-ended questions geared at understanding their experience. Since caregivers shared these experiences in retrospective, I also provided a graphic organizer available (Appendix 5) that was used as a timeline for caregivers in the event that they struggled to remember the nuances at each stage during the identification process; however none of the participants opted to use this organizer. Of the three initial scheduled interviews, one was in person during the second week of March and the other two were via a phone call. Refer to table 4.3 for specific information regarding the modality of interviews depending on the caregiver’s personal preference and availability during the pandemic. The interview questions were designed to be able to examine the ways that caregiver’s experienced the dyslexia identification process in Texas via the lens’ of CDT, intersectionality and the ideological model of reading. In the questions that I asked initially as well as in follow-up questions, I wanted to be sure to elicit responses that allowed each caregiver to describe how their child’s interaction with the literacy acquisition process in public schools was experienced. This is due to the fact that within the ideological model of reading, the process of literacy acquisition is dependent upon socially produced interactions in and between both home and school environments, as well as internally for the caregiver and the child experiencing the process of literacy acquisition.

Selection Criteria for Participants

Participation was open to caregivers of any gender, any minority group, education level, SES level, and marital status as long as they were adult caregivers (18 years or older) and had a
child enrolled in a public school during the time of the identification process. There were three criteria required in order for caregivers to participate in the study: (1) a child who was identified with dyslexia in Texas in the past three years, (2) a child who was assessed in a public school, (3) and since I was interested in understanding the experiences that minority groups have had with dyslexia, only caregivers from minority ethnic and racial groups were considered. Caregivers from (a) groups other than White and those who (b) are multi-racial will be included in this study as long as they met the other two criteria listed above. After the initial oral intake conversation with the caregiver (Appendix 6), if all criteria had been met, we coordinated an interview date and time.

A specific requirement in order for participants to be a part of the study is that they have had experienced the process of dyslexia identification in a borderland community in Texas within the past three years (between 2016 through 2019). Caregivers were allowed to participate in the study as long as their child was identified within the past three years within a public school setting to include public charter schools; this timeframe requirement was needed so that caregivers could reflect on a recent experience to include the challenges that arose before the identification process began as well as experiences that occurred after the initial assessment. I also specified this requirement because it would have been two years after the 2014 Texas Dyslexia Handbook had been implemented with updated requirements and was before a new handbook had gone into effect during late Fall of 2019. Since this community is also located in an area that is near a military base, I was diligent in asking if the dyslexia identification process began in another state or on Department of Defense Military Dependent Schools, and/or if the assessment began in Texas. One of the three participants was military connected.
I was concerned, but it was no surprise that these two other participants, who were very eager to share their stories and had met the study criteria, completely stopped communication with me. I assumed that this was because once the pandemic began mid-March, they may have had more pressing issues such as health and safety. Three participants qualified and agreed to participate in the study, although some interviews needed to be done virtually since we could not meet in person due to COVID 19 restrictions. I appreciate their commitment to participate especially since most of the interviews took place after the COVID-19 pandemic began. The information about the pandemic was still being understood as I was scheduling interviews; on March 11, 2020 the Director of the World Health Organization officially made an announcement that COVID-19 had become a pandemic and that countries should start preparing and make attempts to reduce transmission (World Health Organization, 2020). Then, on March 13, 2020 a state of emergency was declared by the President of the United States, the Governor of Texas, and the local government in relation to the pandemic. By March 19, 2020 the Governor of Texas, Greg Abbott signed into proclamation that Texas’ response to COVID was that schools should temporarily close and that any gatherings should be limited to ten people or less, among other recommendations (Abbott, 2020). I knew that I had to adjust the modality of some of the interviews so that they would accommodate this unforeseen limitation, so some interviews were held via a virtual format. I notified each of my participants that we could certainly schedule a separate interview in the event that they became fatigued in either a face-to-face or virtual modality.
Table 4.2. Inquiries and Selection of Interested Participants

<table>
<thead>
<tr>
<th>Date of Inquiry</th>
<th>Participant</th>
<th>Criteria per Study Requirements</th>
<th>Scheduled Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Ethnicity</td>
<td>Year of Identification</td>
</tr>
<tr>
<td>1/24/2020</td>
<td>a</td>
<td>Hispanic &amp; White</td>
<td>2018</td>
</tr>
<tr>
<td>01/26/2020</td>
<td>b</td>
<td>Hispanic</td>
<td>2013</td>
</tr>
<tr>
<td>1/25/2020</td>
<td>c</td>
<td>unknown</td>
<td>unknown</td>
</tr>
<tr>
<td>2/07/2020</td>
<td>d</td>
<td>Hispanic</td>
<td>2016</td>
</tr>
<tr>
<td>2/10/2020</td>
<td>e</td>
<td>unknown</td>
<td>unknown</td>
</tr>
<tr>
<td>03/15/2020</td>
<td>f</td>
<td>Hispanic</td>
<td>2017</td>
</tr>
<tr>
<td>03/26/2020</td>
<td>g</td>
<td>Latina</td>
<td>2017</td>
</tr>
<tr>
<td>4/17/2020</td>
<td>h</td>
<td>Hispanic &amp; White</td>
<td>2017</td>
</tr>
</tbody>
</table>

After the interviews were scheduled, I made sure to have cleared up space on my recording device so that each interview could be recorded in its entirety. After each interview, I
labeled the file and saved them on my computer. Once all three interviews were completed, they were transcribed. I listened to each one individually for accuracy. While checking for accuracy, I began the iterative process of reflecting on the data. I created field notes reflecting on my connections to their lived experiences, completed the data collection process outlined below, and revisited their transcriptions while continuously creating journal entries on my thought process.

**Data Collection Methods**

The data collection methods listed below have been informed by an IRB approved pilot study that I conducted during the Spring of 2017 where seven caregivers were interviewed using semi-structured interviews regarding their experiences with the dyslexia identification process in public and private schools. The questions guiding this study, format of varied data collection methods during each interview, and the decision to use the theoretical frameworks of Critical Disability Theory (CDT) and Intersectionality as a lens to analyze data were informed by the pilot study. The previous study informed me that I needed to allow for translanguaging and not necessarily require participants to select one language to complete the entire interview in, as they would at times want to go into detail about a certain experience but struggled to find the exact words in English to elaborate more on the topic. Also, in the pilot study, I had required each participant to use the graphic organizer and timeline at the beginning of the interview and found that it was a distraction for some participants. Therefore, in this study, participants were given flexibility in if they wanted to use the tool or not depending on their own personal preference and ability since most of the interviews were conducted virtually due to the pandemic in-person restrictions. Finally, I realized that although participants with children in private schools had unique experiences during the identification process, I wanted to focus on experiences in public schools. This focus was because the different identification process requirements in Texas vary
depending on if a child is enrolled in a public school or a private school. Since this study is informed by some of the areas of concern I had in the first pilot study, I was purposeful during the data collection process to embed a critical qualitative inquiry (CQI) approach into this study to ensure that I focused on a social justice commitment to my participants and aimed to be aware of “the needs to redress inequalities by giving precedence… to the voices of the least advantaged groups in society” (Mertens, Holmes & Harris, 2009, p. 89). This study is focused on hearing the stories of caregivers from minority groups who have not been heard in the past, therefore I wanted to be sure to have opportunities that allowed them to explain their story in detail, in the language of their choice as well as allowing them to have as much time as they needed to tell their unique story. This meant that throughout my data collection process I was intentional in understanding how the process of dyslexia identification affected my participants, being patient and asking questions to get a full understanding so that I was able to document their experiences. I intended to give them an opportunity to share their experiences with other caregivers who may have experienced similar encounters during the process by creating an infographic that had the most valuable resources they used during the identification process.

Questions were intended to draw out reflection from the participant and were altered if needed during each interview (Rudestam & Newton, 2001). The IPA technique of funneling (Julien, 2008; McCormack & Joseph, 2018; Smith & Osborn, 2003) was used when interviewing. This is where a sequence of first asking a broad question and then probing for more specific clarification is integrated as needed throughout the interview(s). Funneling also is a strategy “designed to enhance memory recall… before culminating in a more specific line of questioning that is of particular concern to me, the researcher” (Noon, 2018, p. 76). The interview protocol (Appendix 3) was used as a guide during each interview, with funneling and
probing questions asked throughout as needed. The other IPA interviewing technique of probing allowed for me as the researcher to maintain a conscious balance while interviewing participants and make on the spot decisions during the interview of which questions need to be asked while moving around the semi-structured interview protocol (McCormack & Joseph, 2018). This ensured that each participants’ lived experiences were explored in detail. At the end of the interviews, I let them know that I would be in contact to ask clarification questions. I also reminded them that I would be in contact again so that they could check the story for accuracy.

The interviews lasted as long as needed for each caregiver to convey their experience with the phenomenon, which if predicted would range somewhere around forty-five minutes to ninety minutes.
Table 4.3. Detailed Dates and Times of Interviews

<table>
<thead>
<tr>
<th>Date of Interview</th>
<th>Participant Name</th>
<th>Modality</th>
<th>Time of Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>03/05/2020</td>
<td>Melissa</td>
<td>Face to Face</td>
<td>9:00 am *rescheduled per participant</td>
</tr>
<tr>
<td>03/11/2020</td>
<td>Melissa</td>
<td>Face to Face</td>
<td>9:30 am</td>
</tr>
<tr>
<td>03/15/2020</td>
<td>Melissa</td>
<td>Virtual</td>
<td>4:37 pm</td>
</tr>
<tr>
<td>03/26/2020</td>
<td>Anna</td>
<td>Virtual</td>
<td>12:45 pm</td>
</tr>
<tr>
<td>3/28/2020</td>
<td>Anna</td>
<td>Virtual</td>
<td>3:00 pm</td>
</tr>
<tr>
<td>04/20/2020</td>
<td>Michelle</td>
<td>Virtual</td>
<td>Noon</td>
</tr>
<tr>
<td>06/23/2020</td>
<td>Michelle</td>
<td>Virtual</td>
<td>3:43 pm</td>
</tr>
<tr>
<td>06/24/2020</td>
<td>Anna</td>
<td>Virtual</td>
<td>7:48 pm</td>
</tr>
<tr>
<td>07/26/2020</td>
<td>Melissa</td>
<td>Virtual</td>
<td>3:53 p.m.</td>
</tr>
<tr>
<td>10/08/2020</td>
<td>Michelle</td>
<td>Virtual</td>
<td>3:43 pm</td>
</tr>
<tr>
<td>10/14/2020</td>
<td>Anna</td>
<td>Virtual</td>
<td>1:13 pm</td>
</tr>
</tbody>
</table>

Flexibility during each of the interviews and the researcher created intentional options for sharing their experiences were intentional. Keeping in mind that some participants potentially had the SLD of dyslexia (since it is a genetic neurobiological trait) caregivers were given the option to express their experience with the dyslexia identification process using a range of data collection methods to include drawings, written responses or artifacts (Bruce, 1996; Hyrkas & Paunonen-Ilmonen, 2001). Although participants were able to write, draw, share actual official paperwork and/or their child’s work samples, all three caregivers preferred to share their story orally and did not use the graphic organizer I had provided. It was important to me that I maintained flexibility in allowing participants to linger on some questions more than others and to revisit any questions that had not been answered fully by using thought provoking and open-
ended questions during the data collection process. Allowing participants as much time as they desired to expand on certain parts of their experiences was critical to ensure I understood the different ways that participants experienced the phenomenon; this also ensured that caregivers were able to provide a thorough and detailed recollection of the experience they had during their personal experience with the phenomenon. I also felt that these options were ethical requirements since I wanted to use an approach that respected my participants and did not further marginalize them (Creswell, 2007) by using practices that had not taken into consideration their learning difference. All three participants mentioned that they did not struggle in school as related to reading. The primary modality for each interview was an oral approach, in the language of their choice, because I wanted to make sure that whomever participated in the study was not intimidated by having to write, if they themselves also had dyslexia and preferred to share their thoughts orally.

Ashworth & Lucas (2002) suggest that the interview should be a conversational partnership whereby the researcher supports each participant during their process of reflection. The information obtained from caregivers who participated in this study were: (1) caregiver demographics, (2) basic information about their child(ren) related to dyslexia identification (i.e., timeline of events that occurred between request for initial assessment and findings of assessment will include challenges that arose before, during and after the identification process), (3) how they came to learn about the legal processes related to dyslexia identification, and (4) concerns they have about support, or lack of thereof that they receive from the educational system and the support network of family, friends, and the community around them.

I felt that the IPA approach was best suited for this study since I was hoping to understand each of my participants’ personal experiences with the phenomenon in a borderland
area. IPA “is concerned with an individual’s personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object of event itself (Smith, Jarman & Osborn, 1999, p. 219). I was not wanting to have an objective statement of the phenomenon, rather an overall understanding of the nuances that they went through while advocating for their child. Furthermore, I wanted to be intentional about explicitly integrating questions that helped me focus on each of the participant’s conceptualization of their experience with the phenomenon as related to CDT and intersectionality. The selected criterion ensured that I had a group of participants who were caregivers that had not been given an opportunity to describe their experiences before to contribute to the knowledge base for empirical research.

**Parent Demographics.** At the beginning of each unstructured interview, I asked caregivers to provide information based on survey questions where I collected information on the caregiver’s marital status, ethnicity, age, gender, level of education, income, and geographic location. The construction of these questions was guided by the structural requirements set in Babbie (2011). I was purposeful in allowing each participant to self-identify their ethnicity. While any SES group was allowed to participate in the study, I was curious to see how many participants identified as having a median household income of $57,051 which was the estimate for the state of Texas (U.S. Census Bureau, 2017). The background section of the interview protocol is the only section that was structured. The rest of the protocol was not structured and

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3 I intentionally allowed each caregiver to identify their own personal description for the term ethnicity during this part of the interview. As a person who is Mixed and grew up in an adopted home with parents who had different racial identities than I did, I realize firsthand that ethnicity and race are complex and do not always fit into neat categories. Alcoff (2006) states that “one’s racial… identity is fundamental to one’s social and familial interactions. It contributes to one’s perspective on events- to one’s interpretation of conversations, media reports, and social theories” (p. 92). Therefore, in the categories on Table 4.4 there are various terms such as Latina, Hispanic and White when participant’s identify their race/ethnicity.
allowed for participants to share their thoughts and return to other connections as they saw fit. Pseudonyms were assigned to the local disability agency as well as every school and any school staff names described in each participant’s narrative. However, only one participant, Anna requested that her name and her daughter’s name were pseudonyms. Anna self-selected her name and her daughter April’s name. The other two participants, Melissa and Michelle asked that I please use their actual name and their child’s actual name in their narrative. Michelle’s husband’s name is not a pseudonym. All of the relatives and family members names are also pseudonyms.

**Child Information.** Caregivers were asked about their child’s information at the beginning of the interview. I organized this information to understand how their experiences were related to the other participant’s child details during the initial process of dyslexia identification. Specifically, caregivers were asked to consider their experiences (a) when their child was identified with dyslexia (b) when they suspected they were struggling in the area of reading (c) when the formal assessment began, (d) and their opinion of the effectiveness of academic interventions after formal identification. If a caregiver had more than once child with dyslexia who has been identified in public schools, they can share that experience as well as long as the study criteria had been met (however, each child must have been identified within the past three years). In the event that a caregiver would have wanted to share the experience they had with another one of their children, those interviews for their other children would have been done at completely separate interview, to separate each experience; however, none of my participants had more than one child with dyslexia so this was unnecessary. Since dyslexia is a hereditary trait, I had also anticipated that there would have been a likelihood that a caregiver participant also had dyslexia. In order to be forthcoming, I let the caregiver know that they were able to
explain the experiences they had during the identification process using a variety of formats in which they felt most comfortable to communicate this experience; however, none of the participants identified as having dyslexia themselves.

**Summary of Participants**

Data for this phenomenological study was collected with three caregivers in a borderland community in Texas. In order to participate in the study, caregivers had to meet specific criteria which were shared with them in the initial email exchange. Strategically, the criteria included participants who had a child identified with dyslexia in a public Texas school within the past three academic school years (between Spring of 2016- Fall of 2019) and participants must identify as a group other than White. All three of the participants self-identified as Hispanic or Latinx and their children were each identified in a public Texas school as having dyslexia. A summary of their demographics are provided in Table 4.4.

Table 4.4. Participant Demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Anna</th>
<th>Melissa</th>
<th>Michelle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Anna</td>
<td>Melissa</td>
<td>Michelle</td>
</tr>
<tr>
<td>Age</td>
<td>27</td>
<td>36</td>
<td>39</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>Latina</td>
<td>Hispanic</td>
<td>Hispanic &amp; White</td>
</tr>
<tr>
<td>Gender</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td>Marital status</td>
<td>Single</td>
<td>Single</td>
<td>Married but Separated</td>
</tr>
<tr>
<td>Occupation</td>
<td>Store Manager</td>
<td>Supply Stocker</td>
<td>Homemaker</td>
</tr>
<tr>
<td>Annual income</td>
<td>$15,600</td>
<td>$16,000</td>
<td>Relies on husband’s income who earns $120,000</td>
</tr>
<tr>
<td>Number of children</td>
<td>Two</td>
<td>Two</td>
<td>Two</td>
</tr>
<tr>
<td>Age child was identified</td>
<td>Seven</td>
<td>Seven</td>
<td>Seven</td>
</tr>
</tbody>
</table>
**Data Analysis**

The data analysis method I used was the IPA phenomenological method (Smith, 1996) to understand and interpret a participant’s lifeworld and lived experience (Eatough & Smith, 2008; Larkin, et al., 2006; Smith et al., 2009). To ensure consistency during the data analysis process, audio files were referenced repetitively, ensuring all descriptive meaning of each lived was captured (Smith, 1996; Smith et al., 2009; Smith & Osborn, 2008). It was necessary throughout this process of analysis for me to remember that analysis is a cyclical process, so I cross-referenced audio and hand-written notes to ensure that any emphasized information was captured with fidelity. Each of the interview transcripts were read numerous times to elucidate initial sub-themes. Then, this step was followed by an understanding of superordinate thematic clusters to provide a composite portrayal of each experience with the phenomenon (Denovan & Macaskill, 2012).

Smith (1996) advises that although IPA does not have a prescriptive methodology due to the inevitably personal process of interpretative work (Smith & Osborn, 2006), researchers can follow the following analytic process when analyzing data: (a) Step 1: Transcription of each data set without any discussion or analysis. (b) Step 2: The researcher then immerses themselves with the first interview; reading and listening to each set. At this stage, the researcher begins annotating initial thoughts in one of the margins. (c) Step 3: The researcher begins expanding their initial notes on the other margin. Via the use of a double hermeneutic, the researcher attempts to understand and make sense of the interviewee whom is also making sense of their lived experiences. (d) Step 4: The researcher makes notes of emerging themes and connects these themes to quotes within the transcript. Using only the first interview data set, the audit trail produces reflexive notes, contextual notes, and passages from the transcript. (e) Step 5: The
previous four steps are repeated for each of the transcribed sets of data. Clusters of themes across sets of data are convergent themes and unique themes in only one set of data are considered divergent themes. (f) Step 6: The researcher considers each data set and justifies themes that are substantiated by the data. (g) Step 7: In this step, the researcher has already established relationships between emergent themes and clusters of themes in each individual case and amongst all cases being analyzed. After each draft of the results, the researcher continues verifying that themes are authentic and supported with participant quotes noticing that subordinate and superordinate themes may emerge. Theory should be linked, as relevant, to identified themes within the discussion. I was purposeful in considering how the caregiver’s experiences were informed by CDT considering where the dyslexia was re/produced before, during and after their child was identified as related to their experience with the phenomenon. I also used bracketing and journal entries to make notes of my biases, connections to previous experiences, and questions I have as I am analyzing each of the participants’ data.

**Unit of Analysis.** IPA focuses on what each participant thinks about a topic being discussed, focusing on their cognition of the experience (Smith, Jarman & Osborn, 1999) and an idiographic approach (Smith, Harré, & Van Langenhove, 1995). The unit of analysis in IPA is the individual sharing their engagement with the phenomenon (Shinebourne, 2011; Smith, Flowers, & Larkin, 2009). For this study, the phenomenon being investigated was how each caregiver made sense of the public school identification process of having their child receive the label of being dyslexic. I considered what Smith (2004) refers to as double hermeneutics where “the participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world” (p. 40).
I began the data analysis by reading the first respondent’s individual transcript several times. Each time I did this process, I used the steps mentioned by the literature for this methodology (Shineborne, 2011; Smith; 1996; Smith, Jarman & Osborn, 1999). Meaning that I used the left margin of each data set, analyzing elements that were significant about what the participant mentioned in their response. I annotated reflections and thoughts on the left-margin. After I re-read the transcription two more times, I became more aware of the personal account, commenting on new insights and associations while gaining a more in-depth understanding of each experience. I decided that I would complete this process by printing out each transcript and working on the first analysis on the paper print-outs, so that I could color code each step of the process by hand using different pen colors. Once I did several analyses of the first participant’s transcript, I proceeded in the analytic process toward a second step of analyses with the same transcript. This is where I moved onto a deeper interpretation of understanding their experience by annotating emergent themes on the right-hand side of the transcription, upholding an iterative process between myself and the text. The second step was completed on the electronic version of the transcript. Then, I created a list of emerging themes, grouping preliminary themes into categories with common terms of meaning. After narrowing these themes into similar categories and completing this process with the first participant’s transcript, I moved to the second participant’s transcript and ensured that began “this process anew with the second interview, going through the stages outlined above and producing a master list for this second interview.” (Smith, Jarman & Osborn, 1999) (p. 226). I completed this process of consolidating each transcribed interview using the IPA process until final themes emerged based on analysis of each subsequent participant’s transcript.
Shared Themes Between All Participants. After analysis of each individual transcript was analyzed, I continued the interpretive process by moving to the next stage of analysis, developing an understanding of all of their experiences. I identified clusters of themes and interacted with them, always referring to transcripts as needed. This allowed me to validate themes and find those themes that were relevant between all of the participants, and divergent as well. I illustrated these themes with direct participant quotes, ensuring that they were represented authentically (Flowers et al., 2009; Smith, Jarman & Osborn, 1999) from the original transcript so that my own bias does not distort the interpretative process. This process was integral using this IPA methodology since it is concerned with exploring individual perceptions and subjective experiences (Smith, 2003) with the phenomenon and how it was understood in their own social and personal environment (Lyons & Coyle, 2007). I also made sure to consider the way that elements of CDT and intersectionality presented themselves within the superordinate themes that I discovered during analysis. I made sure to intentionally revisit themes and consider how caregivers described their child’s dyslexia, and how it was impacted by the environment around them before and during identification as well as what this meant regarding the ideological models of literacy. Finally, the themes were combined into overarching themes so that I was able to understand similarities and divergence amongst their lived experiences with the phenomenon.

Trustworthiness

To ensure that elements of trustworthiness were consistent, I followed the procedures recommended by Yardley (2000) during the data collection and analysis process. The procedures are four aspects to ensure quality in qualitative research which are sensitivity, commitment and rigor, transparency, and impact. This research design has sensitivity to the context as I have have thought through each stage of data analysis based on the socio-cultural context of my
participants. In regards to commitment & rigor and transparency, I outlined the steps used in order to be meticulous during the process of participant selection, the interview schedule which was altered based on the pandemic that occurred during the collection process as well as the detailed explanation of how I conducted the analysis process based on Smith (1994) recommendations for the IPA methodology. Commitment to the IPA methodology was also evident in the early stages of my study as I did not accept all of the participants who inquired, if they did not meet the criteria during the participant selection process. Finally, impact of this study was revisited as I entered the final stages of analysis and prepared an infographic to provide guidance and hope for other families who are navigating the identification process. This infographic also has recommendations for educators who work with these families.

**Audit trail.** To ensure trustworthiness, I used an audit trail to document each step of the research to include all of the data collected and analyzed during the data collection process. The audit trail included maintaining all documents used for the study to include any raw data including recordings of the interviews, strict adherence to maintain confidentiality of participants, the interview guide, and meticulously revisiting the data during the process of data reduction during analysis and synthesis.

**Reduction of data.** In the audit trail, I kept reflections in an electronic research journal which had my thought processes, observations, and critical reflections on my own biases. I also consulted regularly with my dissertation chair and committee during collection and analysis to limit bias and subjectivity. I kept notes on (a) the interview schedule, (b) recorded transcripts, (c) revisions to the process due to the pandemic, (d) all annotations to show the process of creating the thematic analysis including pictorial representations of this process, (e) tables that were created during the thematic analysis, (f) processes of writing each participant’s individual
narratives & (g) the analysis of final similarities and differences of all three participant’s superordinate themes and how CDT and intersectionality informed these themes.

Fieldnotes. As recommended by the literature (McCormack & Joseph, 2018; Shinebourne, 2011; Smith et al., 2009) I kept detailed memos of my interpretations of the data, including bracketing my connections with the data. This allowed me to see how my analysis morphed over time as I analyze each of the transcripts. I also discussed my emerging ideas with other researchers, to include my committee.

Ethics

Safeguards were ensured for participants in this study so that they would not be harmed. I purposefully considered potential risks during the creation of the interview question protocol and informed consent form (Bloomberg & Volpe, 2008). The process of informed consent was described in detail to each participant before the interview was scheduled and before an interview was conducted to ensure that they were aware of potential risks and retain autonomy during the interview process (Appendix 1). I recognized that a potential issue that could have arose were that caregivers may have become emotional when describing the experience that they had with the public school system and educators. For this reason, I had planned on scheduling all interviews in a neutral location, away from educators and administrators from their local districts, free from institutional bias or judgement regarding their familial experiences with dyslexia. However, since the pandemic did not allow for a majority of the the interviews to be held in face-to-face modalities, caregivers were able to complete the interview(s) in the location or modality of their own personal preference. Confidentiality for each participant was upheld by the intentional treatment of information or data that an individual has disclosed via the
relationship of trust with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure.

Who Benefits?

This study responded to a gap in the research regarding how caregivers from varied SES and ethnic groups experience the impact of a newly identified child with dyslexia. These personal lived experiences gave insight to the barriers that parents faced before, during and after the dyslexia identification process. The study informed practices of empathy which can be considered for educators coming directly from the second-order perspective or a perspective “from-the inside” (Marton, 1981; Richardson, 1999) for public school systems by describing experiences that caregivers had during the identification process, considering the unique demographic of a community in Texas. Specifically, the data collected will be useful for:

a. those who create policies for education entities about dyslexia identification,

b. individuals who assess students who may or not exhibit characteristics of dyslexia,

c. administrators who make campus decisions of which students can be assessed,

d. educators who identify students and can impact direct instruction of students who may or may not have dyslexia,

e. caregivers who are working with school systems to aide students in learning coping skills.

It had been my original plan to invite all of the caregivers to meet in person for a reception. After the culmination of the study, caregivers who participated were going to be invited to a reception where they would have come together to create an infographic to be shared with caregivers in the same community who may be beginning the journey of the process of identification. Due to COVID-19, this infographic was created virtually and shared the websites
and strategies participants found to be most helpful. Resources available to adults with dyslexia will also include assessment, intervention, mental health services and adult-living skills be for caregivers seeking assistance in the borderland area. This infographic guide was also a way for me to thank participants who were in the study, so that together, we could ensure that caregivers are provided current resources available for children and adults. A reference guide that I have already created based on the pilot study will be used as a starting point for caregivers to elaborate on.

**Limitations**

The study had limitations, some of which were realized upon completion of the study. I work in the field with families who have a child with a disability on a daily basis, and many of the caregivers I speak with are mothers. One anticipated shortcoming of this study was that the experiences of mothers were solely captured. While notices to participate in the study were disseminated through two local community agencies that serve all caregivers, there were not any fathers who were available to participate. This was a predicted limitation, based on my previous experience working with this population. A second perceived limitation was that this study only focused on the experiences that caregivers had during the identification process for SLD of dyslexia. This meant that caregivers who had a child with another type of SLD in the area of math for example were not be captured, because that was outside the scope of this study. Other limitations involved not being able to recruit caregivers because: (1) their child was not receiving services as a result of not having been properly diagnosed; (2) lack of awareness of the study, as a result of not using social media or being connected to local agencies; and (3) due to the global pandemic COVID that began a week after my first scheduled interview.
Summary

In this study, I learned about the nuances between lived participants' experiences during the dyslexia identification process in a borderland community in Texas. Through the methodology of IPA, I understood the multi-faceted ways that participants experienced the phenomenon (Limberg, 2008). Each participants’ experience and analysis were divided into three separate chapters. I implemented the process of analyzing each case separately, “on its own terms, to do justice to its own individuality” (Smith, Flowers & Larkin, 2009, p. 100). Throughout this process, I diligently created detailed journal entries to annotate any findings from previous accounts and my connections to my own experiences to ensure that I did not integrate ideas from past participants into the new analysis in subsequent analysis. Throughout this iterative process, I first analyzed each account separately, referring to the both the transcript and essences of what I had understood.

The following three chapters are written narratives of each of the three caregivers’ lived experiences that participated in my study. These are an analysis of both their personal and contextual experiences with the phenomenon; meaning with the phenomenon. Then, I provide a final analysis and discussion of superordinate themes between the three participant experiences in Chapter Seven. I was certainly eager to learn about the subtle and stark differences between the categories that surfaced in my analysis, dependent upon the ways that caregivers experienced the phenomenon while understanding and seeing the world around them.
Chapter IV “SHE’S JUST BEHIND AND JUST NEEDS MORE PRACTICE”

Anna was about to turn 27 years old when April, her six-year-old daughter, was identified with dyslexia during the spring of 2016. She self-identifies her ethnicity as Latina and has two children. April is the oldest and her second child is a son who is two years younger. Anna earns about $15,600 annually as of 2020 and initially described her occupation this way: “I guess I’m …everything!” She manages her family’s grocery store in their rural town, and she happens to live next door to it. Anna’s income is below the federal poverty level for a family of three according to the Department of Health and Human Services (2020) which is $21,720. In her area, 49 percent of the town residents live below the poverty line, earning around $26,000 annually (City Data, 2020; U.S. Census, 2019). Their town is classified as rural, as it has fewer than 1,000 people per square mile (U.S. Census Bureau, 2016). Anna shared the story of her perspective on the dyslexia identification process in English, saying that although she understands and can speak Spanish, English is her first language.

I met Anna during September of 2016. This was when I was working at a regional center for education in this area of Texas as the project manager for the elementary special education project as well as the family and community network for special education. Anna’s daughter, April, had recently been identified as having dyslexia during the last week of March in the spring 2016 semester. I offered four fall and four spring parent information sessions specifically related to dyslexia for caregivers in the community. Each of these was located and advertised via a local caregiver information center called the Borderland Disability Coalition (BDC) that specialized in providing services and information sessions to area families. These parent information sessions were offered during the week, along with two weekend camps. Anna attended every fall and spring session during the week, as well as both weekend camps. The first time I met her I was
struck by her commitment to learning more about dyslexia since she and her sister had driven over an hour each way to attend these three-hour information sessions.

Anna changed my perspective by helping me realize that I had a bias when thinking about the ways that caregivers commit to learning more about a new disability identification. Before being in my role at the state level, I had been an educator at several area campuses, but had not realized how challenging many caregivers found it was to learn more about a disability outside of the school. I felt like I influenced Anna because she always mentioned how difficult it was to get any clear and upfront answers about why her daughter was struggling with reading and what the identification process was from school staff and administrators. It was clear that Anna had difficulty getting clear answers because there is still much confusion within the Texas public school system about what dyslexia is and how to identify the learning difference with consistency and accuracy. In a recent study regarding perspectives of dyslexia interventionists in Texas, Worthy, Sverck, Daly-Lesch and Tily (2018) stated that as former teachers, researchers, and current literacy teachers, the authors know that student struggles in reading should be taken “seriously and believe there are no clear truths or single answers to the complex issues surrounding reading difficulties” (p. 365).

The discretionary practices that surround the identification of dyslexia can be attributed to the fact that “No two people with dyslexia are exactly alike because dyslexia ranges from mild to moderate to severe to profound” (Barton, 2014, para. Summary of Warning Signs). Since the severity of dyslexia varies among individuals and the national and state policies vary regarding identification processes (Youman & Mather, 2013, 2015, 2018), dyslexia identification can still vary from city to city, school district to school district, and even among schools within the same district. Furthermore, confusion over the validity of what dyslexia is and is not is surrounded by
different points of view from a variety of stakeholders. Elliot & Grigorenko (2014) put the multitude of interested parties into perspective noting:

Geneticists, neuroscientists, medical practitioners, cognitive psychologists, clinical psychologists, school/educational psychologists, speech and language therapists, education researchers, mainstream teachers, special education teachers, education consultants and trainers, lobby and advocacy groups, and of course, struggling readers and their families, may each appropriate the dyslexia label, ascribing to it different meanings and utilizing it for differing purposes. (p. 175)

Due to the complexity and debate over which type of assessment, label and intervention is for children with the label of dyslexia, Elliot & Grigorenko (2014) further complicate the notion of the term dyslexia by asserting that the label should not be used at all until “a truly scientific approach should result in the establishment of a more rigorous understanding and deployment of the term “dyslexia” (p 182). This label is one that I have found some caregivers chose not to disclose to their children in fear that the child will be distraught because of it.

However, in Anna and April’s case, Anna did not chose to keep her daughter’s learning difference from her. I know this because when I met April at one of my first dyslexia camps on a chilly Saturday morning in October of 2016, I was awestruck by her confidence and poise. Out of a group of 22 children between the ages of six and twelve, April was the only one who assertively answered one of my first questions when I welcomed the group of children to the camp after all of the children had settled into their groups. I asked, “Who here knows what dyslexia is and can tell me a little about it?” April raised up her hand and said, “Good morning,
Ms. Owens! Today is my seventh birthday. And dyslexia is what happens when somebody has a hard time with reading, but with help, I know I am going to get better at it [reading].” The reason I was so surprised was because it seemed that many of the children in my audience did not even know they were at the camp because they had a dyslexia diagnosis. It was evident to me that her mother, Anna, had taken the time to inform her daughter that she had the learning difference.

Frank (2002) writes that children with dyslexia experience a kind of secret life in which those around them do not know all of the things they experience each day, because they feel the need to hide their learning difference. That is, the child who is “well aware that he [or she] is not like other kids … may be quite committed to keeping a veil of secrecy over his [or her] disability” (p. 12). When working with caregivers, I later found that some families hide the learning difference from their child to shield their child from feelings such as fear or disappointment. I clearly remember two mothers in the group I worked with sharing that, to their surprise, their child showed a sense of relief and were grateful that they were informed of their learning difference. In order to analyze Anna’s perspectives shared during the interviews, I reflected on her experiences by using the interpretive phenomenological analysis (IPA).

I used an iterative analytic process recommended by the IPA methodology. After independent analysis of Anna’s story I identified three superordinate themes, which include:

• Length and lack of clarity in the identification process;

• Advocacy; and

• Systems of support.

While Anna felt that the identification process was lengthy and unpredictable, she also shared that she been able to yet again sharpen her advocacy skills. She did this by requesting the continuation of specialized services for her daughter during the COVID-19 pandemic. That is,
although April finally had found success with a consistent and predictable intervention support program with her dyslexia teacher at the campus, due to the pandemic, which forced all schools to remove any in-person instruction, April was unable to receive services that were in her Individual Education Plan (IEP). This was a result of social distancing restrictions.

Identification Process is Long and Unclear

Anna’s journey toward advocating for her daughter to be assessed for dyslexia began long before she knew what the term dyslexia meant. Over the course of prior three years, she had experienced the special education process first-hand for April’s speech related education and therapy services. Anna relied on educators to explain the legal aspects of the special education process, along with their professional perspectives on April’s progress in speech therapy. However, once she realized that April was struggling in reading as well, the process of having April assessed for and identified as having dyslexia was deeply ambiguous. Anna was not alone in this experience of ambiguity. Many other parents in Texas have had to learn “an overly complex educational system that forces countless parents to become legal and policy experts and holds educators accountable for following federal law in a state that hasn’t invested in properly training teachers or setting consistent standards for helping dyslexic students” (Swaby, 2018, Feb 26, para. 5). The following section describes the identification process from Anna’s perspective as her daughter progressed from Head Start to first grade when she was assessed and identified as having dyslexia characteristics.

Progress in Each Grade was Confusing

*Head Start.* Anna shared that April began her first school experience when she was four years old at a local community Head Start program, attending half-day schooling. The Head Start program is a federally funded governmental program that provides early learning opportunities to
eligible families who have children between the ages of three and five years old (Office of Head Start, 2020). Children can qualify for free Head Start services if they meet criteria for being low income. Free Head Start services are also available to children in foster care, as well as those who are homeless. Initially, Anna thought the struggles April was having with reading could have been attributed to the Head Start dual language model where both English and Spanish were being taught each day. She mentioned, “They talked a lot in Spanish and she didn’t speak Spanish, so I thought that had something to do with it [the challenges that April was having with learning to read], too.” She thought her daughter had been confused when trying to learn two languages, English which was the only language that everyone spoke at home, and Spanish which was not a language she had been exposed to at home, although Spanish is commonly spoken in public in the region. Many Head Start programs have adopted various models of bilingual instruction that incorporate English and Spanish instruction to reflect the diverse makeup of the communities they serve (Office of the Administration for Children & Families, 2017). The Head Start program in this borderland community follows a dual language program model (Office of Head Start, 2019).

Upon more analysis, I realized that Anna mentioned something that is a common ideology about learning more than one language in the United States. It is the misconception that children may get confused when learning more than one language. For typical learners without specific learning differences, this ideology has not been supported by research (Miller, 2017). Nevertheless, I think Anna did have a valid concern for her daughter, given that she had received speech services. When asked about how being a bilingual child can impact a reader, Genesee (2019) states that “children born with the genetic profile that is linked to dyslexia will have difficulty learning to read whether they are bilingual or monolingual” (Does Being Bilingual
Cause Dyslexia or Increase the Probability of Becoming Dyslexic? section, para. 4). For learners with the specific learning difference of dyslexia, learning more than one language can pose particular challenges as related to the areas of learning the new language that are impacted by dyslexia characteristics (Simon, 2000). That is, depending on whether a language is classified as transparent or opaque, children with dyslexia characteristics may encounter different challenges.

Before I was a dyslexia intervention teacher and before I was trained as a trainer for dyslexia and the characteristics in second language learners (Spanish speakers), I noticed as a practitioner that my students who were English-only speakers showed what I know now to be characteristics of dyslexia. That is, their struggles with reading were evident by the beginning of the winter semester of their kindergarten school year. In contrast, my students who were in the kindergarten dual language programs, and were either native Spanish speakers or native English speakers learning Spanish and English, exhibited characteristics of dyslexia by the middle of their second grade year. That was almost two and a half years later than their English-only speaking peers who had dyslexia characteristics. Although I did not have the training at the time to understand why children in the dual-language program did not show characteristics of the learning difference until several years later, I know now that this phenomenon was not a unique or outlying experience at all. Children who are learning languages classified as opaque (e.g., English) first exhibit hallmark traits related to dyslexia characteristics sooner than their peers who are learning transparent languages (e.g., Spanish). Opaque languages are those that have more than one sound that is represented by a letter. Transparent languages, on the other hand, have a single sound and single letter correspondence.

Because dyslexia is a genetic trait, children learning any world language would have similar challenges in processing the sound-letter correspondence, since they have particular
inherited processing characteristics. The difference between children learning opaque languages versus transparent ones is that they demonstrate dyslexia characteristics sooner with opaque languages, because the components and patterns of the language are unpredictable and inconsistent (Ziegler, Stone & Jacobs, 1997). Children with dyslexia in transparent languages, on the other hand, may have less difficulty with word-level reading (decoding) due to the close letter-sound correspondence (Joshi & Aaron, 2006). However, they may still have difficulty with fluency and comprehension (Texas Dyslexia Handbook, 2018). Davies, Cuetos, and Glez-Seijas (2007) found that accuracy was high among both children with dyslexia and those without it who read words aloud in Spanish. They examined the strategies students used and how accurately and quickly the children could read the words aloud in Spanish. Accuracy was measured by words that were read as rapidly and accurately as possible and the students’ ability to do these tasks were high “given the regularity of orthography-to-phonology mappings in Spanish [which is a transparent language]” (p. 192). For example, a child may have hallmark characteristics of dyslexia in areas related to “accurate or fluent word recognition and by poor spelling and decoding abilities… from a deficit in the as phonological component of language that is unexpected in relation to other cognitive abilities” (Lyon, Shaywitz & Shaywitz, 2003, p 2). This would pose varying levels of challenge for students when learning languages, depending on if a language is transparent or opaque. Thus, a child who learns English as their first language would show differences in learning how to read at an earlier age, because English is an opaque language (Vellutino, Fletcher, Snowling, & Scanlon 2004) where associations between sounds and letters are not consistent. Spanish learners may show differences in learning to read at a later age, since Spanish is a transparent orthography (Lyytinen et al., 2004) where the writing system is made up of a one-to-one correspondence between letters and sounds (see Chapter 2: Dyslexia
& Orthography – Written Systems for an in-depth explanation). It was not until April started school that her mother could compare her daughter’s progress to that of her classmates. She did this by examining work samples that were on display in the hallway bulletin board as well as by comparing April’s progress to other friends who had children around the same age. Anna brought up her concern about what she perceived as April’s lack of progress in reading to her daughter’s Head Start teacher. The first time she did this, the teacher dismissed Anna’s concerns. April’s Head Start teacher, Ms. Little, was a veteran teacher who reassured Anna that April would make progress in time. “When we’d have those parent teacher conferences, she’d be like she’s just behind. She just needs more practice.” Anna had confidence that Ms. Little’s recommendation to wait and give April more time to learn her reading skills would work.

**Kindergarten.** April was Anna’s first child and she had not realized that April had been late in speaking until she was enrolled in formal schooling in kindergarten. Remembering back to when April was five and in kindergarten, she said April was not talking very much. Anna said “She would just say a few words, and I thought she was quiet, you know? I didn’t think much [about her not talking very often]. She was my first kid.” But when April began kindergarten, her teacher Ms. Granado had a hard time understanding April and she requested a formal evaluation for speech services. Anna became familiar with the special education process and laws once she attended April’s first the Admission, Review, and Dismissal (ARD) committee meeting. The ARD process is where a team of knowledgeable educators convene to make recommendations that will provide support and necessary accommodations for a student with a learning differences.

The Individuals with Disabilities Education Act (IDEA) outlines the United States special education law and specifies that the committee must be comprised of the caregiver, an individual
who represents the school system, which is usually the campus administrator, someone who is aware of the child’s abilities as they relate to academic and school tasks, the special education teacher, and any related service providers who are experts in specialized areas. Those areas include (but are not limited to) physical therapists, behavioral therapists, and speech language therapists (United States Department of Education, 2019). There is a required annual meeting that must be held each year to reevaluate the progress each student has made, and they make recommendations about whether the student still qualifies for services and how they can best be supported. At the ARD meeting, Anna learned that April had qualified to receive speech therapy. April’s first IEP was created during her kindergarten school year, when she began receiving speech services for speech sound and communication development (see chapter two for a thorough explanation of the IEP).

However, even though April was receiving special education services for speech in kindergarten, Anna said she could tell her daughter was continuing to have a difficult time remembering reading skills she had developed when she was enrolled in Head Start the year before. Anna would reiterate her concerns about her daughter’s limited progress in reading every time there was a parent-teacher meeting with Ms. Granado, April’s first grade teacher.

Anna recognized that April was constantly struggling with reading concepts because at home they “practiced and practiced and practiced all night… her ABC’s and her numbers… she just never “got it.” The main way that Anna would help her daughter at home with reading skills was to repetitively drill her with flashcards so she would memorize sounds and words. However, Anna was worried because April would forget her letters. There were words and sounds that she had appeared to have memorized. When Anna told me that April never "got it," I could tell that she meant that the learning that she saw happen one evening when helping her with her school
work would not appear to have been internalized by April the following day. For example, April would know how to spell a word and then would forget the spelling the next time even though she had already appeared to have memorized the word.

What Anna was experiencing first-hand during these evening study sessions with her kindergarten child was a characteristic that many people with dyslexia have. It relates to having challenges with retaining information in the long term memory. Anna mentioned that she had shared her concern over her April’s lack of progress as compared to her friend’s child with the teacher, Ms. Granado. However, Ms. Granado continually told her to just wait and give the tutoring some more time. Ms. Granado also told her that April was behind because she had not attended early Head Start when she was three. She explained that many of April’s peers had received this education, and in contrast, April had only attended Head Start/pre-kindergarten when she was four. Although Anna remained concerned about Anna’s inconsistent progress in reading, she relied on the teacher’s recommendation to wait and see if tutoring would help her daughter make progress. Dyslexia is commonly referred to as a hidden disability (McNulty, 2003). This is due to the fact that those who are unfamiliar with the characteristics of dyslexia typically do not notice the hallmark characteristics of the condition unless a reading task is involved.

First Grade. April had Ms. Granado, the same teacher, for two years in a row in both kindergarten and first grade. This process of having a teacher at one grade level advance to the following grade level and teach the same group of students the following year is referred to as multi-year teaching (Rasmussen, 1998), continuous learning (The Northeast and Islands Regional Educational Laboratory, 1997) and looping (Grant, Johnson & Richardson, 1996) in elementary schools. This process is done to create a longer-term relationship between teachers
and students. However, the unintended negative effect of this approach is that if the teacher does not know about how to identify the characteristics of a child with dyslexia, the child would potentially be identified much later in their education since the teacher is not aware of the characteristics.

By the time April started first grade, Anna was concerned that April would again struggle with reading as she had seen her struggle in kindergarten. Anna was growing more concerned about April’s progress for two primary reasons; first, her reading skills had plateaued, even though she was advancing to more difficult concepts in each subsequent grade level. Anna was also worried that by the time April advanced to third grade a few years later, she would not be able to perform well on the third grade high-stakes, standardized test called the State of Texas Assessments of Academic Readiness (STAAR). Anna was also concerned that April was becoming increasingly aware of her challenges with reading tasks because April would avoid completing homework related to reading and was starting to resent going to school, saying she did not want to go anymore.

Anna requested a parent-teacher conference at the start of the first-grade school year to share her continued concerns. Ms. Granado reassured Anna that she would tutor April after school, and if she did not show any progress she would help her get assessed for dyslexia. Ms. Granado told Anna she would help her since she understood the challenges of identification first-hand, as her younger brother had dyslexia. While Anna was hopeful, she was disappointed when after six weeks of tutoring in reading, Ms. Granado let her know that April had not made any progress. However, Anna mentioned that she was not really sure what strategies Ms. Granado used, but she thought they were general ones geared at helping children who were not dyslexic since Ms. Granado did not have formal training in dyslexia pedagogies.
This was when Ms. Granado shared April’s profile and reading assessment scores with the reading specialist, Ms. Romero. Ms. Romero said that there was not enough information for her to assess April for dyslexia and to continue offering tutoring. At the time of April’s first grade year, the previous edition of the *Texas Dyslexia Handbook* (2014), did not specify an exact amount of data that should be collected over a specified amount of time, nor did it provide a timeline for deciding when to assess a child who might have dyslexia. The handbook does state that an array of both qualitative and quantitative data must be collected and that the decision to assess a child must be decided upon by a group of knowledgeable personnel. The data collected should be multifaceted and consider other elements such as environmental factors, socioeconomic factors, and language proficiency. The cumulative data should include both formal and informal data. Ms. Granado knew that she would need to continue tutoring April to see if she would make any progress.

Each time Anna brought up her concerns about April’s slow progress in reading, teachers would recommend more time in tutoring and that she not worry. Both Ms. Little and Ms. Granado had told Anna that April may have just been a “late bloomer”. This idea of the term *late bloomer* was confusing to Anna, since she was not sure how long she should anticipate waiting for her daughter’s teachers to take action. Anna was witnessing her daughter struggle with reading at home. Any time that April was asked to complete reading homework or reading for fun, she would get upset and sometimes cry to avoid the activity. Furthermore, Anna was aggravated that it seemed that April’s teachers were not noticing this struggle in the classroom environment. It was confusing and surprising to Anna that April was exhibiting these behaviors at home and yet April seemed not to be showing them in the classroom.
Anna’s advocacy began by verbally expressing her concern with every single teacher April had, beginning with Head Start through the time of these interviews when the pandemic occurred at the end of April’s fifth-grade school year. It took almost three years of Anna’s mentioning to each of April’s teachers, from Head Start to first grade before April was tested. Ms. Granado was the teacher who validated Anna’s concern midway through first grade and who listened to her apprehensions. Anna thinks that perhaps Ms. Granado was able to assist her in getting April assessed, having looped with April from kindergarten to first grade. The second year that April had Ms. Granado, she realized April’s reading had been so unpredictable that she was willing to help Anna navigate the process to finally convince a committee to assess April. Although April had been receiving special education services since kindergarten for speech, she had not had special services geared towards reading. Anna had not thought of bringing her concerns in the past to the ARD committees, which are required by IDEA to occur at least one time each school year, to evaluate a learner’s progress. The reason for this was because in Head Start, Ms. Little had encouraged Anna to wait longer to give April more time to learn. Then the following year in kindergarten, Ms. Granado had made Anna feel as though her concerns about April’s minimal progress in reading were unfounded and that simple after school tutoring would be able to remedy her reading troubles. Anna was experiencing a phenomenon that has been documented in the literature. Namely, that educators downplay the severity of invisible disabilities, because they do not know how to identify them (Cunningham, Perry, Stanovich, Stanovich, & Stanovich, 2004). This unpreparedness may happen more often in early childhood settings because there are “factors such as varying licensing requirements and the patchwork of early childhood systems” (Hamre, Partee, & Mulcahy, 2017, p. 1), along with limited opportunities for professional development.
**Dismissal of Caregiver Concerns**

Anna was concerned about her daughter’s progress from the time April was in Head Start to when the formal testing for dyslexia began in first grade. Anna felt like the early elementary teachers she had trusted did not take time to investigate whether April actually had a disability in reading. It was evident that April’s teachers just did not have the same sense of urgency that her mother felt. The experience that Anna states about having to force the school to recognize that her child was showing characteristics of a specific learning difference in reading aligns to what I also found according to the literature. It appears that families who primarily identify as white and middle- to upper class also experience similar resistance from school personnel when trying to request that their child be tested for dyslexia. Parent experiences with dyslexia have been documented in Massachusetts (Woodcock, 2020) in Maryland (Devilbiss, 2004) and California (Silverstein, 2015) and the families in these studies have also had challenges with navigating the 504/IEP process for their children. In fact, this phenomenon has also been documented as it relates to other general learning disabilities (Auriemma, 2016; Finan, 2016; Ong, 2004).

My findings indicate that among the three study participants who are women of color; racism and classism were not discussed primary factors as to why their children were or were not identified with dyslexia. There is not an overwhelming amount of literature about this phenomenon other than few statistical studies. My study fills this gap, but because it is an IPA study, it is not intended to be genralizeable to all families who experience this phenomenon. Given that my study is an IPA, it does not attempt to generalize, but rather, goes more deeply into the experiences that families have with this phenomenon. For example, in Silverstein (2015), a concern that was noted by parents was their empathy for other parents who had less access to financial resources than they did. This was in reference to a caregiver who took out a second
mortgage on their home to have their child attend tutoring for dyslexia intervention. However, in this same caregiver’s recollection, they also mention a loss of hope. In what I learned from Anna’s experiences, she did not lose hope, but instead mentioned that she would overcome whatever obstacles arose, and find a way for the school to assess April. Perhaps having a higher income (i.e., being able to take out a second mortgage out on a home as one of the participants in Silverstein’s study did) led to viewing the challenge of identification and intervention as a struggle in ways that it did not for Anna, who didn’t make more than $16,000 per year and did not own a home. Anna did not have the option of taking out a second mortgage, and had no other choice than to rely on the public school system to identify April and provide interventions.

Although Anna had been present at every ARD meeting from the time April began receiving speech services in Head Start until second grade, she had not thought about bringing her concerns about reading to the committee. This was because April was in special education for speech services, and her classroom teachers said that she was making adequate progress in reading. That determination had been made in Head Start, kindergarten and initially in first grade. It was not until a few weeks into the second year in a row that Ms. Granado had April as a student that she realized that Anna’s concerns about April’s progress in reading were a significant concern. Although IDEA states that educators can and should bring up their concerns about a student's progress at an annual meeting, the parent’s concerns should also be shared at these meetings. The final decision to proceed with an assessment is based on a collaborative discussion among the committee members present at the meeting as the data presented is reviewed and analyzed.
**Requesting a Meeting**

Anna expressed that the process of requesting a formal ARD meeting to share her concerns about April’s lack of progress in reading and asking for a dyslexia assessment took longer than she had anticipated. Anna had anticipated that the process would have been similar to what she had done when Ms. Granado requested that April be assessed for speech when she was in kindergarten. Anna was surprised that even though she had finally felt like April could be assessed for dyslexia, there was still resistance among the members of the committee to grant the assessment. Figure 4.1 shows a timeline of when Anna began requesting an assessment for April when she was in pre-kindergarten until the time it occurred in first grade.
Figure 4.1. Anna’s Experience with Advocating for April to be Assessed for Dyslexia
While April’s teacher, Ms. Granado, did not initially share her mother’s concern over April’s lack of reading progress, by the time she was April’s teacher a second year in a row, Ms. Granado knew that in order for the committee to agree to assess April, there would have to be plenty of documentation of lack of progress; the unfortunate part is that there is not a specific number of documentation pieces required to initiate testing however the *Texas Dyslexia Handbook* (2014) recommends that both qualitative and quantitative data be used to consider assessment. Early in April’s first-grade school year, Ms. Granado began documenting April’s progress via a campus-approved reading program for typically developing students that are having minimal difficulties in reading skills and after the first six weeks of tutoring. After six weeks had passed, Anna asked if enough documentation had been collected to request a meeting. Ms. Granado informed Anna that Ms. Romero, the reading specialist advised that there was not adequate proof and that more qualitative and quantitative data would need to be collected. One of the considerations that a committee can consider in quantitative data are a student’s grades in reading; the committee hesitated to agree to assess April was because she had passing grades in reading. Other data that can be collected and presented to justify the need for a dyslexia assessment are anecdotal records, classroom observations, district universal screenings and criterion-referenced assessments (*Texas Dyslexia Handbook*, 2014). After six more weeks, during the first semester of April’s first-grade year, Anna spoke with Ms. Granado and again asked if a meeting could be scheduled; the request was denied again and April was notified that more time needed to pass before an assessment could be scheduled.

Feeling frustrated with the delay from the school staff to grant her request for an ARD meeting and also fearful that refusal to test would happen for a third year in a row, Anna became desperate for assistance. She called and scheduled an appointment with April’s pediatrician for
an annual physical, and planned to tell the pediatrician that April was having a hard time with reading at school. It was her hope that the doctor could tell the school that April needed to be tested. Anna had been requesting that April be assessed to see if she had challenges with reading since April was in pre-kindergarten. The pediatrician wrote a note on a prescription pad requesting that the school assess April in the area of reading. Anna hoped that a note from a medical professional would force the ARD committee to schedule a meeting and realize that April did in fact need to be assessed. After feeling that the school was ignoring her requests for three years, Anna was determined to find a way to make the school test April. Anna anticipated that the note from the doctor would put some pressure on the school staff to arrange a meeting.

Although Anna already knew that according to IDEA, the school staff had to honor a caregiver request to listen to their concerns at a formal meeting, she got the impression that the school was not going to grant her request for some reason.

Upon April’s return to school after the winter break, Anna had a prescription in hand. Figure 4.1 shows the amount of time that it took to get the assessment, from April’s pre-kindergarten year until the middle of her first grade year; almost three years in total.

When Anna spoke to Ms. Granado in January, she had a prescription requesting a reading assessment form the pediatrician and said she demanded testing. Ms. Granado shared this information with Ms. Romero, the reading specialist who was still hesitant to proceed with a meeting. Sensing that Ms. Romero was skeptical, this time Ms. Granado reiterated “well something’s going on because there’s no progress.” The pressure of having a doctor’s note and Ms. Granado’s persistent inquiries finally led to an ARD meeting. Since April was in special education already, Anna’s request to assess her daughter would be done at the formal meeting, following special education protocol.
The ARD meeting can be an overwhelming and intimidating process, and one special education lawyer even suggested that caregivers view the ARD meeting as a poker game, learning how to wager what you need for your child based on the rules and strategies of the game (Bollero, 2013). The analogy of the game refers to the specific legal requirements that school personnel must follow per IDEA. Caregivers have to learn the ARD process and ways to work alongside the school system to get the services that their child needs to be successful in school. Anna says that she will never know for sure if the prescription made any difference in getting April assessed. However, she thinks it is possible that the pediatrician’s note did push the ARD meeting into being scheduled. Anna also felt that Ms. Granado had already been collecting data for an extended amount of time and that her request would be validated because of all of the documentation from the teacher.

**Requesting Dyslexia Testing at the ARD Meeting**

Although the meeting was finally scheduled for February of April’s first-grade year, Anna described the actual day of the meeting as yet another moment when she had to advocate for April in an assertive way. While Ms. Granado was prepared to share data about April’s limited progress in reading from kindergarten and first grade, there were both verbal and non-verbal cues of resistance from the other school staff present at the meeting. The committee members present were April’s first grade teacher, Ms. Granado, the reading specialist Ms. Romero, the principal Mr. Mata, and Ms. Griego, the diagnostician.

The verbal resistance to Anna’s request came from the reading specialist and the administrator, who blatantly dismissed the possibility of April having dyslexia. Of course, they had no formal assessment data to support their opinions. When Ms. Romero and Mr. Mata verbally disagreed with pursuing an assessment because they said April was passing her first-
grade reading class without a problem, Anna reminded them, “Well, she is barely passing with a 70... She gets hundreds on her spelling tests, but they [the spelling words] are on the wall and she [April] would memorize them and would look for them [around her classroom].” Anna knew that the grades on the report card were not reflective of her daughter’s true ability to decode words independently.

Anna could sense that Ms. Granado was becoming agitated, because she knew the request might be denied without even evaluating April. However, Ms. Granado seemed to be reluctant to contradict the principal. This reluctance may have been because of a clear power differential and tense atmosphere of ARD meetings. Anna wondered if Ms. Romero and Mr. Mata were thinking “Why are you [Ms. Granado] helping her [Anna]? You know what I mean?” Anna interpreted the verbal resistance at the meeting stemmed from Mr. Mata and Ms. Romero implying that the only reason Anna knew about requesting a formal dyslexia assessment was because of Ms. Granado’s encouragement. However, Anna already knew she could request the assessment, since she was aware of the ARD process and had requested a speech assessment before when April was in kindergarten.

Anna recounted that there was both verbal and non-verbal disagreement with the request to assess April. She noted that “Mr. Mata repeatedly looked at his watch and he’d be like, ‘We’ll just do what mom wants, she’s not gonna leave here until we agree to it,’ you know?” Anna described that Mr. Mata’s body language appeared to suggest that he was very busy and that the committee needed to move more quickly to make a decision than it was. Furthermore, since Anna was suggesting that April had an invisible disability, the committee was able to debate the origin of April’s reading difficulties since they cannot be visibly seen. I believe that the reluctance to grant assessment for April was due to the concern about what they saw as
conflicting data. That is, April had passing grades in reading and her behavior was not a concern or distraction for Ms. Granado or her peers. This made it seem that there was not a sense of urgency, because April was not failing a standardized assessment like the STAAR test and she was not a behavior problem requiring urgent intervention from the administration. Anna however, did not feel that the passing grades were reflective of her daughter’s ability to read, as she had witnessed April’s challenges with reading at home. Anna knew that April had been failing all of her spelling tests and that the tests she passed were because she had memorized certain words. The committee may also have been concerned because they knew that their only dyslexia teacher, Ms. Short, already had a completely full schedule and it would have been difficult to squeeze another student into her schedule if April did in fact qualify. Nonetheless, after several hours of debate, the request to assess April for dyslexia was granted by the committee. They decided to grant the assessment due to the caregiver’s concern and the documentation that Ms. Granado was able to present at the meeting.

The Test and the Results

Anna shared with me that she was surprised that the testing occurred rather quickly – within two months. During those two months, April received intensive remedial support via the campus Response to Intervention (RTI) reading program. All school districts in Texas are required to have various tailored academic support options for students, to ensure that each child has an opportunity to make targeted progress before being assessed for special education. The services offered at each school district depend on the different programs and interventionists available. These options of specialized support are available to any student and do not have to be implemented after an ARD. RTI is an in-school support model that offers tiered levels of intervention to any learner who needs them, and can be offered to students in special education.
According to the *Texas Dyslexia Handbook* (2014), the assessment in Texas for dyslexia must assess academic skills cognitive processes, and additional areas such as orthographic processing (i.e., memory of letter/symbol sequences), mathematical calculation/reasoning, phonological memory, verbal working memory, handwriting, written/verbal expression, listening comprehension, and processing speed. These assessments must also be conducted by qualified school personnel and in a child’s native language. In this case, the assessment was completed by the campus reading specialist in April’s home language, which was English. Although some families with access to financial resources could have paid for a private or independent assessment, school systems are asked to simply consider the outside assessment. Even if an outside evaluator suggests that a child has characteristics of dyslexia, it does not mean a child will automatically qualify for dyslexia services.

Anna was surprised that Ms. Short, the dyslexia teacher, Ms. Romero, the reading specialist and Mr. Mata, the administrator were all proposing that even though April had qualified to receive intervention services, the services would not begin until the following school year when she started second grade because she would “forget everything over the summer.” Upon hearing them repeat this several times, Anna said she interrupted the committee’s
deliberations and said “she’s already behind, so why can’t we just start now?” The committee repeated that “she’ll probably forget it.” So Anna said, “Well, then you can do it again!” Due to her advocacy and speaking up during their discussion as to when services would begin, the committee ultimately decided that the services could begin immediately and continue for the duration of the school year. Anna and Ms. Granado were both relieved that April had qualified as a learner who has dyslexia characteristics and that the intervention services would begin the following week with the dyslexia teacher, Ms. Short.

**Intervention Services**

After the meeting, April began receiving dyslexia intervention services. When I asked Anna how many times the ARD paperwork specified that she would be receiving services, she said that it did not specify anything in particular. She shared that Mr. Mata had said, “we will try to fit April into the dyslexia schedule for this year.” Anna had initially thought that she could trust that the specialist would give April the intervention services as outlined on the IEP. However, Ms. Granado had witnessed that during the school day, Ms. Short, the dyslexia interventionist did not conduct the intervention in the way that was stated on the paperwork. She told April that it was not happening as planned. Also, the school-wide campus coordinator, Ms. Lucero, had stopped Anna in the hallway one day when she was volunteering and let her know that she had seen that April was being taken out of class to work with a teacher’s assistant who did not have training in dyslexia intervention. Anna was genuinely grateful for the honest communication from Ms. Granado and Ms. Lucero because she would not have ever though that she would have to remain diligent in her advocacy and document the frequency of these services after the assessment had been made. Alarmed by the notion that April was not receiving services from the dyslexia specialist and instead was working with the teacher’s assistant, April sought
advice from her cousin who was a teacher’s assistant at another campus in the district. She wanted to see if her cousin believed she had the training to provide interventions for children with dyslexia. When she asked her cousin if she could work with children with dyslexia and if she had training in this area, she replied by saying, “No! What the hell would I know?” Anna was surprised that the school would have placed April in an intervention program with a teacher’s assistant who did not have any training in dyslexia intervention.

The *Texas Dyslexia Handbook* (2014) recommends that students with dyslexia receive intervention from a certified dyslexia specialist, not a teacher’s assistant. The *Texas Dyslexia Handbook* (2014) also explicitly suggests that intervention for students with dyslexia characteristics must include: explicit, simultaneous, and multisensory instruction that is systematic and cumulative (i.e., that occurs in a methodical and consistent fashion, repeatedly building upon and practicing previously learned concepts alongside new concepts). It must also use both approaches of instruction to learn to read, synthetic (i.e., learning letter sounds first before synthesizing or putting letters together to make sounds) and analytic (i.e., combining larger sounds or using analogies to figure out words by sight).

Anna realized that although she had accomplished having her daughter tested for dyslexia, she would still need to remain vigilant and oversee the services April was receiving to make sure that she was getting the appropriate interventions during the school day. She knew that she would need to continue advocating for her daughter, and that qualifying for services did not guarantee that she would get services. At the end of the year, she realized April had only been provided with some basic reading intervention by the teacher’s assistant, and had not worked with the actual dyslexia interventionist. Between the time of the end of March until the
final days of school in late May, April saw the interventionist for only ten days when she should have seen the specialist for about 40 days.

Anna used five words to describe the initial identification process which were, “Long, overwhelming, stressful, hard… and hopeful.” Although each of these words could be analyzed separately at length, I elected to focus on the words overwhelming and hopeful in this chapter.

When I was analyzing our recorded interview, Anna emphasized these two adjectives with a different pitch and intonation. For example, when she used the word overwhelming, she paused for several seconds and laughed. Raine (2018) found that nervous laughter can be indicative of a psychological response that the human brain uses to diffuse trauma or stress. The span of time between her first concern and when the formal identification was finally granted almost four years later was full of obstacles. When we discussed this process she said she was hopeful when the identification process was over and April was identified as a student with dyslexia. She remembered that in her head she couldn’t help but think, “Oh yeah she does…I told you!” when she heard that her daughter had qualified for services. There were moments where she had to advocate and relentlessly champion her daughter’s needs to school staff so that they would share the sense of urgency that she felt. Anna could tell that April was not reading with ease, as her peers were.

**Fear of Retaliation**

Due to Anna’s advocacy and persistence during the identification process, she found that sometimes she had to push and be assertive, challenging some members of the school staff at April’s school. This included challenging some of April’s teachers as well as administrators’ professional opinions.

*The Not-So-Friendly Former Teacher*
Anna described an instance where she was worried about retaliation. Ms. Granado, April’s kindergarten and first grade homeroom teacher, had sometimes been an ally to her and sometimes seemed to be afraid to confront the principal in relation to April’s dyslexia diagnosis. Anna had gone to pick up April during the first week of second grade, and she happened to pass by Ms. Granado in the hallway. Anna was taken aback by the assertive way that Ms. Granado approached her, especially since they had not had any problems working together in their parent-teacher partnership over the two years she had looped with April. Ms. Granado gingerly asked if Anna would be placing her younger son in her class. Anna said no, she would not be requesting Ms. Granado as her son’s homeroom teacher. Anna was shocked when Ms. Granado’s demeanor instantly changed and immediately answered in an assertive and stern voice saying, “Don’t ask me for no help if you don’t [formally request your son be enrolled in my homeroom]”. Anna was surprised that the working relationship she had with Ms. Granado had ended in this way, with Ms. Granado making a threat to her that she could not rely on her help with Anna’s son.

During her recollection of this moment, I asked Anna a funneling question to find out if she thought that Ms. Granado asked her this in the hallway because she wanted to continue working with her family. Anna clearly stated, “No, I think [it was just] so she could say she had this many requests, and because that’s how she is. It was not to help my son!” When Anna mentions that Ms. Granado said “this many requests”, it is referring to the prestige amongst teachers that signifies parents are demanding that their child be placed in their class because they have confidence in their ability to teach well. While Anna felt that Ms. Granado had placated her concerns during April’s two years in her class and had provided tutoring several times a week in reading in her general education class, she felt that Ms. Granado could have done more to help with identifying that April had dyslexia when she was younger. Anna had to bring her concern
about April’s reading progress to Ms. Granado numerous times before she finally helped her. While Anna initially felt that she could trust Ms. Granado’s professional opinion, and had trusted her to help navigate the complex systems within the school, Ms. Granado’s failure to have the same sense of urgency that Anna had about April’s lack of progress was disappointing to her. The missed opportunity for Ms. Little to identify April and then the following year in kindergarten when Ms. Granado dismissed Anna’s concern were continually frustrating experiences. When April was in first grade, Anna was disappointed that she had to not only challenge the school but also ask repeatedly about Ms. Granado’s documentation of April’s progress, in hopes that there was finally enough evidence to demand an assessment. This process left Anna feeling that she could not trust Ms. Granado to make the best decisions for April. Ultimately, when Ms. Granado approached Anna in the hallway, that unprofessional interaction and threatening behavior further solidified Anna’s perception of this teacher. Having worked with Ms. Granado was ultimately a negative experience. In the context of my interview with her, Anna stated that she was not going to place her son in a class where the teacher had failed to recognize the need for April to get further intervention. At the time, Anna was unsure as to whether her son would also show characteristics of the hereditary trait of dyslexia and she did not want to take any chances that he would not be identified early. Anna’s perception of placing her complete trust in April’s teachers had changed because of her experience with April. While she tries to begin each school year optimistically and to start anew, she mentioned that after some time passes, each year she still follows up with teachers to ensure that they are implementing the accommodations in April’s ARD paperwork as outlined.

**Ensuring Anonymity Before Sharing Revealing Details**
Anna reiterated several times during the interview that she wanted to be sure I would not reveal any identifiable characteristics about her story. I reassured her about how I would ensure confidentiality, and that seemed to help. She did not want the school district to find out what she had said about her experience. I found that this was something I needed to reassure her about, especially since she had shared experiences in which she had challenged the school staff and their professional opinions. She said, “I already get bad looks from there…” and noted that she was concerned that if any of the school staff found out that she had spoken negatively about the special education identification process, that there would be negative repercussions for her children. I reexplained the consent form and processes I would undertake to ensure her anonymity. I also made a point of finding moments when I could share my positionality with Anna and provide brief examples of instances in which I too had encountered similar concerns as a teacher and administrator. There were numerous times that I felt that a decision was being made about a child who had dyslexia characteristics and was told to not speak up, not as a caregiver, but as a teacher. I certainly empathized with Anna’s concern about remaining anonymous and reminded her that by her sharing her experiences with the phenomenon of dyslexia identification, she might be able to help other families during the identification process. Furthermore, I specified that each reference about the school would be included in a general format from the state education agency and that readers would not be able to search which borderland area in Texas I was discussing.

Child’s Emotions During the Identification Process and After the Identification

Anna spoke of the interactions that April had with various teachers, staff and family members before, during, and after the identification process. As I listened to and analyzed Anna’s recounting of this process from her daughter’s point of view, it was apparent that there
were interactions which described how the adults around her either made April feel safe and successful at school or anxious and defeated. The following section describes the themes that I identified as Anna recounted her daughter’s experiences with the identification process. While Anna said that her daughter had avoided reading tasks such as reading for fun at home unless she was being read to, it was not until she was in first grade that she started showing signs of avoiding school. Perhaps this was due to April’s new awareness of challenges with reading tasks and her being aware of how teachers, substitutes, and family members were reacting to her reading abilities. Anna told me that it was the teacher’s body language that gave her clues that they were frustrated with April when she would read. I think that this may have been a combination of several elements to include April’s newfound awareness of her different abilities at the time, such as peers being able to read with fluency and perhaps even to the idea of “passing” since she had not formally received the label of having dyslexia at this point. Devlin and Pothier (2006) explain that “in its purest form, passing is a very deliberate attempt to pretend you are something you are not. People may put a great deal of effort into passing” (p. 15). Since April has a hidden disability, she may have been wanting for her classmates, teacher(s), and substitutes to not know that she had a learning difference. In a socially constructed view of differences and abilities, April’s classmates and peers would not even have noticed that she was struggling with reading tasks until the environment forced her to perform a reading task aloud, write down something, or perform on a standardized or timed assignment/assessment.

**Frustration with Reading.** Anna shared details about the experiences her daughter had had in terms of strong emotions of frustration and anxiety associated with reading, especially in school settings. She observed these feelings of frustration over many of her years in early elementary school, mentioning that they were especially intense in first through third grade, “I
don’t know what it was over there at the elementary, but every day last year she cried. I guess ‘cause it was hard, I don’t know- maybe ‘cause of the STAAR [standardized tests].” Anna explained that at home she noticed from the time April was in first grade and until quite recently, that April would become very frustrated when doing homework. There were countless long evenings where Anna would force April to stay up late and complete all work that had been sent home; this included work that was homework for the rest of her peers as well as any work she did not complete during the school day. On evenings when she had less homework, Anna required April to review her sight words and practice reading skills that she had not yet mastered. April would have to complete her work with either her mother or her Aunt Mary, who also lived in the household. Although her Aunt Mary would require April to finish all of her work, she was one of the family members who noticed how challenging it was for April to finish it in one sitting. To add to this stress, as April got older and her little brother began school, April would often become annoyed with her younger brother because he rarely experienced challenges when completing his reading homework. When April was in second grade, a few months after she was identified as having dyslexia, her little brother began kindergarten. Anna said, “I guess she’s kind of jealous [that he does not have a hard time reading].” Anna said that her son never teased April, but it seemed that April was annoyed by her brother because he found reading easy and she would do things such as turn her back to not see him reading, April was older than he was and she wanted to be the big sister who helped him with his homework. But she could not help him in reading. Her younger brother also received speech services from the time he entered kindergarten but did not show any characteristics of dyslexia or challenges with reading abilities. From the time April was in first grade until third grade, she frequently starting using phrases such as, “I hate school” and “I’m sick and can’t go to school.” She would would cry frequently at
home to avoid having to go to school, and she also resented the arduous chore of homework time. Revisiting the notion of passing and hidden differences, April was unable to pass at home as a fluent reader with her mother; which was something she was doing successfully at school. This is true because when Anna would have parent conferences or would suggest that her daughter was struggling with reading, her opinion was dismissed by Ms. Little and Ms. Granado. During this one-on-one meeting after school while working on homework, April was required to complete assignments and provide a rationale as to why she selected answers that were incorrect and was unable to answer to justify it or to read words aloud with fluency and consistency.

This inability to perform tasks that were challenging for April, due to her learning difference, is indicative of what McRuer (2006) refers to as compulsory able-bodiedness. I think that the “system of compulsory able-bodiedness, which in a sense produces disability…” (p. 2) is one that April was attempting to navigate with success at school until the demands were too challenging. However, April was unable to successfully pass at home as a fluent and successful reader because her mother was listening and responding to her daughters needs in a way that a classroom teacher untrained in dyslexia characteristics and multi-sensory teaching strategies cannot always do, due to the fast-paced nature of classrooms and the multitude of students’ needs.

**Anxiety and Fear of the Unknown.** Anna explained throughout her interviews that April would have extreme anxiety and fear when faced with an impending unknown task. One of the situations that brought April anxiety was when there was going to be a substitute teacher. When recalling experiences that April had during first and second grade, Anna said that April had “bad anxiety like when she had substitutes. Like if she knew she was going to have substitutes, she’ll cry and cry because she’s scared. She doesn’t know how they’ll react if she
asks for help.” In order to ease her daughter’s fear, her first grade teacher, Ms. Granado, made sure to prepare lesson plans that provided substitutes with suggestions on how to help April in her absence. Anna has been sure to reiterate this at each ARD meeting after April was identified, to ensure that teachers knew that they need to embed this in lesson plans if the substitute is someone unfamiliar, whom April does not know.

Another situation that would make April anxious was a high-stakes or benchmark test that was administered in class. Anna recalled that in second grade, April’s teacher, Ms. Frederick called her an hour before an assessment was going to be given at school saying:

   Can you come? I need to talk to you [Ms. Frederick asking Anna]. So, I went in and she [April] was crying. I don't know why... and I was like... I told her, what’s going on? And she was nervous about, I think it was like a benchmark or something.

Anna said that it was stressful to have to go to campus to calm April down, but she appreciated that Ms. Frederick would call and let her know when April was having anxiety. Anna thinks that the high-stakes testing environment may have contributed to April’s anxiety. Anna noted that “every day last year [third grade] she cried. I guess it was ‘cause it was hard. I don't know- maybe cause of the STAAR. I don’t know.” Connor and Gabel (2013) state that “a lock-step, fast-paced curriculum does not provide opportunities for learning concepts in-depth or meaningful differentiated instruction” (p. 111). Standardization of curriculum ignores individual ability and forces teachers to move through curriculum to prepare students to perform well on a standardized assessments.
At the time of this study, April received services for a little over three years. Anna felt that her daughter had learned some strategies with Ms. Short, the dyslexia teacher. These strategies were ones that helped April manage her stress, especially with regards to feelings associated with unpredictable assignments, new school personnel, and high-stakes assessments. April had learned to successfully navigate her school day by using a combination of a carefully crafted IEP with accommodations that reflected her individual needs, along with support from teachers who were educated about dyslexia.

**Preparing Teachers to Work with Students Who Have Dyslexic Characteristics**

Pre-service teachers are required to take at least one course in reading methods during their college coursework. However, courses specifically identifying and providing in-class support to students who may have dyslexia characteristics are scarce in most teacher education programs. The content of reading courses is generally up to the professor, which means they are discretionary. Most courses cover broad concepts which may include specific content to help pre-service teachers understand dyslexia (Peltier & Heddy & Peltier, 2020), or may not concentrate on how to identify and provide support for specific learning differences (Lyons & Weiser, 2009; Mills & Clark, 2017). For example, recent studies have found that professors who teach reading often introduce theories of reading instruction that contradict one another (Hurford & Renner, 2018; Will, 2020), making it confusing for a pre-service teacher to leave college with a concrete view of how to teach reading in general, let alone to a child who may have dyslexia characteristics. It would not be until a teacher is hired at a campus that they would know which reading program is followed within that particular school district.

This may be why Ms. Little and Ms. Granado were not aware of the early signs of dyslexia characteristics that April had displayed, specifically the hallmark characteristic of
delayed speech language abilities that can be related to dyslexia. Early childhood teachers get even less training about dyslexia, as depending on the requirements of the state that they live in, a formal college degree may not be required in order to teach young learners between infancy and eight years of age. Dyslexia structured literacy interventionists on the other hand are required to attain a minimum of 135 training hours of professional development and generally must already have completed a degree from an accredited four-year university. This multisensory, structured curriculum is based on the assessment, progress monitoring, lesson planning, and delivery in topics specific to decoding, writing and comprehension skills under the direct supervision of a dyslexia content expert.

**April and the Social Model of (Dis)Ability**

I believe that equipping April with skills to navigate her learning difference throughout the school day is aligned with the social model of disability rather than the medical model. That is, April has learned how to integrate a skill such as predictably decoding written text because of the analytical multisensory method she was learning in her dyslexia intervention period with a specialist. April independently used these skills so that the tasks in her environment were manageable for her. The academic grade-level requirements are still necessary, as they are for her typically developing peers, however, the environment around her is accommodated when she and her classroom teachers use strategies such as read-aloud texts and electronic texts with the assistive technology of being able to be read aloud.

I believe that the successes that April has had are aligned with the social model of disability which purports that the environment must change, not that a difference must be changed (Devlin & Pothier, 2006; Frazee, Gilmour & Mykitiuk, 2006). April has learned how to calm and self-regulate her emotions when faced with unexpected changes in her schedule, such
as a new substitute or surprise assessments. This is evident now, as the pandemic restrictions have made it so that only virtual learning is allowed for April. Anna explained that April has learned how to navigate her school day and has begun to integrate strategies such as using assistive technology to read words and content aloud when she needs it. April now is asking for clarification when she does not understand either an assignment or content that a teacher is presenting which was something she was not confident to do before in front of her peers. This may also be due to the fact that April is older now, and has some experience asking questions and implementing useful strategies in school. Finally, Anna mentioned that she believes that having multiple teachers throughout the day now as a middle-school student is something that April is enjoying, since each teacher has a different personality and teaching style.

**Systems of Support**

Anna spoke of those in whom she had confided in during the identification process, to get both guidance and respite. She revealed that over the course of four years, she had no other option than to seek answers to her questions about April’s progress from sources such as the Internet, local agencies that assist parents with children who have disabilities, and family and friends. This was necessary, as school staff were not always forthcoming or consistent in terms of support.

**Family and Friends.** Since Anna was working at the family business many evenings after April was home from school, April’s Aunt Mary and sometimes her grandparents would help her complete her homework. At the time April was identified with dyslexia, her Aunt Mary was living in the home with Anna, April, and her brother. April’s father is not involved in her life, and did not contribute to raising her. April’s Aunt Mary was relieved when Anna came home after the meeting in first grade and said that April had qualified for dyslexia services. Her
aunt had been concerned about April’s struggles with reading over the years and had thought that “she didn’t want to do the work.” Her aunt was unsure as to why April struggled so much, given that the family helped her with homework after school.

Anna also shared that the systems of support she had relied on during the entire identification process were, “her teacher, my family, and then … I have a friend. They’re [our children are] the same age, and she was going through some things, too. Her son is autistic. So we were going through that together.” Since the school was not always a place that she could trust to give her honest information about April’s progress in reading, Anna found solace in searching the Internet and attending trainings at a local disability agency about how to help her daughter succeed in school. The BDC was where I hosted some of the caregiver trainings Anna attended, specifically the ones about dyslexia. Anna also would attend other caregiver information sessions that focused on topics such as the ARD process and topics centered around finding success while parenting a child who needs routines and predictability.

**Positive Education Dispositions.** Although April had the same teacher two years in a row, it was not until the second year that she was in her class that Ms. Granado recognized and supported Anna in her confusion about April’s inconsistent progress in reading. During the school year that April was tested, her first grade classroom teacher, Ms. Granado had had a personal connection to the struggles that a family goes through because of her brother with dyslexia. Anna shared, “She [Ms. Granado] pushed me to [advocate and request the assessment]. That teacher pushed me to get her tested… it’s a lot… her brother went through that issue too.” While Anna knew that her daughter had been in fact struggling for several years, it wasn’t until Ms. Granado validated her concern and helped her navigate the identification process that she proceeded with challenging the local education system and demanding that April be tested. The
dyslexia intervention teacher, Ms. Short, was another source of support during the identification process. Anna explained that she appreciated this specialist because even though she was busy, with a caseload of more students than she was able to accommodate, she was willing to take the time and answer each and every question Anna had during the process. Anna said that whenever she went into the classroom to ask how the testing was going, she felt welcome to drop in after-school and “just being able to go to her classroom… in person.” The teacher never would appear to be frustrated by the repetitive questions she would ask.

**Services During a Pandemic**

Anna provided insight into the specific concerns she had at the start of the global pandemic caused by COVID-19, when we completed the first interview on March 26, 2020. Anna felt that her daughter was thriving and had become accustomed to a consistent schedule which included predictable interventions with a certified dyslexia specialist. April was applying all of the strategies she had learned in the dyslexia intervention class in her regular content area courses. However, she was concerned that an unforeseen pause in April’s instruction would negatively affect the progress she had made after being identified. A month after the initial interview I conducted with Anna, only three weeks had passed since social distancing restrictions had been enforced in the state of Texas, and students had not yet returned to school.

Unsure of the severity and scope of the pandemic, school districts in the borderland area had planned an extended spring break to give school district staff more time to figure out how to proceed with the remainder of the school year. While Anna had received a call for both of her children regarding virtual special education speech services, she had yet to hear back about how dyslexia services would proceed during the virtual learning. The time period without speech services was about four weeks. Anna was concerned that school-based instruction was not going
to occur in a traditional face-to-face modality. Anna said, “Um, I just don’t know if she's gonna get them [dyslexia intervention services], you know. I don't know how it's gonna work. But I just hope that she doesn't regress.” Caregivers’ concern over maintaining their child’s access to special education services is a concern all over the world during this time of uncertainty (Grayer, Jarrett & Pomrenze, 2020; Stein & Strauss, 2020) with unique concerns for caregivers who have children with dyslexia (Meyer, 2020; Pons, 2020; Shaywitz, 2020). The challenge to require school districts to continue facilitating special education services as outlined in each child’s IEP is a concern for caregivers and school personnel alike.

IDEA does specify that during times of “exceptional circumstances, such as an outbreak of a particular disease” (United States Department of Education, 2020, p. 2), school districts are granted clemency and can suspend services, if education is not being provided to students without disabilities. However, once school resumes, it is the responsibility of the local education agency (LEA) to make every effort to provide special education and related services to uphold a Free Appropriate Public Education (FAPE).

**Discovering Deeper Meanings in April and Anna’s Story**

In a follow up interview I conducted with Anna, she shared that from the time of our second interview until the end of the school year in May in 2020, her daughter had not received any tailored intervention services. Before the pandemic began, April had been receiving services every day in school. But due to the pause of in-person learning, the school sent home a packet from an online program that April was supposed to complete on her own over the summer. Anna said that she understood that the school district was trying to do their best to navigate special education services during the pandemic. She noted that it actually was best that they were given a paper packet, because at the time they did not have any computers in their home for April to
complete the school work. The only computer they had at their home was her niece’s computer, and she was using it to do homework and conduct research for her computer science degree at a local university.

The Texas Dyslexia Handbook states that “dyslexia instruction must be evidence-based and effective for students with dyslexia; taught by an appropriately trained instructor; and implemented with fidelity” (Texas Dyslexia Handbook, 2018, p. 39). By the time the first day of school for the 2020 school year had arrived, both of Anna’s children had been provided computers from the school district to complete online learning. At the time of this writing, April was back to receiving the originally scheduled daily dyslexia intervention, through virtual means. However, she was receiving her instruction with her dyslexia teacher, Ms. Short, from 12:15 p.m. until 12:45 p.m. via a Google Classroom virtual link. Anna mentioned that she was grateful that both of her children had received their own electronic devices to for the fall semester, because she had heard from other parents that the school district ran out of resources and some families only were provided one computer per household. Both of the computers that were distributed to her children are especially helpful since each of them receives special education services and needs to be on the computer at the same time when certain classes are in session, as well as when their different special education services are provided.

The Digital Divide

The digital divide (Becker, 2000; Cullen, 2001; Warschauer, 2003) was already a phenomenon in the world prior to COVID-19. It required some students to access Wi-Fi by depending on entities such as fast-food restaurants, public libraries, coffee shops, and Wi-Fi enabled school buses (Education Trust-West, 2020). This phenomenon is even more critical for students with special needs (Jackson, 2003). This example of a family from a rural town provides
insight into how families from low-income households rely on the resources provided within their community schools. COVID-19 requires schools who were providing technology within the infrastructure of their campus to think of creative ways to ensure that all students have access to their public education (Auxier & Anderson 2020; Sanford, 2020). The pandemic restricted traditional in-person learning, meaning that students below the poverty line such as Anna’s children, who were offered access to high-quality technology in their public school classrooms lost that opportunity when they were quarantined in their homes.

After several rescheduled appointments due to Anna’s hectic schedule and other responsibilities that she has learned to manage, we were able to complete a final member check. Although she was able to chat, she apologized several times because her son would call for her from the other room saying phrases such as, “Mom, I don’t know how to do this drawing the teacher is asking” or “I can’t log back on!” and April was willing to help her little brother navigate online learning, but after several attempts to help him draw within a text box, April called for Anna to help because she needed to get back to her sixth grade classwork, too. Anna said that she could not wait to tell me that, “April got all As on her report card! It was her first time!” Anna continued to describe that “just the other day, I read the math test to her and she got a hundred, and then on the science test, that I thought was really hard, she got another hundred!” After all of these years of advocating for April to receive the assessment and then services that helped her navigate the complexities of her dyslexia, April finally attained her goal of being on the A Honor Roll. Anna said that the pandemic has been challenging to navigate as her sister just found out a week prior to our final member check that she had tested positive for COVID-19, but after she and the children got tested, everyone came back negative. The family grocery store is fairing well, since it is an essential business, however, some customers refuse to comply with
their in-store rule of having to wear a mask in order to purchase any items. Anna said, “it hasn’t been that bad; only one customer, that is not a regular came in. When I told him he needed to wear a mask, he said he would never shop at our family store again.” The new stressors of managing her family grocery store and supporting both of her children at home with virtual online learning has been challenging, but Anna says that she feels that both of the children are doing well. The school has also scheduled both of their ARD meetings for the beginning of November.

Analyzing Anna’s Story with Critical Disability Theory

Critical disability Theory (CDT) allows me to consider the multiple ways that dis/ability is enacted within school policy and practice. Using CDT as a framework for understanding the experiences that families had with the dyslexia identification process in Massachusetts, Woodcock (2020) notes “the evolving field of disability studies distinguishes the vital roles that family members play in the lives of people with disabilities” (p. 1639). It seemed that in Anna’s case, since dyslexia is a hidden disability, some of the school staff did not believe that anything beyond what is traditionally offered was needed to support April in reading. They seemed to see her as a student who was doing fine academically. This was in contrast to Anna’s experiences working on reading tasks at home with April. The notion that April was performing in a manner that was satisfactory and proven via having minimally passing scores in reading shows that the campus faculty, at least those who Anna was working with at the time, subscribed to ideologies that aligned with mediocrity and reproducing social stratification (Fergus, 2016). That is, by making it difficult for April to access specialized intervention services, the school was structured to accept minimal achievement among students like April.
Students who have invisible learning differences such as April may not be seen as needing any urgent interventions because they are not yet failing. In Woodcock’s (2020) autoethnography and collaborative study with five mothers who had children with dyslexia in Massachusetts, she found that school staff must be willing to listen to families who are stating that they are concerned about their child’s lack of progress, or slow progress in reading. Furthermore, Anna knew that April was struggling with concepts such as learning her ABC’s. Anna explained that she was able to support her daughter as a young learner by enacting some sociocultural literacy practices that were aligned with the ideological model of literacy. When I asked Anna what strategies she used to help Anna learn to read, she paused for a few moments and then described that,

To help her [Anna] with learning her ABC’s at home, I came up with a ABC song of the song *What Does the Fox Say?* Every day it would come out on the radio. So I would say,

A goes /a/, B goes /b/, C goes /c/ and D goes /d/.

This is an example of what this caregiver did at home to try help April learn literacy skills that were being taught in the school setting. Although her teacher may not have been able to visibly see April’s impairment, Anna was aware that the environment in the school had to have been producing the disability; the invisibility of April’s dyslexia was not something her teachers saw because in school she was able to act as though she was reading with high levels of accuracy. If the school staff in April’s case would have been willing to notice the nuances of what her mother noticed, then it is likely that April’s testing would have begun sooner. Anna knew that April was using strategies such as looking for words around the room to barely pass her spelling tests, and was preforming well enough to pass reading. These nuances are what Woodcock describes as the “vague, in-between actions…[which] were precursors” (Woodcock, 2020, p. 1645). These pre-
curses of attributes of dyslexia were noticed by Anna and were voiced to her teachers. This struggle that families go through due to their child having a hidden disability is what Woodcock recommends practitioners become more attune to listening to when families are concerned about their child’s progress in reading. April was already receiving special education services for speech therapy; which leads me to assert that in this case, the school may have believed that since she was already receiving services, she did not need anything further to be successful.

The ideology that faculty and staff had about accepting minimal progress worked to perpetuate binary notions of ability and “the preoccupation with binary understandings” that CDT attempts to disrupt (Meekosha & Shuttleworth, 2009, p. 50). Binaries are problematic, in that they reduce complexity to simple either/or dichotomies. The only way that April would have access to the specialized reading program is if she showed enough struggle with reading and therefore the school would justify that she indeed needed to be granted an assessment.

Fortunately, her mother refused to accept this mentality of minimal getting by from the teachers and administrators and pushed to have her daughter tested for dyslexia. Anna knew that April was able to comprehend complex concepts associated with reading if a challenging text was read aloud to her at home. Specifically, Anna meant that when a text was read out loud to April, she could comprehend complex story lines, character development, and was able to do what Williams (2002) refers to as the distinctive knowledge base that each reader is able to bring to their own interpretation of a text. However, if April had to read a book on her own and rely solely on her ability to decode and interpret a text, she could not comprehend it in the way she could when it was read aloud. This was because April would focus on decoding and making decisions about reading which would get in the way of her understanding even a simple text. But
when a text was read aloud, April could analyze at a higher level because she did not have spend all of her energy on decoding. Rather, she could focus on listening and analyzing.

Anna believed that if April learned some skills that were directly correlated to strengthening her reading abilities via a targeted program, she might be able to do better academically. Anna did not know that the end result would be that April would be diagnosed with dyslexia. She simply knew that her daughter had more potential than what the school was leading her to believe. She was unwilling to accept her daughter’s barely getting by in reading. Another reason that Anna wanted to be sure that she advocated for her daughter to get the intervention she needed was because April saw the trophies that her peers were awarded at assemblies and she told her mother in first grade, “I want one!” Anna said that she knew that April “had been trying. I’m sure she has been trying to [as best as she can in school], because she really wants it [a trophy].” Illuminating the desire that individuals have to participate in and with literacy, critical theorists have claimed that literacy is not simply decoding or making meaning through text, rather Lassonde & Woodcock (2001) note:

> Literacy is not a skill to be acquired, but instead is an interwoven piece of one’s identity as an individual … literacy matters in different ways to different people, based on how writing and reading play a role in a given person’s life. That particular role itself is based on theory that literacy is one of numerous sociocultural attributes which make up an entire continuum of interrelated attributes that affect one another. (p. 97)

Anna had a feeling that her daughter would be able to complete rigorous learning tasks and keep up with or even outperform her classmates. That is, April just needed to have the tools to do well and learn about how these tools helped her with her learning differences. However, due to April’s dyslexia, reading was not only something she did in her reading class where she was
earning barely passing marks, and was never able to be awarded a trophy because of perpetual C or D grades on her report card. Instead of viewing reading as something that is only done in one class, literacy was something that April was having to navigate in every single aspect of her school day and to access in multiple subject areas (e.g., reading in math, reading in science, reading in social studies, and in other unexpected areas such as technology class). In the Violence of Literacy (Stuckey, 1991) argues that literacy does not inevitably lead to social opportunity or economic success as the mainstream Western culture purports. Instead, it is occupied in an “entrenched class structure in which those who have power have a vested interest in keeping it” (p vii). This further explains that there is power within the types of literacy standards that are required and of the educational process which upholds those standards. To explain this concept in more detail, I draw on Cosenza’s (2017) idea which states that “Dyslexia also disrupts the smooth flow of education, regarding the compulsory movement toward cognitive ablebodiedness and the intellectual elitism inherent in the ivory towers” (p. 16).”

When a learner is not able to keep up with the pace of standardized curriculum standardized assessments, the pace of a one-size-fits all model of literacy programs does not work for everyone. Anna knew that April was having challenges with reading and wanted to fight so that April would have access to literacy and not be discriminated against as a person with the impairment of dyslexia living in the day to day requirements of a text and literacy based classroom. Within the framework of CDT, Anna challenged binaries as she demanded that April have access adequate assessments that determined what learning skills she needed to allow her to navigate the literacy rich environment at school (via in-class accommodations and text-to-speech reading software such as Bookshare).
April was already in special education because of her kindergarten teacher’s inability to understand her when she spoke. Ms. Granado’s difficulty understanding April spurred her to take action and present her concern to Anna. This was likely because the speech impediment was something Ms. Granado could easily hear when April spoke aloud. It was a tangible, visible difference. This action on Ms. Granado’s part reinforces the binary of visible versus invisible disabilities. CDT challenges definitions that revolve around the binary conception of disability framing disability as those “who are the disabled (them-us) and the able-bodied (us-them)” (Delvin & Pothier, p. 5). Looking through the lens of critical disability studies helps us understand Anna’s confusion in that Ms. Granado was able to detect and pursue a speech assessment early in April’s kindergarten year. However, Ms. Granado was reluctant and skeptical of Anna’s concern as a caregiver to have April assessed for the hidden difference of dyslexia, only seen when the environment placed pressure on April to perform reading tasks at home. The challenge in this case is that Ms. Granado seemed to have April’s best interests in mind and advocated for her at the ARD meeting requesting assessment. Therefore, the issue is that Ms. Granado did not have the skills necessary to identify the characteristics that April was exhibiting.

This phenomenon is documented in the literature from educators around the United States, regardless of however well-intentioned classroom teachers may be, if they do not have the training to understand the characteristics of dyslexia, they cannot identify or support them (Cook, 2018; Kempf, 2015; Pennington, 2018, Washburn, Joshi & Binks-Cantrell, 2011). Therefore, they will unintentionally create a cycle where a child is not learning the skills they should when they are enrolled in their classes and further complicating notions of difference as the child gets older and progresses through elementary school. Using CDT allows me to also consider that
“research, pedagogy, and policy need to be built on expansive notions of justice” (Annamma, 2018, p 157). Without changes that are radical, problems of the past will be reproduced.

Complicating Minority Overrepresentation in Special Education: Texas Policy

I kept wondering how it was possible that April did not get identified with dyslexia if the literature in the United States overwhelmingly suggests that children of color are more likely to be stigmatized and separated into special education. April is a Latina and comes from a low socioeconomic background. Historically, there has been evidence of discriminatory overrepresentation of children of color in special education in the United States (Ferri & Connor, 2005; Heller, Holtzman, & Messick, 1982; Losen & Orfield, 2002; Mahon-Reynolds & Parker, 2016; Zhang, Katsiyannis, Ju, & Roberts, 2014) which is also punitive (Carbado & Gulati, 2000) and correlative to the school to prison pipeline (Heitzeg, 2009; Legal Center for Youth Justice and Education, 2018; Sussman, 2012). The significant problem of students of color being removed from general education and placed in special education is a discussion that is beyond the scope of this dissertation. However, I propose that the traditional definition of overrepresentation in special education may not be clear in April’s case for several reasons.

First of all, at the time of her identification for dyslexia, April was already in special education. Thus, Anna being assessed for dyslexia would not seem to have been an issue, as the 8.5 percent cap that was in place at the time of her identification would not have negatively impacted the campus numbers. Children who are determined to have dyslexia characteristics would need to have interventions from a highly specialized teacher.

Second, the problem in this instance is that dyslexia in Texas still remains a learning difference that does not automatically signal that a child will be in special education. The Texas Dyslexia Handbook (2014, 2018) states that a child who qualifies as having dyslexia...
characteristics should either be placed in a 504 program or in special education, depending on their individual needs. There is an entire page with a graphic organizer in the *Texas Dyslexia Handbook* that delineates the steps which knowledgeable assessment personnel and committee members towards eligibility school staff should take when deciding if a child should be placed into either a 504 or a special education plan after being identified as having dyslexia. The challenge with this subjective decision making process is that each individual campus can make a determination as to whether a child will receive services under special education or under 504 in Texas. Therefore, depending upon the members of the committee that are evaluating the data, different decisions about whether to assess or not will be made. In April’s case, when the principal uttered the phrase, “she doesn’t have it [dyslexia]” that could have meant that the outcome of this caregiver’s experience could have ended up very differently. Meaning that April would have not been assessed at all when the committee convened and was going through April’s history and qualitative/quantitative data because the administrator used authoritative discourse to exude a finality in the decision before the committee even discussed her profile. Perhaps the principal said that April “didn’t have it [dyslexia]” because of the ambiguity of where funding comes from for students who are being served for dyslexia.

Special education services come with earmarked federal funding for teachers and the 504 classification does not. This means that a school district can make discretionary decisions as to who will provide services to children with dyslexia, based on their own district requirements. Although the version of the *Texas Dyslexia Handbook* (2014) provides guidance that the responsibility of teaching dyslexia instruction is not only on the teacher who has been trained “in the program used and… [also] implemented with fidelity” (p. 29); but multiple opportunities to strengthen skills in writing and reading should be shared by general education classroom
teachers, interventionists and reading specialists. Anna’s experience with an administrator who automatically refuted any possibility of dyslexia and did not consider any of the data was something that I experienced firsthand as an administrator. I was a witness to similar conversations such as this one. I saw this both behind closed doors and right in front of various stakeholders who were deliberating with an administrator who would frequently say “they don’t have it [dyslexia].” Teachers with substantial amounts of qualitative and quantitative data proposing that a student should be initiated in the RTI process as a student who might have dyslexia characteristics were ignored. And perhaps most upsetting, this was also stated in front of families and caregivers who had a feeling that their child was struggling more than they should and were subtly requesting that an assessment be granted to help their child. In Anna’s case, the RTI teacher did not become involved until Anna kept asking Ms. Granado to ask for April to be assessed, the way that RTI is intended to work is not necessarily in this manner.

Parents should have the option of requesting formal evaluations at any point in the identification process, though many are likely to delay a formal referral as the student will be engaged in intervention and they can obtain ongoing data on how the student is responding (Fletcher, Coulter, Reschly & Vaughn, 2004, p. 28).

Although parents can request a formal evaluation at any point in time, the quote from this report suggests that April should have already been engaged in intervention from the RTI teacher, which was not the case.

My positionality as a practitioner and researcher is informed by my varied experiences. I have had experiences that did not fit into a binary and indeed represented a fluidity of agency and knowledge as an educator. The fluidity of my agency as an educator has varied as the years have passed and I have acquired more experience. From the moment that I walked into my very
first general education classroom as a novice teacher, with a class roster that had names, profiles and information about students and families I did not know, I was someone, in the state’s view of licensure, who knew enough pedagogy and content to pass a statewide exam. This certified me to teach. But as an experienced teacher who knew enough about teaching reading to struggling readers, I knew that I needed to learn more about dyslexia. This process of being more experienced as the years passed eventually morphed into my becoming someone who (a) had extensive knowledge about the experiences that families had; (b) understood the implications that a dyslexia label has as an administrator; (c) as a college-track professor who is responsible for creating syllabi in a curriculum and instruction program and, (d) as a researcher. It is my job to teach with content that not only addresses tenets of critical disability theory, but that also requires the pre-service teachers in my care have a broad understanding of what (dis)abilities are as well as what reading is, and how they can support students and families.

Finally, April attended a public school in Texas that was 98.9 percent Hispanic (Texas Academic Performance Report, 2015-2016). The school district makeup is also reflective of the rural community racial makeup which is 96.1 percent Latinx (American Community Survey, 2010). The literature shows that it is not poverty, rather it is the organization and culture of schools that may place children of color at a higher risk of being placed in special education (O’Connor & DeLuca Fernandez, 2006; Skiba, Poloni-Staudinger, Simmons, Feggins, & Chung, 2005). This however would mean that since April was in a community with a 47 percent poverty rate, that there would be more children being placed in special education. April is classified as a student in poverty and had been placed in special education as a kindergartener for speech therapy. But the question remains, why was she not assessed further for a learning difference of dyslexia? Although Latinx are 1.1 times more likely to be identified with a learning disability
than their white non-Hispanic peers (OSEP, 2007), I assert that Anna’s experience as a caregiver is unique to a majority-minority community. April, as a student of color, was in a school environment where she was a part of the majority, and she did not get identified to receive services for her learning difference until her mother demanded she be assessed. Another important point is that April and her family all speak English. It seems that April’s delayed identification may have been a combination of unclear policy in Texas about dyslexia identification and lack of knowledge about the disability from the general education teacher who did not know what dyslexia characteristics were. April attended a high-poverty school and the campus did have the resources to employ a full-time dyslexia interventionist. Not every campus has the funding to have a full-time interventionist, this is why I am making a connection to the fact that Anna had to advocate for April to have the dyslexia assessment. This was the case for other caregivers of color and from various socio-economic groups in recent empirical research data in Massachusetts (Woodcock, 2020). As well as one dissertation from perspectives in California which overwhelmingly consisted of the perspective of middle or upper-middle class mothers who are white and have not been able to have their children assessed with dyslexia characteristics either (Silverstein, 2015). Cook (2017) completed a study for her dissertation in New York, focusing on how schools respond to caregivers who request dyslexia assessment and interviewed school teachers, administrators and parents; however, parent ethnicities and socioeconomic statuses were not provided. This is not to say that the documented pattern of white privilege in the United States is not an issue. Rather, it may be because dyslexia is a hidden learning disability and some educators may not identify it since it is not a physical impairment. The argument from some scholars has been that the problem with only seeing disability via a social model is that a person’s hidden impairment, such as dyslexia is invalidated as an
impairment if it is not physical (Reddy 2011; Shakespeare, 2000). Furthermore, because dyslexia identification is not directly correlated with state funding if children are in 504 programs, educators may not see the need for the assessment or intervention to occur in the first place.

While I could relate to Anna’s explanation of the plight to have April identified and for her receive intervention services, it seems that it is difficult for school districts to comply with hiring more specialized interventionists when there is no money to do so. I certainly could relate to Anna’s concern as to why it took so long for April to be identified from my perspective as a former general education teacher, special education teacher, and as an administrator. Swaby (2018, February 26) states:

Most Texas students with dyslexia don’t get the more-intensive services provided under federal law, including some students who may need them. 80 percent of students with dyslexia receive services in regular classrooms through a broader federal civil rights provision called "Section 504," which comes with no state or federal funding and few requirements for parental input or consent (Texas Schools Identifying Fewer Kids as Having Learning Disabilities Such as Dyslexia, paras. 6 & 7).

In the 2014 version of the Texas Dyslexia Handbook, the guidance regarding what actions school districts should take if a parent suspects dyslexia is confusing. It states that schools can decide to assess a child in either special education or 504. “Generally in Texas, however, dyslexia identification and intervention most often happen through general education rather than special education” (p. 13). It further states that “once a parent request for dyslexia assessment has been
made, the school district is obligated to review the student’s data history to determine whether there is reason to believe that a student has a disability’’ (p. 14). This is troublesome because dyslexia identification is then left at the discretion of each campus, meaning that the decision to assess a child is dependent upon the staff that happen to be at the campus- and their own personal knowledge level of the characteristics of dyslexia.

**Trust**

While the central office administration in large school districts have to oversee multiple campuses and the identification of dyslexia, in smaller school districts, as Anna mentioned, “everybody knows everybody here.” That is, many of her children’s teachers had also been her classroom teachers when she was young. Being from such a small town is one of the reasons Anna was hesitant for the community to find out that she was sharing her troublesome experience with me and the world. Since trust was one of the elements that she felt was broken over several years and that she needed to look outside of her community to find resources to help her daughter, Anna was eager to share her story as long as she remained completely anonymous. Lake and Billingsley (2000) found in their study with 21 mothers and one father who had children in special education, that one of the elements which contributed to parent/school conflict in special education was the element of trust. The authors noted that caregivers who felt that the school staff were trustworthy and were able to overlook sporadic events that were negative, as long as the school staff were considerate of their child’s needs. However, once trust was broken, parents in their study noted that they lacked “confidence to fully accept school personnel’s demonstration of good-faith efforts” (p. 248). While Anna did eventually trust most of the school staff, she did still have hesitation after the experience she had with Ms. Granado. Anna hopes educators can learn from the obstacles she experienced trying to get April assessed in Texas,
regardless of whether they are in a rural town or large metropolitan city. It seems that her experience can inform current practices regarding teacher education, how systems of education listen to families, and the ways that schools and personnel follow laws and guidelines (such as the Dyslexia Handbook and the Response to Intervention model), which were already in place when April was in her early childhood school years. Although issues of trust and total reliance on the knowledge of school faculty and staff in special education are not a unique phenomenon and have been documented by the literature (Angell, Stoner & Shelden, 2009; Blue-Bannin, Summers, Frankland, Nelson, & Beegle, 2004; Burke, 2012; Shelden, Angell, Stoner, & Roseland, 2010), people in small towns may trust one another in ways that are familial. In Anna’s case, several of her children’s teachers were her teacher when she was a child, meaning that she had history with them and trusted them in ways similar to family.

In a study with 22 mothers, Angell, Stoner & Shelden (2009) found that several factors inhibited trust between caregivers and the school. One of the outcomes of their study that I specifically related to Anna’s experience was that the authors found that both general and special education teachers’ competence in being a teacher was “most strongly reflected in the mothers’ desire for education professionals to have knowledge of their children’s characteristics and educational needs. A lack of such knowledge was seen as an inhibitor to trust” (p. 174). The fact that some members of the ARD committee, including the principal, did not validate Anna’s concerns for so many years was troublesome to her and indicative of her diminished trust.

Shelden, Angell, Stoner, & Roseland (2010) found that caregivers mentioned strong trust was able to be built when an administrator was willing to learn about their child’s specific disability and that the principal appeared to be dedicated to authentically listening to their concerns, since they know administrators are very busy. Anna described that over time, she and
the administrator ended up having a good relationship, as they had worked together closely to create the most effective IEP for April. Anna was surprised by how this working relationship evolved, since at that early ARD meeting to request dyslexia testing, Mr. Mata did not appear to be interested in deliberating about April’s dyslexia assessment. He initially said “she doesn’t have it [dyslexia]” without having heard about the data in her case, impatiently looking at his watch during the initial ARD meeting. Anna said that she was surprised that she was able to trust Mr. Mata and that they ended up working together well, seeing past their initial disagreements.

Anna said, “And now, the one who doesn’t talk to me is her teacher, the one from first and second grade [Ms. Granado].” The journey towards identification and continuing to work alongside one another as parent and administrator turned out to be a positive working relationship. In middle school, April has multiple teachers who have worked diligently to keep her classes streamlined during the unprecedented challenge of the pandemic. April has adjusted to the new routine and she logs onto all her classes remotely from home. Most importantly, her dyslexia intervention teacher is able to work with her virtually every day at a designated time, after she has attended all of her core content area classes.

**Intersectionality and Anna’s Story**

As I analyzed Anna’s story and considered how the tenets of CDT were evident within her experience of the identification process, I referred back to the theoretical framework and was reminded that CDT is a theoretical lens that incorporates and challenges critical frameworks drawing upon “emancipatory discourses, such as feminism and critical race theory… and queer theory” (Meekosha & Shuttleworth, 2009, p. 62). Intersectionality is one of the approaches suggested by Carbado, Crenshaw, Mays and Tomlinson (2013) that provides “a counter-hegemonic and transformative intervention in knowledge production, activism, pedagogy, and
non-oppressive coalitions” (p. 6). In Anna’s case, I believe her intersectionalities are present in that she is a Latina, a woman, who works full-time earning income below the poverty line.

Moradi & Grzanka (2017) put forth a call to action and suggest the responsible stewardship of the use of intersectionality for not only for scholars focused on diversity, but for all scholars. Referring to the increased use of an intersectionality approach for critical analysis, scholars should move toward a “fuller use and engagement of its roots and promise for understanding and challenging dynamics of power, privilege, and oppression” (Moradi & Grzanka, 2017, p. 1). In considering Anna’s intersectionalities, I had to think about the ways that her advocacy was evident as she experienced requesting the identification process to begin. Crenshaw (1989) notes that if “efforts instead began with addressing the needs and problems of those who are most disadvantaged and with restructuring and remarking the world where necessary, then others who are singularly disadvantaged would also benefit” (p. 167). As I further consider the different things that Anna had to navigate when demanding April was assessed, she also had to contradict the school staff and administrator all of whom had college degrees. She did this while not exactly knowing what all of the processes of the special education law were, along with being a person with a high-school education. Furthermore, Anna is a single parent, and may have been perceived by school staff as not having as many available resources and/or not being able to parent as well as a family with two caregivers.

In the larger area where Anna lives, about 30 percent of adults are thought to be undocumented, which means they are citizens of other countries, primarily Mexico (Pew Research, 2016). While I this was not true for Anna, it seems that caregivers navigating the dyslexia identification process with the additional intersection of legal status would be dealing with yet another element of complexity when requesting that their child be assessed.
In the section, *Requesting Dyslexia Testing at the ARD Meeting*, it seemed that Anna may have felt that she had to provide rationale and justify why she, as a caregiver, felt that April needed to be assessed for dyslexia. Although Anna knew that IDEA gave her power in an ARD meeting as a caregiver to request that April be tested for her reading challenges, they had been denied several times by the school staff. Ultimately, it took three years to get to the point where a formal ARD meeting occurred. When Anna repetitively voiced her concerns about the progress April was making in reading, she challenged normative relationships of power. In expressing her concern in the past and finally having the ARD meeting scheduled, Anna challenged the systems of power within the local school. Carbado, Crenshaw, Mays, & Tomlinson (2013) challenge us to consider social relations of power and to realize the subtle forces that are hidden so that they may be transformed. The interactions Anna had before the meeting with Ms. Little and Ms. Granado and ultimately the verbal and non-verbal communication from the leadership personnel in the ARD meeting, required that Anna refute any discrimination of power and subjectivity from the school staff.

Lake and Billingsley (2000) describe reciprocal power as the interaction that caregivers use to resolve conflict in ARD meetings by both school personnel and employees. In their study, one parent describes that ARD meetings required that she have “tenacity… powerful enough to turn a situation to her favor after she demonstrated that she was not going to back down” (p. 248). In Anna’s case, the notion of power was something that she exerted, after having to advocate for three years, by demanding her daughter receive the initial dyslexia assessment and then again later at the follow-up meeting. This was when the school staff were trying to persuade Anna to wait to begin intervention until the following school year. In response, she said, “Well, then you can do it [the intervention that she may forget over the summer] again!” Anna’s agency
as a caregiver navigating the special education laws and processes had been formed over the three years she continuously showed concern about her daughter’s lack of progress, and she was finally able to demand that April be tested.

Goodley (2013) considers intersectionality as the process of a variety of interactions that validate or oppose one another across sociocultural categories. I think that the process of a variety of interactions that opposed one another contributed to what Anna experienced because even though the law states that caregivers can request further testing if they feel the need is there for their child, the contrary process happened for Anna for three years. It turned out that all along she was the one who had the ability to demand April be assessed, but she had not asserted that power perhaps due to her intersectionalitites of being a Latina, woman, with only a high school degree, and someone who earned a wage that was below the poverty line. Being a single parent was another challenge that Anna had to overcome when requesting this assessment, going into this meeting alone with four school personnel whom she was unsure would support her concern and advocacy to have her daughter assessed.

In 2017, the Texas State Board of Education implemented a requirement that all schools must screen each of their enrolled kindergarten students as well as first graders for phonemic awareness, and poor performance on this screening can point to the possibility of a student having dyslexia characteristics. House Bill 1886 (Texas Legislature, 2017) is legislation that requires each school district find a screening tool to assess phonemic awareness, which includes learning letter names and sounds, reading words in isolation, and spelling words at the beginning, middle, and end of each school year. While I think this is will assist school districts in identifying and providing services earlier, it still remains to be seen if the assessments being used will serve the desired outcome. Some of the challenges I feel that could arise with this plan is
that (1) during a pandemic, this screening tool is impossible to initiate with consistency due to elements such varied access to technology for students, illness, basic needs may not be being met, and many others; (2) the state refuses to provide guidance on which assessments should be used (if schools knew which ones to select, they would have already done so prior to the United States OSEP sanctions); (3) there are nuances to consider when mandating state-wide imposed assessments for kindergarten and first grade students such as language difference, absenteeism, ability, and training.

Anna mentioned that Ms. Granado was hesitant to contradict the administrator in an initial ARD meeting about April. However, as she described the interactions at the meeting, there was power being displayed between the relationship of the teacher and the administrator. This feeling that she perceived was due to immediate silence from the members of the ARD committee after the diagnostician opened the ARD meeting. The meeting’s purpose was stated by the diagnostician (for Anna to request dyslexia testing) followed by the administrator saying, “She does not have it [dyslexia].” Ms. Granado’s hesitancy to automatically contradict the administrator and provide the qualitative and quantitative data and rationale that supported Anna’s concern, shows that as the caregiver she thought she needed to rely on the rationale that Ms. Granado would provide. Anna felt that she was the one without any perceived authority within the school system since she had advocated for so many years to try and get April assessed.

The intersectionalities that Anna had of being a Latina single mother who worked full-time to earn an income below the poverty line was similar to a finding from a study with caregivers from minoritized backgrounds. In a study with 27 families, Trainor (2010) found that caregivers “from Latino, African American, and Native American Indian groups who were also from low socioeconomic backgrounds… were not always respected, considered, or valued,
potentially undermining their power to garner educational opportunities they deemed appropriate” (p. 255). In the end, it was Ms. Granado that actually was the one who was having to convince Mr. Mata and Ms. Romero that her rationale to support the dyslexia assessment was valid, which was not what Anna had anticipated would happen. Anna had expected that the administrator, diagnostician and RTI specialist would have been more willing to consider the data that she presented to them. This outcome is similar to what Kalyanpur, Harry & Skrtic (2000) found where the expectation that families and educators will equally share power to make decisions may not be customary for some caregivers. Furthermore, when Anna decided to bring in a note from the pediatrician, the power that Anna had not had when discussing her concern with Ms. Little and Ms. Granado completely changed when the medical note was brought to the table. This strategy that Anna decided to try on her own, without guidance from Ms. Granado or any of her friends or family is aligned with the idea that the way that special education in the United States frames caregiver participation, which is based on the notion that families may perceive educational issues and disability similarly, irrespective of their cultural backgrounds (Harry, Rueda & Kalyanpur, 1999). Anna automatically sought advice from the pediatrician because that is who she had trusted prior to April’s attending public school. As the years passed by and April continued to struggle, Anna had to navigate an unfamiliar school system. Although she heard at every single ARD meeting that she had rights as a parent under the IDEA law, she gradually lost faith in the special education process.

Bateman & Frankel (1972) assert that special education professionals “have not always communicated adequately and forthrightly their hopes and expectations regarding the pediatrician’s anticipated contribution” (p. 5) to decisions regarding special education services. The authors go on to say that within the field of education the terminology used to describe
reading problems such as ‘dyslexia’ varies between a clearly identifiable etiology that “can be treated with highly specialized remedial techniques. Another view is that ‘dyslexia’ is a myth and that inadequate initial reading instruction is the sole cause of poor reading” Bateman & Frankel, 1972, p. 5). That caregivers such as Anna turn to medical solutions is, in my opinion, aligned with the model of disability that is typically upheld in the United States. Anna was watching April struggle with the binaries of special education models.

On the one hand, April’s dyslexia was completely invisible to her teachers for almost three years. Conversely, there was no consideration whatsoever by her teachers as to what her caregiver, Anna, was seeing was a separation of the dyslexia. April’s intersections of her dyslexia were multi-faceted in the home environment where her mother was able to detect that her impairment (dyslexia) was made visible when she was in a one-on-one environment reading with her mother. Anna tried to describe this when she told April’s teachers that she was surprised that she was able to listen and comprehend texts aloud but struggled to decode words in isolation or with accuracy.

After further analysis, I realized Anna navigated the cultural hegemony of special education during the final exchange with Ms. Granado, expressing that she would have a doctor’s note at the meeting. Not only did she have the doctor’s note, but Anna knew that she would be able to rely on the support outlined in IDEA to finally demand that April be assessed. Anna did not have the financial ability to have an outside assessment done and she knew that within the school, April should have the right to FAPE. However, I was eager to hear Anna explain her thoughts when she realized the power differential that occurred during the ARD meeting requesting assessment. April stated that the meeting was tense at some points and that it was difficult for Ms. Granado to navigate at the ARD meeting requesting assessment from the
administrator, the school RTI specialist, and the general education teacher. Some caregivers may feel intimidated by the specialized knowledge that school personnel may have, the associated jargon that is used during IEP meetings, as well as the power differentials between parents and teachers who can potentially influence which children get access to which services (Trainor, 2010). Yet, Anna felt that Ms. Granado was intimidated at the meeting and that she had to justify why she had suggested to Anna that she request the assessment. It had been each of the educators’ responsibilities to have helped Anna realize the request for April to be assessed earlier. This leads me to wonder what would have happened if April had not had Ms. Granado for two consecutive years. What if she had had a different teacher each year? Would April have been assessed earlier? Or would she have continued to slip under the radar?
Chapter V “WE’LL TAKE IT”

Melissa was 36 years old when her seven-year-old daughter, Mikayla, was identified with dyslexia during the spring of 2016. Melissa self-identified her race as white and her ethnicity as Hispanic and has two children. Her first-born is a son, Malachi, who is four years older than his younger sister, Mikayla. Both of Melissa’s children identify their ethnicity as Hispanic and their race as Black. Melissa earns about $16,000 per year as of 2020 and describes her occupation as a stocker at a wholesale grocery store. Melissa did not mention anything about her educational background. In the borderland city where Melissa lives, the average annual salary is about $45,000 (City Data, 2020). About 20 percent of the population in her city is below the poverty line, which means that for her family of four, Melissa’s income places them below the federal poverty level of $25,730, according to the Department of Health and Human Services (2020). Melissa and her children live with Melissa’s Aunt Norma in one of the largest borderland cities in Texas. Melissa’s Aunt Norma was a teacher in a public school and her mother, who is Mikayla’s Grandma Grace, was a teacher at a local daycare center on the military base. Although Melissa was connected to the military as a spouse of a U.S. Army solider, she no longer has this connection, since they are divorced. Melissa speaks both Spanish and English, but did not need any clarification or funneling questions in Spanish during our interviews. She did, however, use the word, pobrecita, meaning poor little girl, to empathize with her daughter’s frustration as a result of the constant tutoring, interventions, and summer school classes she had to take.

I met Melissa during one of my caregiver dyslexia information classes in October of 2016 at the local parent information center, Borderland Disability Coalition (BDC). I was the project  

1 Alcoff (2006) states that “Race is mediated by ethnic and cultural identities in such a way that these cannot always be neatly disentangled” (p. 265). Melissa describes herself as Hispanic and white, and her children are half Hispanic and half black, as their father is black.
manager for the family community network at a local regional center for education in Texas and Mikayla had recently been identified as having dyslexia in June of the previous school year. Melissa attended as many of the caregiver information sessions as her work schedule allowed. She said she was eager to attend my parent trainings and had received a flyer from her daughter’s public-school dyslexia interventionist who also attended the Dyslexia Collaborative that I lead at the time. I got to know her Aunt Norma and Mikayla’s grandmother, Deborah as well, since they would all come together in the same car to every session Melissa was able to attend.

I was able to relate to the close relationship Melissa shared with her family, as I too had been a single mother and had relied on support from my family members when faced with new obstacles and challenges. When I asked her about who she was as a person and what she liked to do she said, “I’m a single mama. I’m just working double [laugh]. I listen to country, freestyle—all that cool stuff. Eighties. I don’t drink. I don’t smoke.” Melissa expressed to me that she was a dedicated and hard working mom who just wanted to provide for her kids.

Melissa influenced me by helping me understand that the dyslexia identification process is complicated and made even more challenging when the school personnel do not all understand what dyslexia is and what it is not. I could relate to this confusion that Melissa had about school personnel not being informed about how to assist a child with dyslexia. Before I had been formally trained in the Wilson Language Program, a multisensory reading program for children with dyslexia, I had been one of the school personnel she was frustrated with. I felt like I also influenced her during these workshops, because she said that she appreciated that I would just “say it the way it was” when it came to her questions about the efficacy of the after-school tutoring program, referring to the fact that I was being honest. This was because she had been under the impression that Mikayla was required to attend tutoring the end of each school day and
every summer, and had agreed to it for three years without questioning whether it was working for Mikayla. When Melissa met me, she had already experienced several meetings in which school staff would not clearly express what they meant regarding their intention about decisions that needed to be made regarding Mikayla’s progress. School staff would sometimes say one thing but actually mean something else. Furthermore, she felt that the staff could sometimes not be trusted and would withhold information from her. Similarly, in an empirical study with 65 families from both English and Spanish backgrounds who had children both with and without disabilities, researchers found that family members wanted, but didn’t always receive, communication from school staff was be honest. Families in the study explained that they preferred school staff who were open about their children with various special education need, with no hidden information and no “candy-coating” of bad news” (Blue-Banning et al, 2004, p.173).

This appreciation of being frank with one another was something that I also appreciated about Melissa and her attitude as far as accepting life without thinking too much why things happened the way that they did. Melissa and I both shared that we married young and that it took some time to adjust to the expectations and culture of being a military wife. When we talked our shared backgrounds as having been military spouses, she said she was shocked at some of the things she learned about military culture. She had not anticipated saying, “It’s crap… So much gossip and… I’ll just take care of our kids one-on-one. They [other moms] used to call their babies ‘deployment babies.’ Like, ‘this is deployment baby number five!’ I’m like … are you guys serious?” I laughed and nodded my head in understanding. I told her that I had been married to a Marine too, when I was young. Each of us had gotten married right before the time of the Shock and Awe tactic in Iraq back in 2003. I explained that I had too had been surprised
about the military culture. My experience I said, was a combination of good and bad, the way that some of the seasoned Marine wives were extremely supportive and motherly during deployments along with the completely opposite culture of how promiscuous some of the younger wives were, especially as soon as our partners had left for deployments to Iraq.

Melissa frequently used the phrase with me, “We’ll take it” to describe her experience during the process. She said this in reference to the challenges that she had to confront as a single parent, working long hours and raising two children. “We’ll take it” signifies her ways of coming to terms with the situation. It was about coming to terms with things she saw as out of her control. She further explained that sometimes her mother, whom Mikayla called Grandma Grace, would get extremely frustrated with her attitude and tell her, “We need to push for more!” Grandma Grace would push against Melissa’s use of the phrase “We’ll take it.” This outlook frustrated Grandma Grace and instead of agreeing with decisions Melissa made for her children, she challenged her, disagreeing with school recommendations. Acquiescing to suggestions from school staff was something Melissa saw as not settling for less, but rather, accepting situations for what they were. Her outlook may be due to unexpected situations that she had gone through in her past, such as her divorce, being a single mother and most especially, having to advocate after several years to ensure that Mikayla’s education was as rigorous as it should be. Grandma Grace demanded that Melissa require the school and educators to do more for Mikayla. “But there is no more. You know? I can only do so much with what I have.” Melissa felt that “We’ll take it” meant she was there for Mikayla and was willing to advocate for the best services. She also believed that ultimately the advocacy must taper off at some point, to see if the intervention was working. When she told me about the school letting her down in terms of Mikayla’s assessment and interventions, she said all she could do was move ahead and make do with the
situation. She did everything in her power to help her children. “So, I’ll take it! [laughs]” Melissa would say. Her optimism in light of all the challenges she had to overcome to make sense of the dyslexia identification process for Mikayla was enlightening. It also spoke to her resilience that she worked so hard to be the best provider she could be for her children.

I remember meeting Mikayla at the second dyslexia camp I led for caregivers and children during the fall of 2017. Then, Mikayla was timid and experienced anxiety when her mother had to go to the caregiver section of the camp. As I watched Michelle and Mikayla’s interactions from the other side of the room, I noticed that as a fourth grader, she was reluctant to leave her mother’s side. She clung to her. I approached Mikayla and asked if she wanted to get a bagel. Mikayla smiled and nodded and let go of her mother’s hand. Michelle winked and nodded at me, signaling that she was glad she would be able to separate herself for a few hours to learn more about dyslexia and to meet other families with children who had dyslexia characteristics. The dyslexia camp was completely volunteer based, and I was fortunate that my administrative assistant at the time had a son who was majoring in music. He had come to volunteer for a strand of music activities, and I was glad to have this integrated into camp. Music and art tend to be an area of strength for children with dyslexia and this is a subject that is sometimes not available in public schools. Caregivers were walking into the lobby to pick up their children after camp had ended, and he was there, strumming his guitar and taking song requests from the children. Mikayla was enjoying his version of Bruno Mars’ “Just the Way You Are” as she swayed to the music. Melissa walked into the lobby and saw her daughter dancing to the music, surrounded by other children with the same learning difference that she had. I was elated that Melissa saw Mikayla sway and sing along to the tune of the pop music. She was even humming and singing some of the lyrics aloud. I was happy to see this exchange from across the room, since one of
my goals for the camp was to create opportunities for caregivers to view their children having a
good time with other children and adults, in ways not connected to any academic tasks or
judging (in)ability in reading. Instead, I wanted them to see be able to see their children finding
joy in music and art activities alongside other peers with dyslexia. This was an opportunity for
caregivers to also learn more about dyslexia alongside other caregivers who had children with
dyslexia. I used the interpretive phenomenological analysis (IPA) methodology to analyze
Melissa’s story.

Using IPA, the four superordinate themes that were clearly overarching in Melissa’s interview were:

• The identification process after retention;

• High expectations and no progress;

• Options other than public school; and

• Family and learning about dyslexia through the years.

In this chapter, I will describe and analyze Melissa’s experiences with dyslexia identification on
the border in Texas, as they correspond with these four themes.

**Identification Process after Retention**

Melissa explained that her second child, Mikayla, had not had any developmental or
speech delays. Melissa reflected on the experiences that she, Mikayla, and the rest of the family
had gone through in order to get Mikayla identified and into interventions. She noted that “it [the
process of identification] was overwhelming.” While many people are overwhelmed by the
process, Melissa’s experience is unusual in that her daughter was retained in kindergarten, which
is something that rarely happens, in my experience.
Pre-Kindergarten

Melissa enrolled Mikayla in a pre-kindergarten program when she was four years old. In the region, there are several options for caregivers to enroll their child in pre-kindergarten programs, including local school districts, Head Start, and private school programs. In Mikayla’s case, she attended a public pre-kindergarten school in her neighborhood. Laws about compulsory kindergarten vary from state to state, and in Texas, compulsory schooling begins when a child reaches the age of six by September 1 of the relevant school year (TEA, 2017). This means that Mikayla attended school before it was required, as Melissa wanted her to have every advantage to do well in school.

Throughout Mikayla’s year as a pre-kindergartener, Melissa became concerned about her daughter’s progress when she picked her up at school, noting that Mikayla’s drawings were very different than those of her peers. Melissa saw that other students’ work and art was posted on bulletin boards throughout the school, and she was alarmed that Mikayla’s art did not resemble anything that made any sense. She also saw that Mikayla had a very difficult time writing her name in pre-kindergarten, explaining that “it was very chicken scratchy… you couldn’t understand anything other than the M.” Mikayla’s pre-kindergarten teacher, Ms. Sanchez assured Melissa that although her writing and drawings were challenging to understand, every single child developed at a different pace. She urged Melissa not to be concerned.

One of the early signs that a child may have dyslexia characteristics is if they show limited interest in drawing or writing (Motamedi, 2020). The pre-kindergarten that Mikayla attended was located within the local public elementary school, Shady Pines Elementary School. It was also the school Mikayla would be attending for kindergarten through sixth grade, and
Melissa was hopeful that the transition from pre-kindergarten to elementary school would be a smooth one, in part because the building would be familiar to Mikayla.

**Kindergarten: The First Time**

Mikayla moved to kindergarten and had a new teacher, Ms. Rice. Melissa was happy to see that Mikayla was making friends and enjoying school. In the back of her mind, however, she remained concerned that Mikayla’s drawings were very abstract and not at all similar to what her daughter’s classmates were producing. Melissa also noticed that Mikayla was struggling with the weekly spelling tests. She grew even more suspicious that something was not right when she realized how challenging it was for Mikayla to distinguish rhymes. The ability to identify rhymes is part of developing phonological awareness, and not being able to do so is another sign that a child might have dyslexia characteristics. Melissa recalled:

She [Mikayla] couldn’t do it [rhyme]. I had to do it for her. We would say, “What rhymes with cat?” She [Mikayla] would be like, “Umm… dog.” And it was so… her face was like, she didn’t get it, and I felt sad. Like, you don’t get it? [providing rhymes] It’s bat, hat. And she just looked at me like [she was] lost. And I felt bad. I just left it alone.

Although Melissa did not know this at that time, she learned later in one of my parent trainings that difficulties with rhyming at an early age (*Texas Dyslexia Handbook*, 2014) can be an indication that dyslexia characteristics may be present in the child. Although challenges with rhyming and distinguishing patterns in spoken and written language are one of many potential red flags for early childhood teachers to consider that a student may have dyslexia, many early childhood teachers are unaware of this, and ignore the clue. There are a variety of reasons that
children may have trouble with rhyming, including hearing abilities and exposure to the language being taught. Some teachers may perceive that they have sufficient knowledge in the teaching of reading and in identifying different abilities in reading (Cunningham, Perry, Stanovich, Stanovich, & Stanovich, 2004). This may lead them to overestimate their ability to identify students with dyslexia. Another challenge is that for general education and special education early childhood teachers, there is not a great focus on dyslexia identification in their pre-service coursework. This means they must receive training in language and literacy through professional development sessions and experience on the job (Hamre, Partee, & Mulcahy, 2017; Piasta, Park, Farley, Justice, & O’Connell, 2020).

I can relate to the challenges of being unsure of how to distinguish between characteristics of dyslexia and other reading challenges. As a new teacher, I had several experiences of being unsure about identifying students with dyslexia. When I had my first teaching assignment in 2005, I remember a child in my classroom who was on my roster to be provided services based on his special education Individualized Education Program (IEP) for a significant learning difference in reading. I was his fourth-grade teacher, and he had been receiving special education services since kindergarten. Although I was learning what was required of the district for the reading curriculum and benchmarks, I had a challenging time learning how to scaffold the reading program to his particular abilities. My student had a difficult time even writing his first name down on paper. Looking back now, 15 years later, I was one of the members of the ARD committee that supported advocating for him to be retained so that he could develop better reading skills. Regrettably, I did not know at the time that the likelihood that he would make a four-year gain within one year of being retained was unlikely. Even more unfortunate was the fact that I was not informed about the stigma of retention. The other
members of the committee seemed misadvised about it, as well. Being held back put our student in a predicament that he would never be able to recover from, including but not limited to anxiety (Hartke, 1999), stigmatization from peers, limited attendance, and a higher likelihood of dropping out of school before ninth grade (National Association of School Psychologists, 1998; Holmes 1989; Roderick, 1994).

Ms. Rice also shared Melissa’s concern, and began documenting Mikayla’s limited progress in the at-risk student conferences for students not making adequate progress, as measured by district requirements. During these at-risk meetings, Melissa was made aware of the school district’s reading benchmarks for kindergarten students. I had been a teacher and administrator in the school district where Melissa was experiencing the rigid benchmark guidelines for kindergarten. While these guidelines were meant to ensure that all kindergarten and early elementary students are assessed in a uniform way across the district, developmentally, these benchmarks were set at a very high level that even typically developing students would have had a hard time meeting.

*At-risk* is a label that has negative connotations regarding ability, as it is associated with children from ethnic and racial groups who may perform differently than their white, middle class peers on standardized tests. When asked about how the label of at-risk can impact a student negatively, Swadener (2019) states that “implicitly, if not explicitly [the term is], racist, classist and problematic as children and their parents are very much aware that they are seen as at risk for failure” (No More “At Risk” Students in California, para. 6). Furthermore, the term *at-risk* has been discussed as an idea that predominately funnels children of color to be “encoded as at risk” (Whiting, 2006). *At-risk* also is a way to describe and quantify an assumption that some children will experience low achievement and will need assistance to prevent failure (Franklin
This term can be linked back to 1983, when the U.S. government released *A Nation at Risk: The Imperative for Educational Reform* (National Commission on Excellence in Education 1983, April), which claimed that Americans needed to be made aware of the inability for the United States to compete with other nations, due to unprepared teachers and inconsistent academic curriculum and standards. School reform over the next decades has been informed by the rhetoric within this report to include standardization of curriculum and assessments as well as the standardization of teacher certification.

Many districts in the United States use a formative reading assessment program called the Developmental Reading Assessment (DRA). In this district, kindergarteners are expected to enter kindergarten at level A (0) and per this district’s guidelines, they should make a ten-level gain before moving on to the next grade level. A kindergartener in this district would be expected to reach level 10 (1 meaning the grade level and 0 representing the month – a 10 represents a student who is performing at the first-grade level, zero month, increasing in the amount of two step increments. For example, a level 12 would represent a child who is in first grade in the second month, the one represents the grade level (first grade) and the 2 represents the month of the school year. Another example is level 38, which would mean third grade, eighth month. Some schools in the district raised these benchmarks to be even higher. For example, the campus where I was a fourth grade teacher had an end-of-kindergarten expectation of 16. Meaning first grade, sixth month in order to make adequate progress to be promoted from kindergarten. The reading program is controversial, in that it requires training that some teachers do not ever receive, so without being trained on how to use the program with accuracy, the program and the assessment and can be subjective and ineffective.
Melissa was notified in the middle of the school year that Mikayla was still performing at the level of a reader who had just entered kindergarten, which meant she still had minimal skills at a level 2. A Level 2 text would have predictable sentence patterns, predictable words, pictures and familiar objects, high frequency words, and plenty of space on the page between words, lines, and pictures. In the first at-risk conference in January, Melissa asked Ms. Rice if it was possible for Mikayla to have some sort of assessment in reading to see what her strengths and weaknesses were. Ms. Rice told Melissa it was too early and that they should try tutoring first. Although Melissa was reluctant to begin tutoring for Mikayla only about five months into kindergarten, she agreed to it, in hopes that Mikayla would show progress. When Melissa went home after that meeting, she told her Aunt Norma and her mother (Mikayla’s Grandma Grace), that she had agreed to tutoring. Aunt Norma thought that tutoring at such an early stage was unnecessary, and Grandma Grace was indifferent about it. However, Melissa agreed with Ms. Rice’s recommendation, and was hopeful that tutoring would be effective.

*At-Risk Meetings.* The next two parent conferences were also labeled as *at-risk,* and Melissa had to sign a form indicating that she was aware that her child was not making adequate progress. Each time, Ms. Rice would reiterate that “there was no growth. There’s really no growth at all. She [Mikayla] is not progressing, even with tutoring.” Grandma Grace and Aunt Norma were concerned that Mikayla was showing minimal progress, but told Melissa to be patient, since many children develop at different rates. However, at the final *at-risk* conference in May of Mikayla’s kindergarten year, Melissa asked again that Ms. Rice test Mikayla. Melissa felt that her daughter still had not seen any progress, and she wanted her to be tested to see exactly what areas of reading she was struggling with. As Melissa walked into Ms. Rice’s classroom to attend the at-risk conference, Melissa noticed that the campus principal, Ms. Allen
was sitting next to Ms. Rice. Melissa viewed Ms. Allen as an assertive middle-aged Black woman who held several distinguished recognitions as an elementary principal at the district-wide, state and national level. Ms. Allen was very visible at the campus, frequently out of her office and greeting families outside every morning, both in the lunch room, and after school every day. Although Melissa had not had to directly worked with Ms. Allen before, she knew exactly who she was.

This was a shift. Melissa had become very familiar with these at-risk conferences and Principal Allen had never attended one before. Melissa was concerned and confused about what would happen at this meeting, as she had not been forewarned. Ms. Rice explained that she had been transparent in describing Mikayla’s minimal progress during the school year and since she still was not progressing, the campus administrator needed attend the meeting to discuss what happens when a child at Shady Pines had not made adequate annual progress based on the district guidelines for the entire kindergarten year. Ms. Allen informed Melissa that a decision had been made to retain Mikayla in kindergarten, because of her lack of progress in reading. Melissa shared with me that she automatically thought, “Who retains in kinder? She was so little! Not kinder… maybe first grade, but not kinder…” Melissa asked Ms. Allen and Ms. Rice if it was possible to see if Mikayla had a reading disability like dyslexia. The educators responded by saying that it was too early to test and that anyway, “she [Mikayla] couldn’t be tested until she’s seven.”

The misconception that young learners cannot be identified until around their seventh birthday was created in this large school district by the standardization of policy around assessment. This misconception is refuted in the version of the *Texas Dyslexia Handbook* (2014) that was in place during Mikayla’s identification process and clarifies that a “school district
[should] not delay identification and intervention processes until second or third grade for students suspected of having dyslexia” (p. 13). To keep an abundance of assessment requests low in Kindergarten, this unwritten policy was something that I was aware of as a former teacher and administrator in this district. When I moved to the regional education center, I created the Dyslexia Collaborative, where all lead dyslexia coordinators from each school district and charter school were invited to come and discuss challenges related to dyslexia identification. One of our tasks was to debunk the myth that identification could not begin until the age of seven.

Although there is still much work to be done to educate teachers about the characteristics of dyslexia early during pre-kindergarten and kindergarten, the corrective action plan (United States Department of Education, Office of Special Education Programs, 2018) that came from the United States Department of Education, Office of Special Education Programs (OSEP) is intended to resolve this issue. Texas was found to have too many dyslexia denials when parents requested testing, and this spurred an overhaul of the identification process for dyslexia in Texas in 2018. At the time of this writing, school districts were required for the first time to use district-wide checkpoints/benchmarks at the beginning of the year, middle of the year and end of the year in kindergarten to ensure that if any results indicated the hallmark characteristics of dyslexia, a child automatically would be monitored in the data management system and provided identification and interventions, early on.

While Melissa was unsure about retaining Mikayla in kindergarten again, she consented. She did worry about the effect of being retained on Mikayla’s self-esteem, but she thought that since Mikayla was so far behind, it would be best to put her trust in the school system and accept the retention. Melissa also said that the meeting was tense. She thought it was implied that the principal’s decision was final, so she was not sure it would have made a difference if she had
declined the retention. After sharing the results of the meeting with Grandma Grace and Aunt Norma, Aunt Norma, said “You made the wrong decision on this one. I’m telling you…Retained in kinder? Melissa…We don’t retain [kid]s in kinder!” Although Aunt Norma did not agree with her decision, Melissa felt that she had done the right thing for Mikayla. She mentioned to Mikayla’s pediatrician that the school wanted to retain her, and this is common. When caregivers feel that they cannot trust the school to make decisions in their child’s best interest, the next trusted professional may be the pediatrician. Physicians approach disability using the medical model, seeing it as something that needs to be cured or fixed. Similarly, some schools as well as the United States Department of Education send confusing messages to parents, and view any ability differences as something that needs to be fixed or remediated.

Dyslexia, however, is an example of a learning difference that does not have specific remediation that is aligned with the medical model of disability. Dyslexia can be identified using medical tools that identify brain images, gathered through functional magnetic resonance imaging (fMRI). In the medical model, disability is seen as abnormal and something that must be corrected via medical intervention (McCord, 1983), and the impairment is seen as something that must be overcome (Oliver, 1996). In my experience, there are not any pediatricians in the borderland area who assess children with fMRI technology. Furthermore, if there did happen to be pediatricians who used this identification process, unfortunately, caregivers would learn that school districts are not required to honor the diagnostic assessments performed by a medical professional. Rather, school personnel are only asked to consider information provided from assessments that a pediatrician does. This is because the main focus of the ARD committee and school personnel should be on how the impairment affects the child’s ability to participate in school related tasks. While some pediatricians provide a medical diagnosis using extensive
questionnaires and along with fMRI (Karipidis & Hong, 2020; Sanfilippo, Ness, Petscher, Rappaport, Zuckerman, Gaab, 2020), Mikayla’s pediatrician did not conduct any medical assessments. The pediatrician did reassure Melissa that she had made the right decision saying, “Oh, it’s better that they [the school] caught it now than later.” Melissa felt that the pediatrician’s response validated the school’s decision and she was hopeful that another year in kindergarten would provide the assistance Mikayla needed to find success with reading and writing.

**Kindergarten: The Second Time**

During the summer after deciding to retain Mikayla, Melissa wanted to prepare her to be successful in returning to the same grade her friends had already completed. Melissa knew that Mikayla was likely to see some of her former classmates in the hallway and on the playground, and she would have to confront their questions about why she was not in the next grade with them. Worried that her self-esteem would suffer, Melissa took time to have discussions centered around why Mikayla was retained. Melissa explained “Look, you know what? Your levels weren’t as high as they were supposed to be. You need to do it one more time. One more time, dude. You’ll be fine!” Melissa said that preparing to talk to Mikayla about the retention was something that was “very hard for me, you know.” Melissa had to stay positive and reassure Mikayla that being in the same grade again would not be detrimental, and that she just needed a little more help. A positive point in being retained was that her previous teacher, Ms. Sanchez, had moved up from pre-kindergarten to kindergarten and would be her kindergarten teacher. The familiarity of a teacher Mikayla had found success with in the past was something that was comforting for Melissa as well, since she was unsure that the second year in kindergarten would provide the growth that she was hoping for and that the school staff expected.
Ms. Sanchez said that Mikayla began her second year in kindergarten at a Level 4, which would be a little ahead for a child who had entered kindergarten for the first time, but this was Mikayla’s second time in kindergarten. Fortunately, Mikayla made progress in her second year in kindergarten. She progressed more quickly than she had the first time around. Though she was still behind many of her peers at the end of the school year, Mikayla was at a Level 8, which is indicative of what the assessment should be near the end of kindergarten for children who have only been in kindergarten once. However, this was Mikayla’s second time in the same grade level. As someone who has administered the DRA assessments as a general and special education teacher and an administrator, a level 8 after two years of instruction is definitely cause for concern. This meant that after 20 months of instruction, Mikayla went from a level 0 to a level 8. For a typically developing child, after 20 months of instruction, a DRA level of at least 20 would be expected. That the school did not initiate any formal intervention plan under Response to Intervention (RTI) or initiate any formal assessment under special education is alarming to me. Although she was still below the district benchmark, Melissa was glad to see progress and that Mikayla was only technically one level behind the targeted Level of 10 by the end of kindergarten. DRA levels are in increments of two; meaning that Mikayla was at a level 8 and the next level in this reading assessment is level 10.

As Mikayla’s primary caregiver, Melissa felt obligated to provide consistent and dependable support for her daughter. She viewed Mikayla’s retention as a direct reflection of failing to meet this goal. Melissa felt guilty that she was not able to help Mikayla be successful and that she agreed to retain her. Melissa had been apprehensive about retaining Mikayla, but when the principal recommended it at the last at-risk meeting, she trusted the administrator and teachers’ professional opinions. In hind sight, the recommendation to retain Mikayla did not
work. After ten months of repeating the same grade level curriculum again in kindergarten a second time, Mikayla still had not made the tremendous gains that the principal and teacher had implied would happen. As Melissa reflected on having agreed to retain Mikayla during our interview, several years later, she described being retained as “just awful.” Given the way Mikayla has continued to struggle, I wonder if Melissa felt guilty that she agreed to retain Mikayla. The principal and the faculty put Melissa in a position in which she felt she didn’t have a choice. She felt that making Mikayla repeat kindergarten would have long-lasting effects on Mikayla’s perception of her ability in school environments.

One of the myths of dyslexia is that retaining students who may have dyslexia characteristics will improve their academic abilities. Retention is not advised for children with dyslexia, since they “do not need another year of the same instruction- [rather] they need differentiated intervention that is research-based, systematic, and explicit” (Myth Number 31, University of Michigan, 2020). The fact that Melissa felt that this process was awful can be attributed in part to her family members’ disagreeing with retaining Mikayla. Melissa held her family in high regard, and this conflict meant increased stress and anxiety for her as a single parent, hoping to make the right decision for her child. The literature demonstrates that grade level retention happens most commonly among children who come from single-parent households (Hartke, 1999; National Association of School Psychologists, 1998). Melissa worried about whether the retention would actually result in significant improvement that Mikayla would not struggle to read in future grades. In reality, the literature suggests that only temporary gains are made upon retention, and that students’ achievement gains decline in subsequent years (Denton, 2001; Gottfried, 2013; Hennick, 2008; Hughes, Chen, Thoemmes & Kwok, 2010; Jimerson & Renshaw, 2013; Silberglitt, Jimerson, Burns, & Appleton, 2006).
First Grade

Mikayla’s first grade year felt like a repeat of the first time she was in kindergarten, according to Melissa. Melissa mentioned that Mikayla’s first-grade teacher, Ms. Ash, had been “teaching for like 100 years,” implying that her teaching was old fashioned and outdated. Melissa was unimpressed with Ms. Ash’s ability to work with Mikayla in reading. She felt this way because any time she would mention that she was concerned about Mikayla’s minimal progress, Ms. Ash would say, “Don’t worry… she’ll be fine!” It seemed that every time Melissa expressed concern about Mikayla’s progress, Ms. Ash would abruptly change the conversation and tell her that she was worrying too much. But in fact, Mikayla showed minimal progress in reading, and by the time the spring semester neared, Melissa feared that her daughter was in danger of being retained for a second time. At a parent-teacher conference in the middle of the spring semester, Melissa requested that Mikayla finally be assessed to find out why she was having so many challenges with reading. Since Mikayla was going to be turning seven during the spring semester, Melissa made sure to use the information that Principal Allen had previously used to convince her to retain Mikayla for the first time in kindergarten. At that time, Melissa had requested a dyslexia screening assessment, but the principal had said that it could not be done until Mikayla was seven years old. This time, since Mikayla was almost seven and was still having challenges in reading, the testing was granted. It was completed during the final six weeks of Mikayla’s first grade year, and while Melissa was glad the assessment was going on, she was frustrated that the school waited so long to do it. Melissa knew that if her daughter she did qualify, she would not begin services until the following school year – second grade.
The assessment was done quickly and Melissa was relieved to hear that Mikayla did qualify for dyslexia intervention services. At the 504 meeting held the last few weeks of school, Melissa was told that Mikayla would start services as soon as the school year started in August. The 504 committee recommended that Mikayla attend summer school to work on her reading skills. Melissa agreed to the summer school learning opportunity saying, “you never can learn enough.” Although they had to cancel their summer vacation, Melissa expected that Mikayla would be able to make some growth in reading before her second-grade school year began.
Figure 5.1. Melissa’s Experience with Advocating for Mikayla to be Assessed for Dyslexia
High Expectations…And No Progress in Public School

Melissa said there was nothing but high expectations as soon as the first day of second grade began. While Mikayla did start receiving services for dyslexia, they did not begin until a month into the school year, in the middle of September. Mikayla seemed to be adjusting well to the two new teachers she was working with each day. One was Ms. Castañeda, who was her second-grade general education teacher and who was responsible for teaching all of her core subjects. The other was Ms. Sainz, her dyslexia teacher.

Dyslexia Intervention Class

Although Melissa was glad that Mikayla would be finally receiving the dyslexia intervention services, she was concerned that this intervention was not going to occur within Mikayla’s regular school day with Ms. Castañeda and Mikayla’s peers. Instead, Mikayla would have to leave and go to a separate class for 45 minutes, four times per week, working with Ms. Sainz to receive the specialized instruction. Most unsettling to Melissa was her perception that Mikayla would have to navigate and justify her peer’s questions as to why she was the only one who left their class every day. Melissa imagined that Mikayla would be shunned and bullied by her peers, and she did not want that to happen. She had a gut feeling that this schedule would impact Mikayla’s self-esteem negatively. Melissa was relieved when Mikayla came home after her first intervention session and said that four other children also left the class when she did. To Melissa’s surprise, this meant that Mikayla was not the only student who was being removed from the classroom to work with a specialist.
When Melissa received a call from Ms. Sainz after providing about four weeks of intervention for dyslexia, she was eager to hear about her daughter’s progress in this specialized class. Instead, Melissa was appalled to hear that Ms. Sainz was calling to request that more testing be conducted and that Mikayla needed more intervention than she had anticipated. To complicate the situation even more, Ms. Castañeda was noticing that Mikayla was starting to have a difficult time keeping up with the rest of the class after returning from her intervention sessions with Ms. Sainz. Melissa said that when Ms. Castañeda called, she thought, “Wait, pump the breaks!” Melissa meant that the school personnel needed to slow down and give Mikayla more than four-weeks time to learn the dyslexia-specific strategies before undergoing more assessment. This was especially the case, given that she had only been receiving intervention with the specialist for a few weeks. Melissa also mentioned that during this time she felt that “there should not be different teachers… she shouldn’t really be pulled out [of her general education class].” She was concerned that the new schedule, new teacher, and new interventions meant too many changes at once.

**In-School Tutoring**

Mikayla had attended tutoring each year, from the beginning to the end of the school year, in kindergarten (the first time and the second time), as well as throughout first- and second-grade. She was also in summer school every year, to work on basic reading skills. Still, there was little growth. Michelle was frustrated that Mikayla seldom made gains in the required tutoring sessions. Missing out on countless after-school activities, family functions, and vacations had become Mikayla’s life. Melissa lamented that Mikayla was “going to tutoring all of the time.” She felt for Mikayla saying, “I was like…*pobrecita*[poor girl]. You know?” The traditional interventions for reading were not working for Mikayla, and Melissa was becoming
increasingly concerned. She worried that her daughter was becoming exhausted from so much tutoring and so little progress.

**After School Tutoring**

For as long as Melissa could remember, Mikayla had attended after-school tutoring in reading, offered by her general education teachers. Melissa felt that she was being supportive of her daughter and had placed all of her trust in Mikayla’s public school teachers, assuming they were providing tutoring that was aligned to Mikayla’s specific needs as related to dyslexia. Between the pre-kindergarten and first grade years, Melissa knew that the tutoring was not tailored to the needs of a learner with dyslexia, since Mikayla did not get formally assessed until the end of first grade. However, once she was identified and her teachers in second, third and fourth grade knew that Mikayla had dyslexia characteristics, Melissa expected that her daughter would get the services she needed integrated into the school day. Melissa said once Mikayla was receiving intervention for dyslexia, she did not regularly receive updates on Mikayla’s progress toward mastering grade-level reading curriculum as she had in the past before she was identified. While she did receive the general report card that all students receive, she felt that something was missing and that she did not know exactly how Mikayla was progressing anymore. The phenomenon of caregivers not knowing about their child’s progress once they are in a dedicated program or such as 504 or special education is one that has been documented by the literature. For example, the International Dyslexia Association (IDA) (2020) states that caregivers “may become disillusioned with their child’s school or teachers when progress is slow or the recommended interventions prove unsuccessful. These feelings of confusion or frustration are common” (paragraph one). During the time that Mikayla was identified with dyslexia, the version that would have been followed for dyslexia procedures was the 2014 edition. That
version of the handbook does not state the frequency which families should be notified of progress in a dyslexia intervention program. However, after checking the updated edition of the Texas Dyslexia Handbook (2018), there is still no mention of the recommended frequency of notifying caregivers of their child’s progress. Since Mikayla was receiving special education services and had an IEP, that would lead me to think that she should have been notified at the same frequency as her peers were, during grade reporting periods. The challenge with this, however, is that the dyslexia interventionist was someone that Melissa referred to as the “504 teacher.” That is, Mikayla was receiving dyslexia interventions through 504 funding, and not through the special education faculty. The law required then, that Melissa only be notified of Mikayla’s progress on goals that were identified by the special education teacher for purposes of the IEP, and the dyslexia intervention services were not a part of the services that he special education teacher was providing.

To put this into context, I remember back when I was a dyslexia and special education teacher in the same district Melissa was referring to, I eventually realized the same problem. I saw the same lack of required parental communication about student progress in the dyslexia program. After providing a few semesters of dyslexia intervention, some parents whose children were on my caseload for special education and those parents whose children I had for 504 were asking me about progress. I realized that there was not a system in place that required me to communicate about a child’s progress with the Wilson Reading Program. Soon thereafter, I purposefully made copies of their child’s progress and sent home notifications of this progress via progress monitoring charts embedded in the Wilson Program, so that families had an idea of what progress their child had made for the grading term. Because of this, when I had my parent-training sessions several years later as a regional project manager, I would share information
about the progress-monitoring system, and what parents could ask the dyslexia interventionist to show them regarding their child’s progress. I can see how Melissa was frustrated that the campus dyslexia interventionist was not sending home notifications of Mikayla’s progress. Since Mikayla was already in special education, her progress was not being aligned to the required notification of student progress required by special education law regarding her progress with the dyslexia program. Mikayla’s other providers who were serving her, such as her general education teacher, special education teacher, and dyslexia interventionist should all have been working together to understand Mikayla’s progress and to share that with Melissa.

Additionally, Melissa assumed that all of the after-school tutoring was aligned to what Ms. Sainz was doing in the dyslexia intervention class. After speaking with each of Mikayla’s teachers, Melissa found that the reading programs that happen during the school day are not aligned to what Mikayla is doing in her dyslexia reading class with Ms. Sainz. It was at that time, when Mikayla was in second grade, that Melissa realized the two programs were not connected, and she decided to remove her daughter from after-school tutoring provided by the general-education teachers at Shady Pines.

After considering her experiences with literacy instruction up to this point, it seemed that Melissa saw that the school was using a model aligned with the autonomous model of literacy with Mikayla. Although the school staff had been providing instruction to Mikayla for years both during the school day and afterschool, Mikayla was not improving. Melissa had voiced her concern about Mikayla’s challenges with writing her name and other words, as well as with rhyming and decoding texts. Even though she had been clear about her concerns, the school staff was unable to align the autonomous model of reading instruction within their school to a model which was more similar to the idea of construction of meaning in literacy practices, so that
Mikayla could relate to the purpose of literacy by using tools that supported her impairment (Hall, 1998; Stewart, 2011; Street, 2006). Mikayla had to go to school every single day and attempt to learn in an environment that did not provide adjustments for her invisible and undiagnosed learning difference of dyslexia.

**Summer School**

Between Mikayla’s kindergarten years all the way until her second-grade year, Melissa supported each teacher’s request to place Mikayla into intensive remedial support that reintroduced and taught concepts form the previous school year during summer school. Although Melissa felt that there was too much intervention without enough progress, she wanted to show the school that she was a supportive parent. While Melissa was appreciative of the efforts of each general education teacher, she grew concerned that Mikayla was constantly bombarded with endless interventions during the school day, after-school, and throughout the summer. Melissa tried to find fun opportunities so that Mikayla would be able to relax during the summer, given that she had missed out on so much. Melissa wanted Mikayla to be able to play and be a child. She wanted her to draw, color, play outside, watch TV, and play around on YouTube. Melissa felt that Mikayla was missing out on opportunities to just be a child and have fun, because of all the tutoring. Ultimately, Melissa declined after-school reading tutoring after Mikayla’s second-grade school year. She told the faculty and staff at an ARD meeting that:

I didn’t wanna do the whole tutoring stuff. If it is not geared toward dyslexia and only reading tutoring. No! I got brave with that one. I said no. We’re not doing it. I just saw like, she was not making progress.

When I asked her how the staff at the meeting responded, she said they did not argue and they let her make that decision.
Options Outside of Public Schooling

Melissa’s Aunt Norma was adamant about finding outside options for Mikayla, such as private tutors and private schools. Aunt Norma knew that there had to be specialized instruction from an expert in dyslexia interventions available in the community. I remembered meeting her at one of the parent-training sessions, and I knew that other caregivers were searching for independent tutors, as well. One attendee shared with Aunt Norma that she needed to be careful when calling the ‘so-called’ teachers specializing in multisensory techniques, because she had sent her child to one who charged $100 per hour, with no progress in 20 of tutoring. Melissa had been clear with me that she did not want to seek private options. What she really wanted was to place all confidence in the public-school educators, rather than struggling to pay for private tutors. However, Aunt Norma did agree with Melissa’s approach. After searching online and calling all the private tutors, tutoring centers, and charter schools she could find, Aunt Norma convinced Melissa to explore a number of private options to support Mikayla. They pursued these until just after Mikayla was identified as having dyslexic characteristics.

Seeking Family-Funded Interventions

General Tutoring Center: Sylvan. When Mikayla was retained in kindergarten a second time, her mom’s Aunt Norma suggested enrolling Mikayla in a reading program at Sylvan Learning Centers. Sylvan Learning Centers state that their method guarantees that “students in our centers see up to three times more growth in their math and reading scores that their peers” (Sylvan Learning, 2020, para, Our Centers Offer a Highly Personalized Approach to In-Person and Online Tutoring). Melissa agreed to this, hoping the interventions would lead to consistent gains in reading before first grade.
Sylvan Learning Centers also advertise that when a family places their child in their intervention program, the child will receive individualized tutoring not only school but all areas of life, with a plan that adapts to their individual level. The individualized programs guarantee that children will make progress in academic areas, as well as in social and emotional development. Melissa shared that Mikayla “made one year’s growth at that place [Sylvan], saying, “Yeah she did make progress because when they tested her it was preschool and she bumped up to a first grade.” However, Melissa stated that a discouraging element of the after-school learning center was that all of the instruction was on an electronic tablet. While Melissa saw that Mikayla was able to read with more fluency and was building confidence in decoding with less frustration, she decided to take Mikayla out of the program. Even though Aunt Norma had recommended Sylvan and was paying for it, Melissa wanted Mikayla to work with an actual human being. Melissa shared that it was important to her that Mikayla have human interaction to follow up to make sure she was using the skills she was learning on her own, providing scaffolding and guidance in real-time. She saw using an app as a less-than-legitimate intervention, even though Sylvan Learning Centers assert that the instruction that is provided is a delicate balance between individualized instruction and independent practice. Melissa had assumed that this balance was going to be more focused on the tutor and Mikayla working together. Instead, it consisted of Mikayla practicing skills on a tablet for most of the tutoring sessions.

**Private Tutors.** During the time that Mikayla was retained in kindergarten all the way through second grade, Aunt Norma called around to see what new private services were being offered by dyslexia specialists. Although Melissa had previously agreed that Mikayla receive after-school tutoring instruction at Sylvan for about one year, she started to feel that Mikayla was
getting too many interventions in the form of after-school tutoring and summer school. Melissa wanted to return to the public school, Shady Pines Elementary, in hopes they could provide the additional instruction Mikayla needed. While Mikayla had made progress in her second year in kindergarten, Melissa noted that it was hard to know why. Was it because Mikayla was more mature? Was it because it was her second time hearing the instruction? Or was it because of the interventions from the Sylvan Learning Center? In spite of what Melissa wanted, Aunt Norma continued to research private options, and after several calls to local tutors who said they really did not specialize in dyslexia, Aunt Norma came across a dyslexia-focused charter school.

**Charter School.** Aunt Norma called the charter school and learned about their specialists who were trained to focus on dyslexia interventions and social/emotional support. She asked Melissa if she would be willing to go on a tour of the school, and Melissa thought for a few moments and decided that she would agree to an in-person tour. Excited that she might be able to find support that would help her grand-niece, Aunt Norma eagerly called the charter school back and scheduled an appointment. Although unsure about what to expect, Melissa said that as soon as she and Aunt Norma stepped into the front lobby of the school, she had a bad feeling about the school. As she looked around the main lobby, the lights were dim and everything was silent. Melissa was taken back to memories of her high school years, when she volunteered to work with children with severe disabilities at lunch time. She said, “I didn’t want that for Mikayla [separation from her peers].” As the two of them were guided through the charter-school campus, Melissa felt that if she sent Mikayla there her self-esteem would be severely diminished. She could almost hear Mikayla saying, “No, mom! Why do I gotta come here?” Hearing that the successes of past alumni and current students were due to the philosophy and format of the campus did not convince Melissa. She wondered about where all the students were,
questioning how the campus could be so silent and gloomy. Their tour happened on a school day, and yet there were no signs of children playing, talking, or learning in an interactive and vibrant environment. The school was dark, in part because they had creative schedules and some kids were in other parts of the building learning and doing hands-on projects, while others already gone home for the day. As the tour neared an end, the principal welcomed Melissa and Aunt Norma into the main office for a final interview and to clarify any questions they might have.

The administrator began the discussion by asking what Melissa did for a living and how she was going to fund Mikayla’s education there. After hearing that tuition was $12,000 per year, Melissa explained that she worked as a stocker at a local store, saying, “I’m not gonna pay for this.” Even though her Aunt Norma had graciously offered to pay for the tuition, she declined the help, due to the unappealing ambience and what she saw as a stoic and child unfriendly environment.

**The Never-Ending Search for Private Tutoring**

Aunt Norma accepted Melissa’s decision to not enroll Mikayla in the dyslexia charter school, and she told Melissa that she would help her, and that she had to “just say the word.” Melissa said that to this day, four years later, they still call around once in a while when they hear of a new program or tutoring system that could help students with dyslexia characteristics.

**Family**

Melissa recalled that before, during, and after the identification process, she generally found solace and support and relied heavily on her family to help navigate, understand, and cope with the years-long process of finding reading instruction for Mikayla. When confronted with the occasional naysayers, such as her sister Becky, Melissa said she found support from other family members, friends, some professionals at the school and in support groups.
Supporters

As I analyzed Melissa’s experience with the phenomenon of dyslexia identification in a public school setting, I recalled that she had told me about several family members and friends who were supportive before, during, and after Mikayla’s dyslexia identification. Aunt Norma was a key supporter that Melissa trusted and respected. Not only had Aunt Norma been formally trained as a teacher, she also was willing and able to support Mikayla monetarily for extra reading interventions. Aunt Norma had paid for the Sylvan intervention which ended up being about $2,500. Grandma Grace and Aunt Norma were both supportive of Melissa and provided a unified support system as Melissa navigated school meetings and sought to learn more about how to help Mikayla find success at home and at school.

Tough Love

Melissa wanted to make it clear at school that she wanted Mikayla being held to the same standards as other students in her class. She talked about having to hold all members of the ARD committee accountable, along with other teachers Mikayla had had over the years. She wanted to make sure they were not lowering their expectations, noting that sometimes at ARD meetings she saw “them thinking of Mikayla like she’s just this little puppy, and she can’t help herself.” Melissa said that she would tell them, “No! You guys got to push her. At home? No! I’m not like…. ‘Aw, you are dyslexic.’ We don’t even say that.” Melissa was adamant about the school following a similar child guidance approach that they implemented in their home, which required Mikayla to be held responsible for the tasks she was presented with, whether they were household chores or completing homework.

Additionally, Melissa said she was surprised the faculty and staff, all of whom worked in the Latinx community, did not use the child-rearing philosophy, including behavior redirection,
employed in her household. Melissa said she told the staff that in their family they would say, “You don’t get it [a new concept or task]? Figure it out. It’s just you know, being Hispanic. We don’t say, ‘Aww…’ We push her!”

**The Nay-Sayers**

Melissa’s sister, Becky, had been a trusted and relative since the two were young children. Becky had moved to Arizona, and in the past few years, the sisters still talked when they could. Upon receiving Mikayla’s dyslexia identification, Melissa called her sister Becky for advice, assuming she would support her, as Becky’s son Carlos is deaf. Instead, Becky said, “Oh …maybe you shouldn’t tell people she’s dyslexic. You know you really shouldn’t, you know, you shouldn’t tell too many people [about Mikayla’s reading difference].” Surprised by her sister’s reaction, Melissa said it was “totally different [than what she had expected]. I don’t know why [she told me to keep it a secret]. And I didn’t ask her, ‘cause her reaction upset me.” Melissa said that when Becky came home a few months ago, she decided not to engage with her on the topic of different abilities. Melissa said Becky did not accept her son’s diagnosis for a long time, and when she finally did accept that he needed to be taught in a different way, she decided that she would allow him to attend the School for the Deaf.

Separate schools for deaf students are located throughout the United States, and they are dedicated to teaching American Sign Language (ASL), academic content, how to navigate public schooling, Deaf culture, and they provide a space for them to socialize with their deaf peers (Gallaudet University, 2020). Becky repeatedly said that Mikayla “would be fine.” Melissa was tired of hearing educators say that to her, and now her sister was using the same response that she saw as indifferent and calloused. Melissa thought this was because dyslexia cannot be seen physically, and as a result, people think that dyslexia should be managed without help.
Although she is not a blood relative, Irma, Melissa’s father’s girlfriend also has dyslexia. When Melissa talked about people who were reluctant to accept that Mikayla needed extra support in school and at home, she remembered that Irma was also indifferent about Mikayla having dyslexia. Melissa recounted that Irma said, “she’s dyslexic and she was in school a long time ago and didn’t get help and made it without that kind of stuff [multisensory based interventions], saying ‘Oh, I’m fine.’” Melissa said that although she knew Mikayla would grow up and be fine eventually, she also wanted her to get support for her learning difference.

It seems that Melissa was thinking about Mikayla’s learning difference in a way that would require the school environment be supportive of her, and that belief is aligned with what critical disability theorists challenge us to consider. They argue for “empowerment, agency, and social change” (Woodcock, 2020, p. 1639). They state that it is the social environment that forces people with different impairments to either eliminate or equalize their differences. “Inclusion and participation are essential to human dignity and to bringing about a genuine equalization of opportunities” (De Schauwer & Davies, 2016, p. 84).

People with dyslexia need to learn to interact with the literacy opportunities around them through a variety of media. For example, Michelle explained that Mikayla enjoys listening to books on apps like Audible, which allow her to interact easily with texts, both for school and for pleasure. She also likes to play with elements such as font size, and the speed and pitch of the person reading. Sometimes there are embedded videos that add an extra element to help her understand the text she is listening to. This example is just one way that young learners with dyslexia access and interact with texts, through a CDT perspective.

Learning About Dyslexia through the Years

The final superordinate theme was regarding all of the ways that Melissa learned about
dyslexia throughout the years. Melissa told me she felt she needed to learn as much as possible about the characteristics of dyslexia in order to help Mikayla find success in school and at home. Melissa said at the start of our first interview, “I just love life, and being a mom – and trying to raise these kids to the best of my ability.” The literature about families with children who have developmental differences has looked at perceptions of difference through cultural lenses (Harry, 1992; Harry, Rueda & Kalyanpur, 1999). Although dyslexia is not a developmental difference, I see a similarity in Melissa’s outlook toward parenting that is similar to caregivers of children with developmental disabilities. Mary (1990) found that Hispanic mothers were more likely to embrace a perspective of self-sacrifice toward their young children with intellectual disabilities than were White mothers. African American, and to an even greater extent, Hispanic mothers, were more apt to view the challenges of raising a child with disabilities as a blessing that had been sent as a gift from God (Bailey, Skinner, Rodriguez, Gut, and Correa, 1999; Skinner, Correa, Skinner, and Bailey, 2001; Harry, 1992). “She’ll be fine” was a phrase used by several people in Melissa’s life, including Ms. Ash, Becky, her stepmother, and the principal. Melissa said she knew Mikayla would be fine, but she grew frustrated that so many people urged her not to worry about Mikayla’s progress in reading and later in math. As Mikayla’s primary caregiver, she felt that the only way she could support Mikayla was to learn more about the learning difference of dyslexia herself, especially because it seemed that the school staff knew little about it.

**General Characteristics of Dyslexia**

As Melissa has learned more about what components should be in a dyslexia intervention program, she said that she felt it was her duty as Mikayla’s advocate to share information with her daughter’s teachers. Ms. Sanchez, for example, had been eager to receive any new materials
that Michelle could share, and she wanted to learn more about dyslexia. Melissa saw her as someone who was disposed to learning more about dyslexia, especially since she was a new teacher. Melissa said that learning more about the general characteristics of dyslexia was not something she did online. This was because there much of the information on the internet revolved around what Melissa called “the misconception of everybody thinking that its backward letters… It’s not. You know? It’s a combination of like, how you guys do the whole short-term and long-term. [It’s the] parts of their brains that they use.” When Melissa said you guys she was referring to the caregiver dyslexia classes that she would attend at the local BRC with her aunt and mother.

**Co-Morbidities**

Melissa is very passionate about learning everything she can about dyslexia. This is mostly because she wants to “be prepared for whatever comes next” with Mikayla’s education and social emotional growth. This is also because she has learned that not all children and adults with dyslexia have the same characteristics; nor do they have the same comorbidities.

Comorbidity refers to the association, overlap or relationship between different conditions. For purposes of this section, Melissa was referring to the comorbidity between ADHD and reading differences (Beitchman & Young, 1997). Although there is empirical literature suggesting an association between children with speech/language differences (e.g., articulation, expressive oral language, and receptive oral language) and Attention Deficit-Hyperactivity Disorder (Cantwell & Baker, 1991; Halperin, Gittelman, Klein, Rudel, 1984; Sahoo, Biswas, Padhy, 2015), at the time, Melissa was unaware that there is an established correlation between dyslexia and ADHD. She explained that when Mikayla was in the third grade, she finally agreed to allowing the school to do more testing. It was during Mikayla’s third-
grade year that Melissa learned that Mikayla also has characteristics and needed accommodations for ADHD, as well as for dyscalculia and dysgraphia. She learned that dyscalculia is a learning difference that impacts one’s ability to learn number-related concepts including mathematics, computation, and reasoning.

Melissa has become increasingly frustrated that the school district does not have any specialists trained in this dyscalculia. She asked the school to write dyscalculia on her daughter’s ARD paperwork, but the school diagnostician said that she would not, writing instead that Mikayla has a specific math disability. When she advocated for the ARD committee to specify dyscalculia, the diagnostician and the principal both said, “We don’t have that in our district.”

Melissa also learned that Mikayla has dysgraphia and that this is a learning difference that impacts her ability to express herself in written form. This is another label that the school said they were not able to put on her ARD paperwork. Melissa said that she told them, “I don’t care if you won’t put that label on there, I just want the teachers to actually help her in the way that she needs. The label doesn’t matter!” Melissa shared that she didn’t see the big deal about their doing this, and she “just wished they did their jobs.” She had placed all of her trust in the school and the ARD process to get Mikayla help. Ultimately, she felt frustrated that the faculty and staff were not transparent about what they were actually doing for Mikayla. Furthermore, Melissa explained to me that she had recently learned what some of the ARD terminology definitions were and that she was not exactly sure when Mikayla officially was switched by school personnel from receiving 504 services and instead began receiving special education services.

As Melissa was retelling her experience, she described that it had been clear that Mikayla had some characteristics of ADHD when she was young, but Melissa refused to have her identified for it. She was adamant about not wanting Mikayla to take medicine for ADHD. While
she was aware that there was a strong possibility that Mikayla did have ADHD, she wanted to just find strategies to help her that didn’t include medicine, such as structuring the environment and schedule around Mikayla, so that it was predictable and reduced her stress levels. Melissa also said that her mother, Grace had been insistent over the course of several years about the possibility of Mikayla having ADHD, and pushed for testing. Grandma Grace was concerned that Mikayla had been able to draw, watch television and listen to music all at the same time as a very young child. Having been daycare teacher for young children, she was concerned that Mikayla’s ability to multitask was an indicator of ADHD. Grandma Grace had told Melissa repeatedly that multitasking can be an indicator of ADHD, having seen children at the daycare center who could not complete one task before moving on to another. When Grandma Grace saw Mikayla drawing, coloring, and listening to music she was reminded of what she had heard and seen about children who manage multiple tasks at once.

**Supporting Transitions**

While she was not sure exactly how to help Mikayla in early elementary school, before the diagnosis, she wanted to be as prepared as possible to support Mikayla as she transitioned into upper elementary school, secondary school, and ultimately, as she moved into adulthood.

**Analyzing Melissa’s Story with Critical Disability Theory**

Melissa elaborated time and again that the school staff were unfamiliar with the invisible difference of dyslexia. I chose to refer to staff and faculty rather than not just the educators, because Melissa felt that the diagnosticians were insensitive in their work with Mikayla’s specific needs. For example, Melissa spoke about understanding the importance of being a knowledgeable member of the ARD committee. It was a role she held in high regard, and she wanted to believe that she was a valuable part of the ARD team. Sadly, the actions of the school
staff made her think they did not value her role as much as they should have. Melissa shared that she had worked closely with Ms. Sainz for three years and had relied on her expertise and knowledge during Mikayla’s second grade, third grade, and fourth grade years. Ms. Sainz had been a constant source of support during the identification process, and then years later when she provided Mikayla’s dyslexia intervention. She was able to balance both supporting Mikayla and challenging herself to learn the strategies taught in the dyslexia intervention classes. Ms. Sainz also espoused the tough-love mentality that Melissa demanded each of Mikayla’s teachers show her. She felt this was similar to the philosophy her family held at home, and she didn’t want Mikayla to be pitied.

Unbeknownst to Melissa, however, in the middle of Mikayla’s fourth grade school year, Ms. Sainz moved to a new school. Mikayla’s special education teacher moved at that time, as well. Melissa did not receive any notification that Mikayla no longer had the teachers with whom she had been working up until that point. She was surprised at the fourth grade ARD meeting that no one had notified her of this change. She knew it wasn’t that she was difficult to find, as she was at the school frequently, helping out as a volunteer. “How come I was never notified?” she asked. “You never called me or sent me a letter. And they [the staff at the ARD meeting] were like, “Oh we’re sorry. It’s just that the other one transferred without notice and…” I was like, ‘OK…’ You know?” Melissa expressed her frustration in this meeting and said that she asked that they please notify her the next time things change. She said that when this was brought to their attention, they said, “Yeah, yeah [we will notify you].” Melissa sarcastically thought to herself, “Yeah right. Sure [you probably won’t do it, because you didn’t do it this time].” She felt that the ARD committee was not sincere. Also, the meetings were rushed and she felt they were not actually there to help her learn about the process. Comparing the ARD
experience to what she learned at the local BRC, she said she had just learned what some of the acronyms meant in special education at a recent BRC training. Laughing throughout this part of the interview, she said:

Barely, right now [did I learn these terms three years after Mikayla’s been in special education]. I know! [laugh] But it’s okay cause, hey, I’ll take whatever I can get! [laugh]. I didn’t even know what the ARD meant. Or, even IEP. I didn’t know what IEP means. I was like, “What’s IEP?” Cause sometimes we [parents] don’t even know, like, what that is, you know? Or what does this mean?

Melissa’s outlook on the identification process was that it was difficult and complex. She said she realized that each child with dyslexia has particular ways of learning how to cope with their learning difference and that some children have it more severely than others. What made the process even more complicated was that Mikayla has still struggled to make progress in the structured multisensory program that she has been in for three years.

Melissa is sure that Mikayla will do well as she gets older, but she was surprised that she ended up having the other comorbidities. This was unexpected. When describing what Mikayla wanted to be when she grew up, Melissa said she was passionate about becoming a veterinarian. While Melissa is supportive of her dream, she said she has tried to let her know that it would require a lot of college. She told her, “Oh dude… that’s a lot of school! Books and books that you have to read [to finish that schooling].” However, Melissa knows that Mikayla enjoys science and said, “she’ll get [understand] all of the other subjects, over math and reading. She’s on point in those, you know? She likes science, and says ‘Oh science, this is this and this is
that… So I’m like OK [laughter]… Check you out!’ Melissa wants her daughter to feel supported and not limited by her learning differences. Mikayla’s interest in content areas that are generally more hands-on and not solely connected to reading and decoding texts is indicative of individuals have dyslexia. They often see concepts in more global manner, which has been called the Dyslexic Advantage (Eide & Eide, 2012) the Gift of Dyslexia (Davis, 2010).

In The Power of Neurodiversity (2010), Armstrong suggests that altering “our educational systems to provide more opportunities for children with dyslexia to learn through visual-spatial strategies, since it seems that we’re becoming a more picture-oriented and 3-D world (p. 94). In Mikayla’s case, if the environment around her facilitated her disability of dyslexia, then there would be opportunities for her to learn and be assessed in less traditional ways that are more aligned with her ability to see concepts in varied ways, not solely by memorization or paper and pencil tasks.

Using CDT as a lens to understand how educators interact with curriculum suggests that some may have a mindset of reductive curriculum. Reductive curriculum highlights basic skills over critical thinking, meaning that a child with a disability or difference has to exhibit mastery of basic skills before they can have access to more rigorous content (Broderick, Mehta-Parekh, & Reid, 2005). The challenge becomes that in cases such as Mikayla’s, even though she was showing progress, it was not enough for her to be prepared to interact with the increasing difficulty of new content. Melissa stated, “So when is she ever going to learn about specific concepts in language arts and reading? I mean she keeps moving to the next grade and the work is getting harder, but no one is teaching her basic skills.” Melissa further explained that she had to keep reiterating to the school staff that they needed to hold Mikayla accountable for the same content as other children in her grade level, while integrating her accommodations into her work.
Melissa felt that the teachers embraced a philosophy of reductive curriculum (Reid & Valle, 2004) and this included the special education teacher, who was not raising the level of rigor for Mikayla either. However, Melissa did perceive the dyslexia interventionist as someone who challenged Mikayla and kept her accountable. The challenge was the dyslexia interventionist who only saw Mikayla for 45 minutes a day, in a separate classroom. Melissa was worried there was a disconnect between the skills that Mikayla was learning in her dyslexia class and the ones that she was expected to do in other settings (i.e. her general education classes and her special education classes).

There were several different educators working with Mikayla – the special education teacher, the dyslexia interventionist, and the general education teacher. I remember Melissa having said she wished Mikayla’s general education/homeroom teacher was her main teacher, instead of the dyslexia teacher, because “she could do everything.” She felt that the dyslexia teacher could help Mikayla in learning those multisensory language skills across the entire curriculum, integrating the language and reading skills into content areas such as math, science, and social studies, not just in reading. Melissa asked me why this was not possible and I explained to her that it was a systemic issue based on the model of dis/ability that is perpetuated in public schools, and that it is akin to the medical model. If a child has a learning difference or disability, they are removed to a different setting or someone more specially trained comes into the classroom to “fix” them. This is rather than the other way around, where the general education teacher would ideally have a skill set that integrates multisensory language and reading strategies to address the needs of every single child in the classroom. Sadly, this philosophy is flawed as well, since it would be difficult for every single teacher to have the
different kinds of specialization and experience needed to meet the varied needs of every single learner.

Furthermore, I think that in Melissa’s story, Mikayla had several years of targeted intervention with numerous educators and specialists, and still did not make the expected grade-level progress. However, since I did not have access to Mikayla’s special education full individual evaluation (FIE) or any of her individual education plans (IEP), it was difficult for me to say the exact areas that the diagnostician, general and special education teachers felt she needed assistance in. Melissa described that Mikayla was identified as being eligible for special education services due to specific learning disabilities in both reading and math. More explicitly, as I considered the information Melissa had shared about the challenges Mikayla had each and every year with limited progress, I could not help but think of a few students I had worked with who had similar outcomes. Torres (2017) provides an explanation about students with profiles similar to Mikayla’s, saying

A student who is a slow learner will struggle regardless of targeted intervention. School is difficult [for these children]; academic tasks are supremely challenging. Intervention practices usually prove ineffective because these students do not possess the necessary cognitive abilities to handle academic tasks.” (p.53)

One of the most challenging moments I had as a second-year teacher was for a student I call Samantha, whose progress and profile had some similar elements as Mikayla’s. However, when we had the meeting to go over Samantha’s results and FIE, her family and I were notified that she had not qualified for any special education services. The diagnostician went on to explain that for some students, special education services cannot aid them in learning academic content. I was devastated to understand how the special education system was set up for students who are
classified as slow learners. For students like Samantha they “are simply cast off as slow learners-as someone else’s problem” (Torres, 2017, p. 53). Since I was at a K-8 campus, I would check on Samantha over the next several years and found out that she later qualified for special education services due to a other health impairment (OHI) and had started receiving services in middle school. It was students like Samantha, that I was always worried about because I felt like the school system failed them and their families. I would worry about their future and if they would be able to graduate and live independent and successful lives. I saw Samantha about two years ago as a server a local restaurant. Samantha smiled and told me about how well she was doing in her new job; I could not help but give her a hug and tell her how glad I was to see that she was doing well and had graduated from high school. In Melissa’s story, she was supremely frustrated that Mikayla was still struggling after eight years of public schooling. Mikayla was at the end of her fifth grade school year when we had our first interview in March, that meant that for five of the last eight years, Mikayla had been receiving instructional support through the special education system. However, she still was not able to read with fluency and was having significant struggles in math. Melissa is hopeful that Mikayla will continue to be resilient in her school endeavors and find ways to navigate her impairments in a system that does not always accommodate her learning needs. Furthermore, Melissa ultimately also hopes to support Mikayla in finding a career that integrates all of her talents so that she can be happy as an adult.

**Intersectionality and Melissa’s Story**

Melissa was clear in her disappointment with the public school and the emphasis placed on standards and standardized assessments. In *Readicide: How Schools Are Killing Reading and What You Dan Do About It*, Gallagher (2009), explains that U.S. students are being completely turned off to reading for pleasure by teachers and school leaders, because of the high-stakes
assessment environment of today’s schools. Readicide is defined as a noun that represents “the systematic killing of the love of reading, often exacerbated by the inane, mind-numbing practices found in schools” (p. 2). Gallagher explains that the Texas Miracle, which purported to reduce dropouts and increase achievement through standardized testing in Texas under Governor George W. Bush’s watch, and was later implemented nationally when he became President of the United States, is a serious problem. Holding students back if they do not meet 100 percent of reading standards, as well as denying funding to schools if students did not meet these goals became the norm.

This would not be the first time that such a mandate was enforced by the President of the United States. In 1998, President Clinton challenged schools to end the practice of promoting students who did not learn the academic standards stating:

Students should not be promoted past the fourth grade if they cannot read independently and well, and should not enter high school without a solid foundation in math. They should get the help they need to meet the standards before moving on” (Clinton, 1998, pp. 1-2).

Melissa’s frustration with the school was due to the rigid guidelines that completely ignored individual students’ abilities and promoted a mentality of ableism within public schools. Although high-stakes assessments vary from state to state, there are several generations of students who have been retained more than once in the upper elementary grades, due to limited progress as measured by the standardized assessments. Instead of placing more effort into continued professional development and targeted reading intervention for educators, students were retained if they did not pass the state assessment (Hauser, Pager, & Simmons, 2000).
Intersectionality allows me to consider how Melissa’s experience as a caregiver was impacted by school district and state policies and guidelines. Specifically, the multiple dimensions that Melissa navigated advocating for Mikayla as a single mother of color, with two children with special needs and abilities, and a full-time job as a minimum-wage worker, is complex and nuanced. Intersectionality allows researchers are able to see how they “can mesh, blur, overlap and interact in various ways to reveal knowledge” (Annamma, Connor & Ferri, 2016, p. 12). Melissa’s experiences with retention, the dyslexia identification process, and the implementation of accommodations for Mikayla’s other learning differences are all examples of how the public school system does not view each child as a unique learner. Instead, it forces children to fit into a one-size-fits-all mold. Furthermore, race, culture, and disability are systems of oppression that intersect and the intersection of the three are likely to diminish access to an equitable educational experiences (Blanchett, Klinger & Harry, 2009; Ferri & Connor; Harry, 1992; Klinger, Blanchet & Harry, 2007; and Sleeter, 1987).

Melissa stated that the ARD committee made an alarming claim at the end of Mikayla’s fifth-grade school year, suggesting that they retest Mikayla. Melissa was aware that children receiving special education services are regularly assessed for progress, however, the ARD committee wanted to retest Mikayla, “in case she doesn’t [have dyslexia anymore].” Appalled by the very idea that the characteristics of dyslexia could somehow disappear, Melissa was glad that the 504 teacher was at the ARD meeting. She affirmed that, “Yeah it’s [the dyslexia characteristics are still] evident.” Melissa said she spoke up also and told the committee:

Yeah. Like, she’s [Mikayla is] still at a—she’ll get at 6th grade [next year] with a 3rd grade reading level. That’s…come on, now. She [the diagnostician] was like, ‘No, I’m
just making sure. I’m just making sure.’ Like, she had to let me know? I don’t know. It was weird. She was just like, “But if she doesn’t have any [characteristics anymore, we can eliminate the services in sixth grade].

Melissa said that she felt that the school was trying to find a way to exit Mikayla from all of her special education services before the end of the school year. Melissa was shocked, especially because Mikayla is still having a challenging time with not only reading, but with math as well. Also, Melissa knew that once someone has been identified as having dyslexia, they cannot be cured, as it is a lifelong condition (Yale Center for Dyslexia and Creativity, 2017). This was the reason she was so shocked by the proposal to reassess Mikayla to see if she still had dyslexia characteristics. Blanchett, Klinger, & Harry (2009) communicate that general education and special education teachers in urban settings must work alongside one another to ensure equity regarding the intersections of race, culture, language and disability. As I considered Melissa’s experience, I thought about the way that the school system had placed her and her daughter into a category of “other” and was not acknowledging the possible ways that as a school system they were discriminating against this family. “Other” is a label that exists to rationalize, explain, and distance the labels and realities of inhumanity and inequitable conditions (Deloria, 1999). Melissa refusing the notion that Mikayla was eligible to be exited from special education shows that she learned to advocate for her daughter and refute inequitable suggestions. This especially allows me to consider her intersectionality of belonging to a group that is socioeconomically disadvantaged. In Disability, Disadvantage, or Discrimination? (Porter & Walters, 2017) the authors state that in regards to special education placement, families should be involved in the process by having adequate communication “using nontechnical language, [and] numerous
opportunities to ask questions” (p. 89). Learning to navigate the ARD process was an intersectionality attributed to learning the expectations of the process. However, the “degree to which communities of color are excluded from the civic process” (Ladson-Billings, 2006, p. 7) is referred to as sociopolitical debt. Thorius & Tan (2016) expand on this notion to include “the extent to which individuals with disabilities and their families are excluded from decisions about their lives, civic engagement, and education” (p. 92). I believe that when the diagnostician suggested reassessing Mikayla, the school staff should have explained in more detail why the suggestion was being made. In Mikayla’s case, she was in special education for both reading and math specific learning disabilities. The law requires that a reevaluation has to occur at least once every three years, unless the caregiver and school system agree that a reevaluation is unnecessary (34 C. F. R. § 300.303 (b)). A Review of Existing Evaluation Data (REED) is necessary in order to consider current levels of ability. These decisions should be based on a combination of parent input, classroom-based, local, and state assessments, as well as on observations made by classroom teachers and other service providers. When the committee said, “in case she doesn’t [have dyslexia anymore],” this was not aligned with what Melissa knew about dyslexia or what she was observing at home. She felt that the school was not being honest and perhaps was attempting to remove her from special education to: (a) have one less child in special education at their school; (b) reduce the amount of children on the dyslexia interventionists’ schedule; or (c) give up on her making any progress in special education.

The mixed messages that the school staff sent Melissa throughout Mikayla’s elementary school years were a consistent source of frustration. While she overall felt that the staff cared about Mikayla, they did not help her to read in ways that she could remember or apply independently in a consistent way. Although Mikayla has had intervention services from various
specialists, her growth has not been significant. This is concerning to Melissa, and she said she did not understand how it is that the education system is unable to help her daughter. “After a certain amount of time, if a lesson is not working,” she said, “then maybe they [teachers] should go a different way. If there’s no growth... it’s pretty pointless, you know? They should be able to, I feel, either see it, identify it, or speed it up.” Melissa said the school staff did not know anything about dyslexia or how to provide support and interventions for Mikayla. When thinking about the faculty and staff she said, “If they haven’t experienced it [dyslexia], or taught it [structured multisensory intervention], then they won’t know either. So maybe they can learn from each other, you know… the student and the teacher.”

Melissa understands that training educators to provide multisensory dyslexia instruction does take a long time. However, she wished that the school did more to ensure that her daughter was learning how to overcome her behavioral and learning differences. Until this is realized, Melissa knows that she will have to advocate for Mikayla as she transitions into middle school. Her phrase, “We’ll take it” is one that shows perseverance and patience as a caregiver who has navigated the complexities of the public education system and special education services which have shown Melissa and her Mikayla multifaceted elements of support, indifference and oppression.
Chapter VI “TRY EVERYTHING!”

Michelle was 40 years old when her nine-year-old son Matthew, was identified with dyslexia in one of the largest school districts within Texas’ borderland communities. Born in Puerto Rico, where most of her family still lives, Michelle identifies racially as White and ethnically as Hispanic. She describes her hobbies as riding bikes as well as being a couch potato who watches Netflix at hours on end. During the three years that I have known Michelle she has moved two times; I met her in the borderland area in Texas, then she moved for nine months to Puerto Rico due to her husband Marco’s work, and finally moving to Alabama after getting separated from Marco. Marco works as a helicopter pilot for the Department of Homeland Security (DHS). She was grateful to be able to say that her profession is homemaker, although she does have a professional license as a pharmacy technician. Michelle has not used that license in the past 12 years since she has been at home raising her children. Her oldest child, Salma is 18 and is from her first marriage, while her youngest is Matthew, who is 11 and is from her second marriage. Michelle now lives with her mother Naomi and her father Robert, who are Matthew and Salma’s maternal grandparents. At the time of Matthew’s dyslexia identification in Texas, Michelle stated that she and her husband had made a decision that they could afford for her to stay home, since his yearly income was $120,000. When Matthew was identified with dyslexia he and his family lived in one of the suburbs located within the larger county of this borderland town, near the border with New Mexico. Their community is classified as a census designated place by the United States Census Bureau since it is so close to the larger metropolitan city. Their town has a population of 5,000 and an average household median income for families of $22,000 per year (United States Census Bureau, 2000). That is, their single-person household income (since Marco is the only one who works outside the home) at the time of Matthew’s
identification, was $100,000 per year more than town average. Even though the town is small, Michelle described it as being nestled very close to the larger metropolitan city area and they are literally a few steps from being in the largest school district, although their smaller town had a separate smaller independent school district that Matthew could have attended. Michelle described her home as being near the school district boundary lines of the largest district in the city while her children can easily “walk across the street” to their own neighborhood school. This proximity of being in both a small town with a smaller school district and near the largest school district in the city meant that Michelle and Marco had several options when deciding where to send their children to school for elementary, middle, and high school.

While she is currently married, she is looking forward to her divorce being finalized, saying, “Okay, I'm getting there. I'm going up the mountain and getting to the top now. Once it's all over with... then I can be on my own, buy my house or an apartment.” She jokingly said, “and it’s my second time doing all of this … again.” Michelle was referring to the fact that she had been married once before, and that Salma is her child from her first marriage. At the time of this writing, Michelle and her children are living in a multigenerational home with her parents in Alabama. According to the Pew Research Center (2016), multigenerational homes are defined as homes where at least two adult generations, including grandparents, live with grandchildren younger than 25 years old. Furthermore, the organization found that it is not uncommon for families of color to live in this sort of living arrangement. That is, 29 percent of Asian Americans, 27 percent of Hispanics, and 26 percent of African Americans live in multigenerational households as compared to 16 percent of white non-Hispanic people (Pew Research Center, 2016). According to Muenning, Jiao, and Singer (2017) multigenerational living arrangements are positive in that they can allow for sharing of resources such as utilities,
childcare, and food. However, these arrangements also are characteristic of “families with less access to social or financial capital who are simply living together out of need rather than choice. This, too, could prove to be more stressful for multi-generational family arrangements” (p 74).

As Michelle shared her story of the impending divorce and new living arrangement, I found it to be a natural moment to share that I had had a similar experience, explaining to her that I had gone through a divorce when my daughter was born. I already was a teacher and made enough money for us to be on our own, but I made the decision to have my daughter grow up in a multigenerational home alongside her grandparents who helped me raise my daughter for seven years. In my situation, my daughter was even able to be raised by her uncle and aunt, as well as live with her newborn cousin for six months before I wanted to move on and “be on my own” as Michelle mentioned to me in our interview. Michelle said that when they finally get their divorce finalized, which is taking much longer to process due to the pandemic, she will relocate and take her mother, Naomi, along with Matthew and Salma and move to North Carolina, where Michelle’s sister, Stephanie and their father Robert live. She plans to continue to share a space with Stephanie and brother-in-law until she gets settled. However, if for some reason she has to stay in Alabama, she will live with her mother indefinitely, with plans to take care of her as she ages.

The languages in Matthew’s household are Spanish and English. Although Michelle said “it’s embarrassing but they cannot read it or write it well, [but] they understand it” referring to the fact neither of her children speak Spanish fluently. However, Salma did speak fluent Spanish when she was a toddler. Michelle mentioned that, “when she [Salma] was around three, she would speak both languages – English and Spanish. Because “I [Michelle and her ex-husband] had a roommate then, and she [the roommate] did not speak English. And her dad only [spoke]
Spanish, so she [was] brought up with both.” Salma’s ability to learn both languages as a toddler and progress through her K-12 education with high grades and to eventually graduate from an early-college high school was another reason that Michelle said “I don’t understand,” when a teacher later brought it to Michelle’s attention that Matthew may have characteristics of dyslexia. She had not experienced her first child going through any challenges at school, and since Salma had always excelled, and knew two languages, she was surprised to find out that Matthew did. However, Michelle noted that Matthew does not like to speak Spanish, but that she still “makes him say his prayers in Spanish at night.” Additionally, Michelle was glad that Matthew was able to attend English only classes in Texas, something he did later as well, when they moved to Puerto Rico and then to Alabama. When we began the interview, Michelle said that English was her second language and reminded me that, “If I can’t pronounce the words, just let me know.” She also asked me to correct her if the words came out wrong in English.

Michelle and I did not translanguage, nor did I have to clarify any questions for her. However, I did reverse the order of one of the phrases she used, as she said potato couch instead of couch potato. Michelle used one word and one phrase in Spanish to explain different concepts and these will be discussed in my analysis. She used the word vejiga [bladder] as an example when she described the purpose of a medical intervention she tried called biomagnetic therapy. The Spanish phrase she used was no puedo tapar el cielo con mis manos which is an idiomatic phrase that means you cannot hide from the truth. She used this phrase to explain why using a pseudonym was unnecessary for her. She noted, “why hide it [my real name]. It’s not like anybody is going to contact me. Even when I change my name [to my maiden name].” Meaning that if she decided to change her name to a pseudonym, it seemed that she would be hiding from what happened or acting as if this experience with the phenomenon never happened. Michelle
was consistently trying to learn new things and being honest when things were challenging. This is a trait that she also tried to instill in Matthew when he got frustrated or struggled with academics or behavior.

I met Michelle at a parent information session during the fall of 2018 in my role as a regional project manager as an elementary special education inclusion manager and also for families that have a child with special needs in K-12 schools with the Texas Education Agency (TEA). I was intrigued by her for two reasons. First, she had grown up in Puerto Rico and moved to the borderland several years before I had met her. This was interesting to me, as I had always dreamed of travelling to Puerto Rico. As the child of a military family, the idea of traveling around the world and exploring different cultures was always a dream of mine. Because I was adopted into a biracial family (Black and Hispanic), I remember vividly being stopped and asked if I was a Puertoriqueña while I was growing up. I had assumed people were basing their question on the color of my skin and my mostly-fluent oral Spanish. I recently found out through commercial DNA testing that I am 44 percent Scottish, 27 percent Nigerian, 9 percent Malian, 6 percent Cameroonian, and 5 percent Irish. Growing up I yearned to be like everyone around me and would check “Hispanic” on my school forms and demographic questionnaires. Even though I was not biologically Hispanic, I was raised in this culture and saw myself reflected as a part of it.

Another element that spurred my interest in Michelle her interest in alternative medicine to treat dyslexia. In the dyslexia parent information sessions, we had many discussions in which she talked about cutting edge medical interventions for dyslexia, along with homeopathic therapies. Before I met her, I knew that most caregivers attempt to do whatever they think is going to help their child find success in light of their learning difference. I had worked with
families in the past who had changed their child’s diet. Some families gave their children with ADHD coffee before school, in hopes of reducing hyperactivity. However, I had never before heard about the things Michelle was trying.

Michelle always had a positive outlook on finding ways to support Matthew as he transitioned between developmental milestones and navigated new challenges at home and at school. She seemed to always embrace a growth mindset in light of any adversity. Throughout the interviews, as well as when we were in the same room during the parent trainings, she always used analogies, phrases, and dichos [proverbs] to give meaning to situations that she had encountered during the identification process. Often, what she said seemed to resonate with the other families. Even though we had to do interviews over the phone, I always had plenty of context, explanation, and clarity from Michelle. She was able to compare her personal experience with the dyslexia identification process in three different areas in the United States. While I consider myself to be fluent when writing and reading in Spanish, when speaking it aloud I sometimes have trouble finding the exact words I want to use and would describe myself as not being as fluent in terms of speaking as I am in reading and writing. Sometimes I need support, especially when it comes to technical language. I would frequently check with Michelle and other families who attended my parent trainings and ask them to translate dichos I had trouble understanding. The caregivers at my sessions seemed to appreciate that I was able to understand their explanations in Spanish and our conversations would often merge between Spanish or English interchangeably, embracing translanguaging in real-time.

There is not any documented history of dyslexia in Matthew’s family. However, Matthew’s diagnosis led his father, Marco, his grandparents, Robert and Naomi, and Salma and Michelle to have in-depth conversations about their experiences in school. They continue to
question whether some of them should have gotten dyslexia identifications too, when Matthew was identified as having the characteristics in third grade. The family’s overall disposition toward dyslexia is positive, in that they all support Matthew and want to find resources for him so that he can be successful in home and school settings. They want to afford Matthew every opportunity to be successful as he grows up.

I was never able to meet Matthew. However, his mother describes him as a youngster who enjoys playing video games, especially now during the pandemic. Although he sometimes gets aggravated when trying to play with other children due to his desire for games and activities to be played the exact way he wants, he enjoys socializing with a very small group of friends.

Using the Interpretative Phenomenological Analysis (IPA) approach, I discovered three superordinate themes in Michelle’s story. They were:

1. Surprise! Matthew is a child with dyslexia;
2. Try everything, including homeopathic, medical, and assistive technologies;
3. Wisdom from Michelle to caregivers and educators.

These three superordinate themes reflect the identification process that Michelle experienced as Matthew was identified with dyslexia through the Texas system, Puerto Rico, and Alabama. The second theme describes her passion for finding support strategies for Matthew based on interactions that she had experienced through educators, other families who had already experienced the process, and medical professionals. The final theme reflects Michelle’s passion for learning all that she can in order to support Matthew.
Surprise! Matthew is a Child with Dyslexia

A Path Toward Identification in Texas

When thinking back and remembering the identification process in Texas, Michelle said that the suggestion that he had the learning difference came as a surprise. She said

When Ms. Elguea told me he had the characteristics, I did not believe he had it. She [Ms. Elguea] said it was ‘because he put p’s and b’s and d’s [backwards]... But he had always done that. If you just address it, he erases it and re-writes them the correct way. OK, I thought… I’ll request it [the dyslexia assessment]. Let’s see where this goes.

Although Michelle had corrected Matthew’s oral language, along with his writing occasional letters backwards and remediating his behavior over the years, she stated that it did not seem “that bad.” She mentioned that he had never struggled with reading, writing stories, or creative narratives – except for letter reversals – until he was in third grade. This may seem contradictory, but she reiterated that his grades were high in school and since she was able to provide therapeutic support for him, she did not see that there was any need for him to be further assessed in terms of reading.

Early Childhood Intervention

I conducted interviews with Michelle for approximately five hours, all on the phone. Recalling nuances in the experiences that led up to Matthew’s dyslexia identification in Texas, she was adamant that the primary issues he had had from pre-kindergarten to third grade were difficulty with sensory processing and speech. Matthew’s pediatrician recommended that Michelle and Marco have Matthew assessed for autism, due to the family’s concerns about these
issues. His assessments showed that did not have the characteristics of autism. I asked if she had requested a dyslexia assessment and she said, “No, the pediatrician said we should rule everything out first. Our insurance covered all of the testing.” Michelle said that ruling out an Autism Spectrum Disorder (ASD) was the right way to approach things. I think Michelle prefers investigate the root causes and do research on anything related to Matthew’s overall development.

Matthew’s challenges with speech began when he was one-year-old. At that time, Michelle realized he was only speaking a few words. Matthew was receiving therapy for difficulty with speech expression and pronunciation, along with therapy for sensory processing - - for exhibiting behaviors of throwing himself on the floor and/or at the wall. All of this was done through the Early Childhood Intervention (ECI) program, which he had access to between the ages of two and three years of age. These therapists would come to their home and show Michelle and Marco how to work with Matthew. ECI is a federally funded program that employs specialists in early childhood development to work with children who have various developmental delays and disabilities (Centers for Disease Control and Prevention, 2019). ECI services include physical therapy, speech therapy, and other services based on an individual child’s and the family’s needs. These services are free or at a reduced cost for children who are eligible, based on income and their pediatrician’s recommendation. Michelle noted that she also sought out further assistance for Matthew and his speech delay from local speech and language pathologists.

Michelle and Marco also privately funded an America Sign Language (ASL) tutor named Ms. Lopez, who provided these services at their home. Ms. Lopez came highly recommended as a tutor and was referred to them by other DHS families. Michelle explained that the community
of DHS families is very tightly knit, and they rely on each other in a familial way. She attributed this to the fact that they frequently have to move from one community to another and that the families that have already been there for a while help them make connections with reliable resources. The DHS families recommended her because Ms. Lopez had helped their children learn sign language, along with the federally-funded speech services their children received through ECI. Michelle said that Matthew took to learning sign-language quickly and that it helped him communicate “basic words such as bathroom, hungry, thirsty,” as he was learning to express himself with the therapy from ECI.

As he grew, Michelle saw minimal improvement in his speech development. Most concerning to Michelle was Matthew’s difficulty with sensory seeking behaviors. Sensory processing is a neurological disorder in which sensory information does not get organized into appropriate responses by the brain (Sensory Therapies & Research Center, 2020). Specifically, Michelle noticed that at a young age, Matthew could not feel pain and would throw himself on the floor anytime he was seeking sensory feedback and especially if he was bored, angry, or frustrated. He would intentionally bump himself into walls and would not realize that it hurt until many seconds or even sometimes minutes after he had done this to himself. Michelle wanted to be sure that he received interventions that would help him learn how to stop self-harming behaviors that were related to pain. Michelle knew that she could help Matthew through specialists who could support him as he entered pre-school.

As Michelle reflected on what happened after the ECI therapy for speech and sensory processing, I found myself having to ask funneling and probing questions as she retold Matthew’s history with schooling. This was because she would sometimes mention one experience or interaction and then after discussing it in detail would change her mind on the
order of how things had actually happened. This is understandable, since it did happen several years ago, and there have been many life changes for her and the family since then – not to mention that I conducted the interviews in the middle of a global pandemic.

**Pre-Kindergarten**

Michelle noted that “Pre-K was fine. The only thing was the hyperactivity. That he was always hyper, he never liked to take any naps. And his teacher couldn’t understand what he was saying.” Matthew had received intervention via ECI for speech until the time the program is intended to end, which is around three years of age. Matthew’s speech services transferred over to the school setting when he entered pre-kindergarten. Michelle explained that, “at five… no, at six years old, or until he was eight… I took him to a counselor, and he received neurotherapy.” With the recommendation of his pediatrician, she took Matthew to private counseling and speech therapy to ensure that he would make progress with speech. She said, “Yes, it [all of the private and public therapies] did help him a lot, in my opinion.” Michelle said that she was a firm believer in the benefits of counseling for Matthew. She mentioned that she and Marco had done marriage counseling for several years as well. While she explained that she did see the benefits in counseling “even going to counseling gets tiring and you just have to take what you are able to [from it] and try and make ourselves better.” By the time had Matthew neared the end of pre-kindergarten, he was diagnosed with Attention-Deficit Hyperactivity Disorder (ADHD). Michelle was adamant that she would not place him on medication until he was a little older.

**Kindergarten through Second Grade**

Matthew was enrolled in a free charter school called the Red Apple Charter School, within a fifteen-minute drive of their home. Michelle said that she and Marco always had wanted to provide the best education they could find for their children. They found an innovative charter
school that served children from kindergarten through twelfth grade, featuring a rigorous curriculum that integrated the fine arts into each grade level. During this time, Matthew was still receiving private and public speech therapy. Since it was a charter school, she explained that, “no the charter [school] did not have their own speech teacher. She would come from one of the local school districts to give Matthew therapy.” Even though Matthew had been making adequate progress from kindergarten through the middle of his second grade year, in his mother’s opinion, it was not until second grade that she started feeling that the rigor of the school was not enough for Matthew. At this time, Matthew was on a 504 plan for his ADHD, with accommodations such as allowing him to redo assignments, have extended time to complete assignments, and to sit near the front of the room to help him focus.

During the summer between Matthew’s kindergarten and first grade school years, Michelle and Marco applied for him to become eligible to switch over to the largest school district in the borderland community. Michelle had mentioned before that the local school was very close to where they lived. Michelle said that Marco was growing concerned that the charter school was not going to do a “good enough” job in teaching him as he was getting older. Marco wrote a letter to the district in May of Marco’s first-grade year, describing his specific needs, saying that they wanted him to have access to better qualified teachers. They completed the steps outlined by the school district for out-of-district transfers, but unfortunately, the school district took several months to respond. The delay was beyond the anticipated timeframe of one to two months. Marco and Michelle finally received a transfer approval letter in October, which meant that Matthew could transfer to the public school in their neighborhood. However, Michelle and Marco did not want to transfer him then, as the semester had already begun. Therefore, Matthew
stayed at the Red Apple Charter School throughout his second grade school year, because Michelle and Marco did not want to move him to another school district mid-year.

Michelle explained to me that she later regretted that decision, because Matthew’s second-grade year did not go as well as they had hoped it would. Matthew had begun second-grade with a full-time teacher who ended up quitting in the middle of the school year. After his teacher left, Matthew had a multitude of substitutes and two long-term substitute teachers between January and March of that year. A long-term substitute is someone who is on a long-term job assignment which can vary in length depending on local district policy but generally is understood as being assigned to the same class for ten days or more, meaning that for an extended period of time he had the same teacher each day. Michelle said she was not sure if any of the substitutes had teaching credentials, but nonetheless, he did have someone who was there continually, for a period of time.

It was during the time that Matthew was had multiple substitutes in second grade that Michelle started noticing he was having new challenges. He started skipping over words when reading out loud and omitting letters when writing. Michelle attributed this change in his ability to the plethora of inexperienced and unqualified substitute teachers. This was because she had not noticed any issues such as these with her son until the substitutes arrived. One of the long-term substitutes mentioned that Matthew had a hard time reading and that he was not able to sit down and complete his work. Michelle responded by saying, “he needed more play time and more structure.” Michelle reiterated that she did respect the hard work substitutes do each day, but that she and Marco had already thought about moving Matthew before he started having more pronounced ADHD symptoms and difficulty with reading. They were rethinking their decision to leave Matthew at the charter school, and were already planning for him to transfer to
the large school district. Toward the last two months of the school year, a permanent teacher was hired. Unimpressed with the charter school, Matthew’s parents decided that they would again try to move him, this time long before the start of his third-grade school year. They submitted their transfer request letter in May, turning it in to the school district this time. Marco asked his supervisor at DHS to provide a letter as well, justifying why the district should accept Matthew. I asked Michelle what she meant by this and she said “it is like a letter of recommendation from your boss that you can put in with your out-of-district transfer request.” She and Marco hoped that this extra letter would speed up the approval process and explain why the family would be a beneficial addition to the large school district. Marco and Michelle reapplied for the transfer to the school district near their home, Mountainside Elementary School, and this time the request was granted a few days before the school year began.

Third Grade

When Matthew started third grade, his parents were glad that he would be at Mountainside School, which was part of largest school district in the region. Michelle mentioned that she had heard good reviews about the local school and was hopeful that Matthew would be successful there. Within the first few weeks at his new school, the speech therapist called a meeting and informed Michelle that would be placed on a 504 plan for ADHD. The speech therapist recommended that Matthew be exited from the speech program. Michelle said although the speech therapist thought that there was no longer any assistance that would help Matthew, Michelle should keep holding him accountable for targeted speech pronunciation, and he would continue to develop good habits. Michelle said that when he was exited from speech therapy:
He did improve overall throughout the years. [But] he still has speech delay, in my opinion. I don’t think he speaks as a nine-year-old kid should. It improved to a point to where I understand 90 percent of the things that he tells me.

Although Michelle did not agree that Matthew was ready to be exited from speech therapy, she felt that if the speech therapist recommended that he had made as much progress as possible, then she respected her determination. Matthew’s 504 plan integrated accommodations to ensure that he could move around, have flexibility in the proximity of where he sat during lessons, and most importantly, that he could have extra time to finish assignments. Matthew had been on a successful trajectory in all of his schooling in years prior. He had high grades, and had had them since kindergarten.

Matthew transitioned well and Michelle could tell that he was starting to thrive again with the structure, rigorous instruction, and the positive learning environment at the new school. To her surprise though, Matthew’s new third grade teacher, Ms. Elguea, requested that they set up a parent conference only a few weeks into Matthew’s transfer to Mountainside Elementary School. At the conference, Ms. Elguea shared with Michelle that she was concerned about Matthew’s reading skills and word-problem solving skills in math. Ms. Elguea recommended that Michelle request that Matthew receive testing for dyslexia characteristics. Since Michelle perceived that Matthew was doing well both academically and with behavior at his new school, she was shocked by this advice. She did not think he had dyslexia characteristics. However, Michelle trusted Ms. Elguea’s professional opinion, and wrote a letter requesting that Matthew be tested for dyslexia as soon as possible. Michelle appreciated Ms. Elguea’s directness and honesty when recommending this to her. This was because Ms. Elguea said, “I should not be
telling you this, but you need to write that letter and the school will do the test.” Although Michelle stated that she did not necessarily agree with everything that Ms. Elguea did as a teacher, and that her demeanor was not always welcoming, she had a feeling that this teacher was truly helping the family seize an opportunity they would not have known to do otherwise.

This is an example – Ms. Elguea recommending that caregivers write the school requesting a dyslexia assessment – of a practice that does happen in many public schools in Texas. After the state education agency placed a target or cap limiting special education enrollments (Rosenthal, 2016), it created a culture that implied teachers could not guide caregivers about their children have learning differences. However, in some instances, there are educators in Texas who do share information that helps caregivers understand how to navigate the exceedingly complex identification processes of dyslexia identification. One of the reasons that Ms. Elguea may have been willing to share this information with Michelle was because she had extensive training in dyslexia. Ms. Elguea had been a general education teacher and later was trained as a dyslexia intervention teacher. She served in this capacity for four years before deciding to go back to being a general education teacher. Michelle says that this was also why Ms. Elguea was able to pick up on Matthew’s dyslexia characteristics so quickly.

Michelle explained that she had assumed the dyslexia assessment would take somewhere between two to three weeks. However, when Michelle requested the assessment and spoke with Ms. Griego who was the assistant principal, she was informed that the testing in the district would take at least three months. Michelle officially requested a dyslexia assessment in October of 2017 and the results of the assessment were shared with her in early February of 2018. Upon hearing of this timeline –having to wait three months to find out if Matthew had dyslexia
characteristics – Michelle scheduled an appointment with his pediatrician. She said she was not going to just “sit and wait.”

**Consulting the Pediatrician**

The discussion that Michelle had with Matthew’s pediatrician was a disappointing yet enlightening experience. She was trying to find a faster way to have Matthew assessed. Michelle said that she thought:

Are there any other tests? Where do I go? Oh I don’t know… Do I go to the school? Do I Google it? You know, it’s like, uh… OK…The first thing you do when your kid is sick… What do you do? You go to the pediatrician. Something happens, you have questions, you call the pediatrician.

Michelle was sure that the pediatrician would give her guidance and help her find out more about dyslexia. She also hoped he could speed up the identification process. But when Michelle spoke with the pediatrician, he was very clear that she needed to be patient and trust that the school would do it as fast as possible. Therefore, Michelle waited and did what she had done in the past – trust the opinions of the professionals. As she remembered their exchange, she said that he told her, “There’s nothing I can do. You have to go through the school system. You have to work the process … no matter how long it takes.” Michelle appreciated the pediatrician’s frankness and took his advice, waiting for three months and learning as much as she could about what dyslexia was, in the event that Matthew actually did have dyslexia. But she was frustrated, saying, “If they [pediatricians] don’t know, [and] I don’t know, what am I going to do? Just keep googling it [laughter]?” Michelle broke into exasperated laughter. Understanding the legally
required identification process, which varies from state to state, city to city, and even within the same school district, is exhausting. “There’s really no therapy for dyslexia. Insurance don’t cover dyslexia. There are a bunch of centers, [but] they all cost lots and lots of money! For $500 they will retest your kid, even though you already have the testing from the school,” Michelle explained. She expressed that she was deeply frustrated that during that time. When the school finally informed her that Matthew did have dyslexia characteristics, she felt helpless. The dilemma was that Michelle was experiencing a lack of consensus as to how to identify and treat dyslexia.

In some parts of the medical field, dyslexia is not necessarily viewed as something that can be ameliorated with a specific procedure or medical interventions. Elliott & Grigorenko (2014) discuss the complexity of assessments available in both education and medical contexts, asserting that, “Despite having accumulated a vast wealth of research findings on the many sensory, cognitive, and motor processes that have been associated with reading disability/dyslexia, we have achieved only rudimentary understandings and even less consensus about how causal mechanisms operate” (p. 172). Michelle noted that when Matthew had been younger, he had a speech delay along with a sensory processing disorder, and she had been able to find therapies or interventionists to help Matthew in the private sector, along with services supplemented by the federal government. The confusion she encountered regarding dyslexia assessments and treatment did not fit the model she had used with in addressing Matthew’s other conditions. She could not fix this issue using the combination of private and public services as she had done in the past.
The Stay-at-Home Mom Affordance

Matthew was assessed by one of the diagnosticians in the school district. Michelle said that she was surprised that the process took as long as it did. It was a three-month process, excluding the multiple school vacation holidays. Furthermore, she said “[I] have to say it's…it's… it's a very hard process. And I thank God that I have the opportunity to stay at home. It makes a huge difference.” Upon hearing the news that Matthew had dyslexia, Michelle was determined to try everything possible to make sure that he had the tools to find success in school. Adding, “I don’t wanna say [it’s a] disability, but you know, it's… it's frustrating. It's hard, and then you really don't know what to do. Thank God I had a good school that really helped me.”

Since Michelle had not ever even considered the possibility of Matthew’s having dyslexia before Ms. Elguea, she was grateful that Mountainside Elementary had a teacher who knew so much about dyslexia and had even been a dyslexia intervention teacher prior to returning to the general-education classroom. For this reason, Michelle felt that in her experience, the dyslexia identification process in Texas “wasn't such a hard process.” She knew that she did not have to initiate the identification process on her own, as many other families have had to. She saw that other families’ experiences were different from hers when she attended the parent training sessions. In many cases, it was the parents who had picked up on the dyslexia characteristics and were fighting with the school to have their child assessed, running into resistance from the school to grant the assessment. Michelle said,

I know there are many other schools that you [are] like, "What's going on? You get [the] run around. But [then everyone says] you have to wait four months to be tested. So what's going to happen in those four months? You don't know. Your kid is still not advancing.”

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After going through the initial process of identification in Texas, Michelle said that she realized she was fortunate to have a classroom teacher who had suggested she have Matthew assessed. Ms. Elguea was certain that Matthew had these characteristics, and wanted to be sure he was identified and started receiving services as soon as possible, if he qualified. Having access to a formally trained dyslexia intervention teacher who is in the general education setting is a rare occurrence. Michelle said that Matthew did not necessarily believe he had dyslexia. He would ask her why he was different. “At the beginning, he was feeling separated from everyone – isolated – because the way he learns is different from the majority. So he was really [struggling]. . . [it] took him some time to adjust.” Upon finding out that the person who tested him said that he did have dyslexia characteristics, Michelle said that Matthew seemed to feel defeated. He had already received therapy for his sensory disorder, speech, and ADHD. Michelle said that Matthew seemed to feel afraid and would say, “Oh, no…What else am I gonna get?” Michelle said that she was purposeful in finding different ways for him to see that the dyslexia diagnosis was not something negative. She said, “I’m just trying for him to feel positive about it [dyslexia].”

Michelle expressed that Matthew went through depression when he was initially identified dyslexia, which seemed like it was situational, since there are many emotions to deal with as a child matures as well as comes to understand their learning differences. He would frequently utter phrases that exhibited negative self-talk such as “Oh, I can’t do nothing… I’m nobody.” Michelle said that she repeatedly responded to Matthew by saying “No, no, no, no. It’s just a different way that you learn. Chill out. You’re going to learn and you’ll be OK.” Michelle shared that it was at this time that she started looking for other ways to teach Matthew skills that would help him develop a strong sense of identity and ability. She frequently looked for
opportunities to show him that he was not the only child with dyslexia. She would intentionally show him positive representations of adults who were successful in spite of their dyslexia. This is another time that she expanded on her positive ability to support her son both academically, as well as socially and emotionally. She was able to dedicate a significant amount of time to Matthew’s growth and development as a stay at home parent without worrying about a job outside the home. She said:

> There are gonna be days they don't want to be helped and you can't push them, because then they get frustrated, angry. And you know, they [have a] tantrum. But just, just to be able to be there… it makes a whole difference.

Michelle said she felt fortunate to have been able to stay at home to help Matthew during his initial identification in Texas. This allowed her to learn more about what dyslexia is and was also be able to provide Matthew with support when he got home from school.

**Moving to Puerto Rico**

Matthew was diagnosed with dyslexia in a borderland Texas school during third grade, at the age of nine. He received intervention services at the public school from the beginning of February until the end of his third grade school year – almost five months. At the beginning of his fourth-grade school year, he continued receiving those intervention services at Mountainside Elementary School in Texas. Michelle said that he was making significant progress and that overall, she was pleased with the school as well as the identification process in Texas. She also mentioned that she thought that Matthew had every single accommodation available and that sometimes it seemed that he actually had more help than he needed.
Around December of his fourth-grade school year, Michelle explained that Marco was offered a new position via DHS in Zoë, Puerto Rico. Since Marco was working for the DHS, their children were able to attend schools that are provided for Department of Defense personnel. Their family moved from the borderland back to Puerto Rico, where both of Matthew’s parents had grown up. Michelle provided all of the paperwork to the school as soon as they arrived in Zoë, documenting the services and accommodations that Matthew was receiving in Texas. Unfortunately, and to her surprise, she found out that Matthew would need to be reassessed to determine his present levels of performance. The new campus did not honor the 504 plan that Matthew had in place at his previous school and requested that Matthew be re-evaluated in all areas to see if he qualified for dyslexia interventions or any other services.

This practice is customary in special education and 504 programs in the United States. However, the new campus must do their best to provide the accommodations that a transfer student has, and they typically retest a student to see if there are any new areas of concern and to align the student’s needs with the resources at the new campus. Labels can be added or removed “based on a review of existing evaluation data on the child, that the child does not continue to have a disability or does not continue to need special education and related services (Department of Education, 2011). Conversely, the (dis)ability label can also be removed for other reasons, such as varying definitions of what a (dis)ability means state by state, and based on what services are available in a particular school district or area (Harry & Klinger, 2006).

In the case of Department of Defense (DOD) schools, military families are typically provided assistance from a service coordinator within the Exceptional Family Member Program (EFMP). Services available vary from location to location, and “states differ in who pays for
services; with some paying for services, while others require some to all of the costs to be paid by the parent” (Lieutenant Colonel Schuchs-Gopaul, n.d., p. 22). Michelle’s frustration with this policy is one that I had experienced as a teacher and administrator in an area with a high percentage of students from military families, as well as later, when I was working at the regional office with families that had children with disabilities. Finding placement, coordinating resources, and adjusting to a new city and state are elements that military families with children with different abilities have to navigate. I remember when I became a full-time special-education teacher after four years as a general education teacher, one of my students who was in a separate classroom for behavior had a problem. Her mother called me and said that our having classified her daughter as having an emotional disturbance was keeping them from being able to move. The caregiver was adamant that this label needed to be removed from her daughter’s special education file, as her new husband was hoping to get transferred to another military base. At the new base overseas, they did not have personnel able to provide their child with special education services. In the end, after the family advocated for several months with the school leadership team, the label was in fact removed, and the family moved to their new base.

The lack of special education services at DOD schools was something that Michelle had not anticipated. She assumed that since it was a DOD school, Matthew would have access to cutting edge resources for special education and 504. DOD schools are a network of schools that serve military and civilian DOD personnel in three areas of the world including Europe, the Pacific, and the eastern United States and Caribbean (Department of Defense Education Activity, 2020). This process of being reassessed again only about a year after he had been identified in Texas was frustrating for Matthew and Michelle alike. Matthew was assessed with an array of criterion-referenced and normed tests, as well as by the school psychologist and other staff at the
school. By the end of the assessments, Michelle was notified that he did not qualify for special education at their school. Furthermore, the campus staff explained that although he still had dyslexia, their campus did not have services for dyslexia. The availability of services at Michelle said the school psychologist explained that Matthew would:

Have to follow the same curriculum as everyone else. I was against that because my, my son would not learn the same way, as any other person would. So, that was a struggle and yes, I had to push through.

Michelle saw that Matthew was having a difficult time navigating the new school curriculum without any accommodations. Michelle explained that her son was embarrassed that they said he could not use any of the accommodations he had used before. He was confused that the new school said he did not qualify for help. This was especially confusing to Matthew, because Michelle had been proactive in getting him assessed in Texas and had discussed the characteristics of dyslexia with him. Matthew was aware that dyslexia was hereditary and would not go away. She was flabbergasted that the DOD, which she thought would have a wonderful system, denied any dyslexia services and that in fact, the school did not have dyslexia services. Michelle explained that in Puerto Rico, Matthew was treated like, "There's nothing we can do, you’re [a] regular normal kid. So deal with it, get tutoring or stay after school.” Michelle recounted that at this school, students were dismissed at 2:30 and that two-hour tutoring sessions were available each day after school. These tutoring sessions were provided by the general-education teachers and took place after school, divided up by alternating days based on the subject matter. For example, Matthew generally participated in the two-hour after school sessions every other day that were specifically for reading for fourth graders. However, these
tutoring sessions were generic tutoring sessions. Michelle said that there were not any teachers trained in dyslexia intervention during the day or after school at the campus.

Michelle explained that this was when Matthew realized the accommodations that he had in Texas were actually something that were useful to him. The family remained in Puerto Rico for nine more months, and during that time, Michelle said:

I had to talk to his teacher and try to [see if she would] agree that he would get extra time. If he didn't finish his work, then at least [I got the teacher to] send it home and I will try to help him over the weekend. That was something I had to talk to the teacher about, as it was not approved by the school, because he did not qualify for the program.

Michelle described searching for a support group in Puerto Rico and said that she did find some other families who were attempting to find dyslexia intervention services, but that particular DOD school had denied all requests. Michelle said that Matthew played in a little league football team that practiced twice a week and played games on Saturday mornings. She explained, “You know, the M.W.R. (Morale, Welfare & Recreation) has activities and sponsored events so one of them was football for our kids.” I knew exactly what she was referring to about the MWR; my dad retired from the U. S. Army and shopping on a local Army base and participating in recreational activities was something I was familiar with. Later, as an adult, my ex-husband was in the U. S. Marines and we also participated in events sponsored by the M.W.R. Michelle described that Matthew enjoyed the new children he met on the base, but that he missed his friends from the borderland area. She was especially grateful that there was an option of an all English school since via the DOD system saying, “he [Matthew] doesn’t speak that good of Spanish!”
Reflecting back on having lived in Puerto Rico for nine months, Michelle said that she was disappointed that the DOD school had failed her son as badly as it had. She had pride in where she had grown up and was excited to share her heritage as well as Marco’s with their children. Salma was enrolled at a local high school via the DOD school system and she adjusted quickly, making new friends and enjoying the culture and new city. However, the experience was not a positive one for Matthew, and it wasn’t positive for Michelle and Marco, as they decided to separate and file for divorce during their time there.

After many heated arguments with Marco, Michelle called Matthew’s grandfather, Robert, who had just retired as a civil servant and said that she needed his emotional help. Robert moved to Puerto Rico from North Carolina and offered emotional support for his daughter Michelle, and grandchildren Matthew, and Salma during this transitional time. By July of that year, Michelle and the children had moved to Alabama. Michelle was fearful that Marco would be angry about the family moving back to Alabama, where they had lived for some time beforehand, and where her parents lived. Michelle did not need financial help from her father, Robert. Rather, she wanted her father to be there in case she needed help during the time that she was waiting for the courts to grant the separation and for her to have joint custody of the children until the divorce was filed. As soon as the courts allowed Michelle to leave with the children, Michelle left Puerto Rico, and her father helped her move and get readjusted to living in Alabama again.
Figure 6.1. Michelle’s Experience with Advocating for Matthew to be Assessed for Dyslexia
Moving to Alabama

After living in Puerto Rico for nine months, Michelle moved to Alabama and she and her children lived in the multi-generational home there. The town they live in Alabama has close to 70,000 people and residents have a median household income of $44,200 (City Data, 2018). She explained that the process to get separated and move was challenging and that “my dad was trying to help me during the really hard moments... He went over there [to Puerto Rico], and stayed with me two months. It was a big thing. I had to go to court. I had to call the cops.” Michelle had to rely on law enforcement to help her because Marco did not want her to leave Puerto Rico with the children. However, they were able to come to an agreement the first week of August in 2019. Michelle left Puerto Rico and returned to their town in Alabama where they owned a property. However, she had to rent an apartment for a few months, until she and Marco’s home became vacant, since they were renting it to another family.

Before moving to Alabama, Michelle said that she wanted to make sure that she found a good school for Matthew. Upon doing research on the internet using sites such as www.greatschools.com, she found out that the state she was moving to was ranked three out of ten on a scale of zero to ten, a ten being the highest and zero being the lowest to rate schools in the area. When they arrived in Alabama, she continued her research both online, and by driving by schools she had found in their new neighborhood. She found a school about 15 minutes away from their new home that had good reviews. What she went to enroll him, she found out that the school had been permanently closed along with a few others in the areas that had seemed like good options. As Michelle usually does, she found a way to make the best of the situation and persevered, finally finding a private school in the area that seemed like a good fit for Mathew.
Michelle explained that she is still currently a homemaker and that she will continue to be a homemaker until the divorce is finalized. The private school that Matthew attends does not have any services for dyslexia, but his teacher was eager to learn new strategies and Michelle gave her information that she had learned over the last two years that were useful for Matthew.

**Navigating Dyslexia: A Caregiver’s Perspective of their Child’s Point of View**

Michelle said that Matthew’s views of dyslexia have changed over the past three years. Since the pandemic has happened and he is doing all of his schooling online, Michelle said he has learned to navigate parts of his schedule each day such as getting ready for school and attempting to login to all of his classes independently. Although she said that initially Matthew was discouraged and frustrated with his dyslexia, he has learned to embrace his learning difference and sees the value in using accommodations that he learned in the nine months that he was receiving dyslexia intervention services in Texas. Though it seems like a short period of time, he did learn techniques that helped him cope with dyslexia such as how to attack words that he is unfamiliar with, how to integrate self-regulation skills related to skipping over words he does not know, and how to find ways to comprehend challenging texts by using apps such as Bookshare or Learning Ally, both of which have audio-text. Although some of the strategies Matthew uses came from the many therapies he has done over the years, he has also learned to implement other strategies such as self-calming behaviors. For example, he quietly moves around the room if he is frustrated or bored with a task. Basically, Matthew has had to learn how to implement some of these strategies himself, because he had no other choice in Puerto Rico or Alabama. Although he knows he still has dyslexia, his previous accommodations have not been implemented since the fall of 2018 when they left the borderland area to Puerto Rico. Michelle
noted that it is not easy, but they are doing the best they can during this very challenging time of the pandemic and completely virtual learning.

Try Everything!

Michelle was very clear that she wanted to try everything that might help Matthew to learn strategies of how he could be successful at home and at school. She explained that this meant that she relied heavily on trial and error; attempting new things that did work and some did not, such as altering his schedule or diet. Michelle heard about these new ideas through feedback from both medical experts and Matthew’s third-grade teacher, Ms. Elguea. Ms. Elguea helped Michelle understand some new and innovative suggestions and resources that were available back in Texas. Furthermore, Michelle explained that trying to allocate resources for Matthew has meant coordinating services and therapies that are not always available in every area, and it was sometimes hard to know exactly which strategies were working since she was, in fact, “trying everything”. That is, some approaches have worked better than others, with the exception of one: medication. For Matthew, medication has had prohibitively severe side effects.

Medication

When Matthew was in third grade, Michelle decided to seek some intervention for him because he was having a hard time concentrating on more complex tasks and concepts at school, so she got him onto medications for ADHD. One of his private psychologists in Texas also diagnosed Matthew with Obsessive Compulsive Disorder (OCD) as well, and Michelle searched the internet, spoke to professionals, and found other parents via support groups on Facebook for help. She talked with other parents about what they were witnessing and experiencing as their children took various medications.
Matthew was prescribed a variety of medications under the supervision of a local psychiatrist, Dr. Montes. Dr. Montes advised Michelle that they begin Matthew on a regimen that did not include medication with higher dosages and stronger side effects such as Concerta. Concerta is a federally controlled substance that is used to treat children and adults with ADHD between the ages of 6-65, and has similar active ingredients as Ritalin (Rodden, 2020). Instead, Matthew began with lower doses of medications that Michelle described were each all supposed to help minimize his ADHD symptoms, such as Adderal, Klonopin, and Prozac. Unfortunately, there was not any improvement at home or school. Dr. Montes had alerted Michelle that some of the side effects of these medications would perhaps intensify his symptoms. Symptoms such as general anxiety and mood swings were things that Dr. Montes said Michelle would need to be aware of. Michelle said Matthew “suffered from all of that [anxiety and mood swings] naturally.” She did not really notice any intensification of those symptoms since Matthew had been managing them since he was in kindergarten and first grade. Matthew was already used to navigating those side effects and they did not increase with the medication. However, Michelle said that negative changes in his behavior began as the doctor adjusted each of the different medicines. She recounted, “he was just like, a zombie.” She said he lost elements of his personality and had almost no energy, along with a reduced appetite. She explained, “I prefer for him not to have so much medication inside of him that actually, it [just] affects him overall.”

What troubled Michelle most was that Matthew was very sensitive to the side effects. However, Michelle said she was not willing to force Matthew to endure the horrendous side effects associated with some of the medications they were trying. Michelle explained to me that side effects he experienced were:
Erectile dysfunction, severe constipation, and a lot of stomach pain. It was not worth it to me. [For example,] My son [was] not being able to walk because he felt uncomfortable. His private parts were not feeling normal, or the way they should be for a third grader. I did not have a good experience.

At this time Ms. Elguea was working closely with Michelle to ensure that Matthew found success within his school day. As Michelle observed all of the side effects that were happening to Matthew, she decided to start searching for new suggestions to help Matthew with his ADHD and OCD. She mentioned that Matthew’s third grade teacher, Ms. Elguea was a tremendous resource as Michelle worked with medical experts (i.e., the pediatrician, counselors, therapists, psychologists) to adjust and eventually discontinue all of Matthew’s medication use.

**Homeopathic Supplements**

During the year that Matthew was identified with dyslexia in Texas, Ms. Elguea, Matthew’s third grade teacher, was the teacher who Michelle appreciated most because she shared interventions that could be done at school as well as at home. Michelle felt that Ms. Elguea, who appeared to be Latina, genuinely wanted to make sure that Matthew had all of different resources he needed. It also seemed that Mrs. Elguea was passionate about finding unconventional ways to make sure that Matthew was successful.

Michelle was giving Matthew “an Omega-3 [homeopathic supplement], flaxseed powder in her cooking, and adding wheat germ into his morning breakfast smoothies.” Michelle used a variety of supplements, oils, and powdered supplements in her cooking, so that Matthew would get several opportunities to digest them. Integrating homeopathic supplements was an approach to treating his comorbidities of dyslexia and ADHD that I personally was not familiar with, and Michelle explained that she had heard of this not only on the internet but also from Matthew’s
most knowledgeable teacher, Ms. Elguea, so she wanted to try them. Michelle believed this regimen would help to naturally foster better management of his ADHD and dyslexia symptoms. Michelle was hopeful that this remedy would help Matthew with the differences of dyslexia and ADHD. Michelle may have thought that various homeopathic treatments would be feasible remedies because they are not drugs with negative side effects, as Matthew had experienced previously, and the advertisements for them are directed to families and they are described as good options to improve ADHD symptoms and even reading.

**Perceived Rationale to Help with ADHD.** Michelle’s use of homeopathic interventions is a practice that is used by many people in the popular culture. According to Reid & Valle, “it is not uncommon for children’s learning styles, individual learning patterns, and neurodevelopmental functions or dysfunctions to be a topic of discussion in popular media (e.g. news magazines… parent and women’s magazines, newspaper articles, talk shows, television news shows” (2004, p. 470). Furthermore, popular websites that families may come across when researching ADHD and dyslexia may lead families to organizations such as the online ADHD caregiver community called ADDitude. ADDitude is a non-profit organization that provides articles related to caregiver questions about ADHD. These articles discuss different perspectives and options for treatment and are written and presented as solutions that parents can try for their children. In a recent post to the ADDitude online caregiver community, Hallowell, Marner & Adler (2020) provide families with an article called *Can a Daily Fish Oil Supplement Help Curb Symptoms of ADHD?* Although I do not know if these supplements work for every child, as educators we need to understand that caregivers are trying to do right by their children. Michelle
was eager to share with me one of the new supplements she has started trying with Matthew during the pandemic, shown below in Figure 6.2.

![Homeopathic Supplement](image)

**Figure 6.2. Current homeopathic intervention Michelle is giving Matthew.**

Michelle described that she is not sure exactly if there has been any tremendous difference in Matthew’s ADHD and OCD because of this new homeopathic supplement, Matthew has been able to independently navigate getting ready for school each morning and logging onto his first class. After the first class, however, Michelle has to be in the same proximity to ensure that he stays focused and on task with the virtual instruction he is doing. She added, “you are not going to be able to get a kid with ADHD, OCD, and dyslexia to sit in front of a computer all day long!” I think that as educators we should work together to find solutions and support that make the most sense for each family’s cultural, religious, and educational beliefs.

**Perceived Rationale to Help with Dyslexia and ADHD.** The Omega-3 supplement that Michelle gives Matthew, for example, is considered a homeopathic supplement that she
considers to be a natural treatment. This intervention has had mixed reviews regarding the ability to improve school-aged children’s ability to read or in improving focus for children with ADHD. For example, a study conducted by the University of Birmingham and the University of Oxford (Richardson, Burton, Sewell, Spreckelsen & Montgomery, 2012) found a positive link between beneficial effects of ingesting omega-3 oils and slightly increasing word-level reading decoding abilities, working memory by recalling digits forward and backward, and reducing unwanted behaviors such as anxiety, emotional lability (mood fluctuation), impulsivity, and inattention, based on parent rating using the Conners’ Parent Rating Scale (CPRS). The assessment tool used to verify the children’s initial word reading levels was the British Ability Scales II (BAS). Although there was minimal increase, a similar increase was found in children who were taking the placebo. However, the same researchers (Montgomery, Spreckelsen, Burton, Burton & Richardson, 2018) tried to replicate the study several years later and found that there was not as strong a correlation as they had originally purported. Stating that the correlation between ingesting omega-3 oils to have an inconclusive correlation to increasing word-level reading decoding, working memory and unwanted behaviors. However, the researchers call for replication in this study but noted that even between the first study and second attempt at replication, it was challenging to enroll the same participants in the study and to use the same methodology. While elements such as changes in the national curriculum and changes to the process of accessing primary schools had changed between the first and second trial, one of the biggest differences was the criteria for children to participate based on their reading ability. This was changed to children who were identified as the poorest readers based on an either the BAS II or the updated version, BAS III. Therefore, research cannot support if the supplement that Matthew takes is effective in improving his impairments of ADHD and dyslexia.
Bull (2009) conducted a study in the United Kingdom with 148 children with dyslexia and their parents who preferred alternative therapies for their children. Bull recommends that educational and medical professionals alike realize that families may choose to use homeopathic interventions since they may feel that mainstream medical treatments are ineffective or have severe side effects.

Based on these three studies, it is not exactly clear that certain homeopathic interventions for dyslexia and ADHD work to improve reading or behavior. Replication of studies can be a challenge as noted by Schulz, Altman, Moher, & Consort Group (2010) who assert that researchers must ensure that when designing two studies, elements such as measurement and recruitment have to be explicit in order to determine heterogeneity among studies. Replication of studies is a unique endeavor in social sciences as well since it can be difficult to reproduce the exact same methodological elements from one study to another (Pashler & Wagenmakers, 2012); this phenomenon has been referred to as the replication crisis.

I wonder if caregivers may overestimate the role of non-educational interventions in their children's learning and might invest time and money in unproven therapies or treatments, rather than focusing on educational interventions. That is, perhaps both medical and educational professionals need to inform themselves first and foremost about different therapies that families may try. While some information is contradictory or has been identified as effective or ineffective through research studies, ultimately it is of the utmost importance that practitioners use culturally sensitive practices and respect families in their decisions to integrate other therapies.

It is also important to note that the studies listed above are from the United Kingdom. I found literature regarding the various available complementary and alternative medicine (CAM)
treatment options for ADHD from researchers in Johannesburg, Africa (Pellow, Solomon, & Barnard, 2011) and positively correlated empirical studies about the effectiveness of alternative therapies for ADHD from a study in Switzerland (Frei et al., 2005). On the other hand, inconclusive or minimal gains came from studies conducted in Seattle, Washington (Jacobs, Williams, Girard, Njike & Katz, 2005) and in Canada (Brulé, Sule, Landau-Halpern, Nastase, Jain, Vohra & Boon, 2014). All of the studies mentioned that future studies were warranted regarding the integration of homeopathic treatment for the improvement of ADHD symptoms.

As a former teacher and administrator, I am not sure about guiding families so much in making these very personal choices for their children, but I do see why it is important to listen and respect families own decisions.

Assistive Technologies

Michelle said that Ms. Elguea did not always have all of that materials that she needed to help Matthew and would let her know what to purchase. These materials included items such as colored overlays and different types of writing utensils, and Michelle appreciated that Ms. Elguea would let her know what these materials were so she could purchase them and send them to the class for Matthew to be able to try out and use.

The use of colored overlays is a debated accommodation for individuals with dyslexia in the United States and other countries with some studies and organizations supporting its effectiveness (Burke, 1999; Singleton & Trotter, 2005; The Dyslexia Shop, 2016; Razuk, Perrin-Fievez, Gerard, Peyre, Barela, & Bucci, 2018), while other researchers and for-profit organizations have found little, inconsistent, or no evidence of its effectiveness (American Academy of Pediatrics, 2009; Henderson, Taylor, Barrett, & Griffiths, 2014; Henderson, Tsogka, & Snowling, 2013; Hlengwa, Moonsamy, Ngwane, Nirghin, & Singh, 2017; Howard-Jones,
2014; Law, 2019). Be that as it may, I feel that in the constant search for different solutions for Matthew, Michelle mentioned that although not all of the ideas that they tried were successful, she wanted to make sure that Matthew had access to as many tools as possible so that he could learn to cope with his learning difference.

For example, I remember that during the four years I worked as a dyslexia specialist, I learned about these colored overlays and was initially skeptical. However, I clearly remember asking one of my fourth grade students, “What does putting that over your paper help you do?” and my student explained that without the colored overlay the “letters looked like they were swimming on the paper. It [the overlay] makes the words stay in a line.” I am not a person with dyslexia, therefore, during the time that I was learning more about dyslexia back in 2009, I had to realize that not all interventions work for each person in the same way. I remember talking to my student’s mother about this accommodation and mentioning what her son said. Neither of us could say exactly why this overlay worked, but with the descriptive example he gave, we knew that if it worked for him then we were pleased with a positive outcome. We were willing to “try everything,” just as Michelle had. For Matthew, I think it may have been a combination of many interventions that his mother and Ms. Elguea were trying such as the dietary changes, the assistive technology (colored overlays), along with the multi-sensory dyslexia intervention program, the Wilson Reading System (2020), which helped Matthew find success when he was newly identified.

**Intervention Expectations**

Michelle described that she had thought Matthew was going to get dyslexia interventions every single day of the school week. She said that in her eyes it seemed like it made sense that if a child goes to school every day to learn content areas like reading, math, social studies, and
science, why would it be any different for him to receive daily intervention for dyslexia. Something that was specific to Michelle was that she did not refer to this intervention the way the school did. Instead, she referred to Matthew’s dyslexia intervention as dyslexia therapy. I wonder if perhaps Michelle’s inclination to use the word therapy instead of intervention is associated with her professional training as a pharmacy technician. When Michelle found out that Matthew was only scheduled to go to his intervention two times per week, she went on a long search for the local private schools and private/out of pocket therapies to see if Matthew could get more assistance and learning how to independently use different coping skills that work best for children with dyslexia.

**Private School**

Michelle described that she also looked into transferring Matthew to a private school after she heard about his diagnosis. She felt that perhaps by moving Matthew to a private school he would get intervention services every single day when the committee explained to her the frequency of Matthews therapy or intervention at his local school. Michelle said that although the school was going to be offering either groups or one on one intervention two times per week, in her opinion this was not frequent enough. She inquired about several private schools, and although the class sizes were smaller, there were no special education services. Michelle was surprised to find out that children in private schools are not offered federal, free special education services within the private school setting and that children have to go to the local public school to get services, if the school district has availability. Contrary to what she believed, private schools are not afforded the same funding for services for a Free and Appropriate Public Education (FAPE). The special education law does not guarantee free
education or special education for children who do not go to public schools. However, if a private school has a child enrolled who requires assessment due to a suspected disability, the nearest public school is required to provide that assessment. If the child happens to qualify for services, it is up to the discretion of the local public school district to provide the services, provided they have the funding and resources to do so for a child who is not enrolled. That is, unenrolled students are not part of the calculation for how federal funding is used to serve students with learning differences.

For example, when a family was referred to me in the Fall of 2019, in my new role as an assistant professor in early childhood and special education, I had to explain to a parent why dyslexia services are not provided at their child’s private school. The caregiver explained to me that they were a tax payer within that local school district and that it was not fair that their child could not receive free dyslexia intervention services, because they pay property taxes in that area. Although they are taxpayers, since their child is not enrolled at the school, the campus is not required provide FAPE to a child who does not attend the school. The law states that identification services must be provided for all children, which is ambiguous. Though the small class sizes were enticing to Michelle, she felt that transferring Matthew to this setting would be futile, since the teachers were not reading or dyslexia specialists. Transferring Matthew to another new school would not have been a concern for Michelle or Marco since they had moved around frequently due to his profession. The main goal was to coordinate services that would help Matthew to be successful, regardless of whether he would have needed to move again, and regardless how much it cost them financially.
Family Funded Therapy and Counseling

Michelle explained that when she heard that Matthew had dyslexia, she automatically sought medical intervention for Matthew. She explained to me that after Matthew was identified with dyslexia, the pediatrician gave her different recommendations for medical therapies. She explained that she wanted to help Matthew as much as his possible since it seemed like “he just couldn’t put everything together… his brain wasn’t working.” She learned that there was private biomagnetic therapy and neurotherapy which held claimed that would help with ADHD as well as dyslexia, so she looked into it.

*Biomagnetic & Neurofeedback Therapy.* Unfamiliar with these types of therapy for children with speech, ADHD or dyslexia, I promptly asked Michelle funneling questions to understand what the therapies were and how they related to dyslexia. Michelle explained that biomagnetic therapy is “when they put magnets in certain points of your body, and it’s supposed to channel the energy in your body.” She was eager to provide several clear and concrete examples, explaining:

So let’s say [the concern] is bed-wetting.. they put the bio-magnetics close to your vejiga [bladder], and it’s supposed to help you control [bladder use].. or like if you have knee pain or back pain or stress, they put those magnets and it’s supposed to stabilize that part of the body.

Biomagnetic therapy is something that Michelle felt that gave her some respite as a caregiver. She explained that Matthew enjoyed it since it helped him relax and it helped her because he would calm down a lot, and sometimes he even fell asleep during the sessions. Since Michelle
was always taking Matthew back and forth between therapy sessions, she said after he would leave those, he was very calm and that in turn allowed her to be calm as well. Each time he went to those sessions, the therapist would put magnets on the specific area of his body to divert energy there. He had to lie down and relax, and much of the time he would fall asleep during his 45-minute session. Michelle found out about this therapy from her pediatrician who referred her to a doctor at the local university medical research center when Matthew was six and his teacher said that she could not understand his oral language. From the time that Matthew was six until they left for Puerto Rico, he had received both biomagnetic and neurofeedback therapy. Michelle said this therapy used sensors, and that the sensors are placed “somewhere on your head, and it depends on the points [that are being addressed]. They’re like little sensors... which transmit a wave and frequency.” Neurofeedback is a therapy that is believed to redirect brain waves and function in a non-invasive manner (Hammond, 2011). Furthermore, Duarte, González, and Alvarado (2016) define neurofeedback as a neuronal self-regulation technique that teaches people to modulate their brain frequencies using visual and auditory reinforcements that can be presented on a computer screen. In Matthew’s case, his neurofeedback therapy sessions would happen in a variety of ways however he always had to be focused on a particular object. then when he finished there. Michelle explained:

    Depending on how his day went it was one of two things. Sometimes he would read a book or he would be watching TV. The type of session his therapist would do be doing his homework or reading a book and his therapist would ask guiding questions.

Michelle described the neurofeedback that Matthew received included some sensors that were taped on his head, then those plugs were connected by some wires to a machine that monitored
wavelengths, that machine was connected to a laptop that would show you the data of what was being changed in real-time. Another plus to having Matthew at this particular therapist was that Michelle was told that they could do her therapy in a separate room and Matthew’s in another “as a two for one.” While she still had to pay for two sessions, she did not have to schedule so many different appointments and coordinate different trips back and forth, since she had to drive about 35 minutes each way for that therapy. So sometimes she and Marco would go together for marriage counseling, and Matthew would be in another room receiving his therapy, or Michelle would go on her own for her counseling and Matthew would be in his session.

In a 2016 study by Tehran, Raesi, Dadgar, Soleymani, and Hajjerforoush, the authors state that after 20 sessions of neurofeedback therapy, they documented improvement in the spelling, accuracy, and comprehension reading in four boys, between ages 8-12 who were in their study. A similar study with 12 children with dyslexia showed that neurofeedback shows improvement in areas such as speed reading and comprehension, but not in reading abilities (Breteler, Arns, Peters, Giepmans, Verhoeven, 2009). Two other small studies claimed that this technique assisted struggling readers, although the sample sizes were small as well and cannot be generalized (Thornton & Carmody, 2005; Walker & Norman, 2006).

Michelle said that Matthew benefitted from both of these therapies especially during the first three months that he was doing them. However, she said it is hard to tell how much they actually helped, since they were also doing so many other interventions at the same time. Finally, she said that she had considered stopping these treatments after about three and a half months, but since she was not sure if they were helping him, she did not want to remove any of them. Overall, she said it likely was a combination of many different strategies that they tried all at
once that helped Matthew with his speech, sensory processing disorder, dyslexia, OCD and ADHD characteristics.

**Counseling.** Michelle felt that the counseling that Matthew was able to receive was helpful for him, as well. In these sessions, he developed skills that allowed him to accept all of the different diagnoses that he had. While Michelle said that the counseling did help, she also took it upon herself to facilitate a system of support for her son. She explained that a movie we watched during several parent training sessions and at the two dyslexia Saturday camps that I created was very helpful in counseling Matthew. When I created these dyslexia camps, I knew that I wanted to have pictorial and film representations of families who had navigated the process of dyslexia identification. Michelle appreciated the dialogue that ensued at each of these camps, and mentioned that this integration prepared her for conversations with Matthew. The primary facilitator in the parent sessions at those camps was one of my committee members, Dr. Beverly Calvo, who has extensive knowledge of the dyslexia identification process in Texas, since she herself is an educational diagnostician and a professor of special education.

In the parent sessions and at the dyslexia camp, we used the documentary called *The Big Picture: Rethinking Dyslexia*. This film was created to reveal the myths, stigmas, and truths about dyslexia (James Redford, 2012). The film is used for trainings with families and educators learning more about dyslexia and it tells inspirational personal stories about navigating dyslexia. The film takes viewers on a journey of how children work through their dyslexia experiences in K-12 settings, and includes perspectives from experts and examples famous adults with dyslexia. Specifically, Michelle said she appreciated the different representations of families navigating the dyslexia journey that were in the documentary as well as the examples of successful adults with dyslexia. Michelle purchased this documentary on Amazon and
intentionally watched it with Matthew and other family members several times. She found that
this was a useful tool when counseling Matthew as he has navigated the diagnosis of dyslexia
because she could use it as a springboard to have long conversations about his learning
difference(s). When Matthew would come home feeling particularly defeated, she would remind
him of the different adults in the movie who had challenges as children, including filmmaker
Steven Spielberg and entrepreneur Richard Bronson. These representations of the challenges and
strengths of individuals with dyslexia were helpful as Matthew has navigated dyslexia
identification in three separate systems around the United States and territories.

**Wisdom from Michelle to Parents and Caregivers**

Michelle was passionate to learn about dyslexia when she was initially informed that
Matthew had dyslexia characteristics. When sharing her experience with the phenomenon with
me, she laughed and said, “I’m able to share a lot and give you a real big range of experiences
with the identification process across three states”. While Puerto Rico is not a state and Matthew
was in a DOD school there, not a public school, Michelle did navigate figuring out three
separate systems of identification for ADHD and dyslexia. When thinking of the entire process
and what advice she could give to families, she said, “Life is a roller coaster, as long as you
could learn how to um, surf the wave, you're good [laughs].” She clarified that in her opinion, the
identification process in Texas was much more comprehensive and clearly delineated than it
was in other places, even though she knows her experience is particular.

Michelle said that initial school where Matthew was identified was “very good,” and
even though Matthew was only there for five months, Michelle had met many parents who had
not had as simple a process in advocating for their children to get tested for dyslexia.
had only been at Mountainside for about five weeks before Ms. Elguea noticed how much he struggled with the environment throughout the school day, and recognized the impairment resembling dyslexia characteristics. That is, the “very good” experience Michelle and Matthew had completely depended on the chance that Matthew’s teacher knew about dyslexia characteristics. Michelle realized that this experience was in many ways, a fluke. However, Michelle was adamant that if Matthew had originally been enrolled at Mountainside from kindergarten to second grade, another teacher would have seen his dyslexia characteristics earlier. Michelle felt that the school staff at Mountainside was better trained than at his previous school. This was because at Red Apple Charter School, none of Matthew’s teachers has noticed that Matthew might have dyslexic characteristics. It was not until he transferred to Mountainside elementary that his new teacher, Ms. Elguea had an inkling that Matthew may have dyslexia. Michelle elaborated on this point saying that if she had left him at Red Apple Charter, she probably would have never known to even demand for testing at that school, mostly because she did not realize he had the characteristics to begin with.

**Parent Resources and Support Groups**

Michelle noted that one of the things that helped her most during the initial identification process was the parent trainings that I led. Michelle found out about these trainings when the dyslexia intervention teacher sent home the information about them. These parent trainings were available to her when Matthew was initially diagnosed, and she appreciated the current information about what dyslexia was, as well as learning what the myths about dyslexia were. She said she was grateful to be able to network with families who were either in the initial stages
of having their child identified or who had children with dyslexia who were in various stages of their K-12 schooling career.

Michelle noted that one of the things that helped her most during the initial identification was attending a local disability agency, Borderland Disability Coalition (BDC), which had parent trainings, support groups, and learning opportunities for families. Although Michelle knew that the *Texas Dyslexia Handbook* stated that parents should be offered training and information about what dyslexia was, she said that the only place she could find learning opportunities for herself as a parent was at the BDC. When I asked her if the school had information about dyslexia, she said they didn’t share much information and that the only way she found out about the local parent center was through a flyer that was sent home by the dyslexia intervention teacher.

Michelle suggested that having similar support groups at local schools would be really helpful for parents who were new to the process of dyslexia identification, so they can learn from other families going through the same experiences. The trainings at the BDC were useful to her, as they allowed her hear about different perspectives and ideas. It was a sort of ‘one stop shop’ where she could learn about different topics with other families going through the same experiences.

This made me connect to an experience I had as a teacher sitting in ARD meetings many years ago. I remember families asking my colleagues and me where they could learn more about their child’s disability. We used to say, “there are so many agencies out there to help you. Just look them up.” The problem with this is that when a family goes onto the internet (if they have access), or if they do a search in the community, there is so much information that it can be
overwhelming. It is easy for caregivers to fall down an information rabbit hole. Because these families were from the borderlands, some of their experiences were particular to the school districts and did not apply to Matthew’s situation at a charter school. Having support groups within local school districts would have been beneficial, since each school district has its own guidelines and processes. Michelle explained that having parent training sessions specifically for dyslexia would be best if they rotated to different campus locations within the school district. “At least you can see other people who … are going through the same situation that you’re going with your kids at the same school…It’s just easier, I guess. I don’t know…” Being able to pinpoint why having other caregivers around that were in similar situations in their journey of navigating the identification and intervention process in Texas was hard for Michelle to explain, but she did say she learned more about what the learning difference was and about the laws regarding 504 and special education. However, the purpose and goal of the BDC and nearly 100 other Parent Information Centers and Community Parent Resource Centers around the United States is for the organizations to collaborate with professionals in the field to provide resources for caregivers who have children with various neurological, behavioral and developmental abilities (Center for Parent Information & Resources, 2020). These Centers are located in the United States and its territories, including Puerto Rico, and are federally funded by the United States Department of Education, Office of Special Education Programs. These locations bring together caregivers and professionals so that they can be informed stakeholders in their children’s education and development.

**Blame.** When thinking about her experience with the dyslexia identification process, not only in Texas but into other states, Michelle said that one thing that she learned was that as a parent you cannot feel guilty that your child receives the label of having dyslexia characteristics.
Philosopher Sher (2006) defines blame as an attitude that an individual takes toward themselves or someone else because there has been failure to conform to a moral standard. When thinking about coming to terms with what dyslexia was and learning that it is also hereditary Michelle mentioned, “It’s not your fault, you did not do anything wrong. There's nothing wrong with your child. You just have to learn different things, different ways.” Michelle remembered that she really appreciated the unintimidating atmosphere and the openness of the parent training sessions, including opportunities for caregivers to share their stories and discuss their concerns.

Michelle was able to come to terms with this because she had felt guilt and blamed herself initially when she found out that Matthew had dyslexia. She searched and came across articles that pointed blame at pregnant mothers who took any medication while pregnant and reflected on the fact that, “I do not ever like to take medicine. But when I was pregnant I had a really bad headache and the doctor said it would be ok to take one Tylenol. So I wondered if that made Matthew have it… Ultimately, she said that she learned that there are somethings that just happen and are out of your control as a parent.

Michelle was thankful for the raw emotions that other parents shared during the support group sessions, and used the terms parent training sessions and support groups synonymously. Being surrounded by families who were going through having the same questions, challenges, and joys helped Michelle feel supported during the identification process and when Matthew began his intervention at school. “You know you have a kid with some type of disabilities, so you want to learn and sometimes sharing is just gets it out of your chest and you just feel better.” The vibrant discussions were something she looked forward to and they also helped her understand more about what Matthew was experiencing as a person with dyslexia.
Broomhead (2013) found that caregiver experiences with guilt and blame vary and depend on if families felt that educators blamed them for their child’s different abilities as well as the nature of their child’s special education needs. Coming to terms with the realization that a caregiver has a child with a disability and moving past the stages of blame or guilt is a unique element that caregivers sometimes have to navigate. Michelle learned to navigate the feelings of guilt by also relying on her faith, stating that “some doors open and some close, and that happens for a reason.” She said that she definitely is religious and that when circumstances get particularly challenging she knows that her faith will guide her through the challenge.

**Honesty with your Child.** During the long discussions at the BDC dyslexia-specific trainings I facilitated, Michelle said she enjoyed hearing different parents’ perspectives. She explained that she appreciated being able to justify the choices she was making as Matthew’s caregiver in relation to his dyslexia. She made clear that every family has to make their own decisions based on their circumstances, including if their child will be medicated or take a natural approach, along with what access they have to resources in their area for private schools and private therapies. She added that depending on personal parenting beliefs, culture, and ideas surrounding different abilities and learning differences, she knew her experience was different in that she was able to stay at home and fully dedicate her time to finding therapies for Matthew. She was also able to attend seminars during the day. Finally, she also realized she had access to financial resources that not all caregivers had. She also knew she had what she called “wonderful insurance.”

Although families at the training sessions did not always feel that everyone’s parenting decisions were what they would have done for their children, the environment at the sessions was
something that Michelle said was respectful and in the spirit of learning without judgement. Michelle remembers several instances where families were adamant about not telling their child that they had dyslexia and were keeping it a secret from their child. She shared one specific example:

…that one lady [another caregiver at a session] who was not telling her kids about dyslexia… and I told the example [where] I told my kid. He needs to know. Why [are] you not telling them? Let me hear your point [of view]. And here’s my point of view. Which one makes sense? Well, everybody makes their own decisions, but at least I know from another person in front of me telling me their experience. So yeah, I don’t mind [parents that disagree with me].

That is, the occasional debate among caregivers was something she welcomed, since Michelle felt that all of the caregivers that she had met at BDC were there to learn more and to find ways to help support their children. That was something she was doing, as well. This honesty as a caregiver also was beneficial as Michelle helped Matthew navigate dyslexia after the school system in Puerto Rico said they did not have any services to help him and he did not qualify.

**Educator Preparation and Identification Process**

Michelle was passionate about providing suggestions as to how the dyslexia identification process can be improved, based on her experiences with Matthew in Texas, Puerto Rico, and Alabama. She was most concerned that at each campus Matthew went to, the teachers had extreme differences in their knowledge about what dyslexia was and was not. This even
included the way that other staff treated Matthew and also how they treated her as a parent who was able to stay home and go to the school at any time.

**Dyslexia-Friendly Teachers**

Michelle explained that Ms. Elguea communicated with her very well. She mentioned, “I got a great teacher for Matthew when he was diagnosed.” Marco and Michelle had made a decision to move Matthew to the largest school district in the borderland, hoping that the educators were more qualified and had access to more resources. Michelle felt that Ms. Elguea “worked for kids with dyslexia for a year so she had the knowledge, and even though she did not have the supplies.” The supplies were basic assistive technologies such as the writing utensils and the colored overlays. Moreover, Michelle just wanted for educators to keep trying a multitude of strategies. The reason she spoke so highly of Ms. Elguea was because she did not give up and if something did not work, she would continue searching for another solution that would help Matthew. Michelle wishes that all teachers would embrace this philosophy and at least make an effort to not only educate children but also find ways for parents to help them at home with innovative and cutting-edge supports.

**Dyslexia-Unfriendly Teachers**

Michelle felt that Matthew’s early childhood teachers from pre-kindergarten until the end of second grade did not know enough about dyslexia and perhaps missed many opportunities to identify that he had dyslexia. For example, a specific finding when I conducted a final member check with Michelle was that she elaborated more on Matthew’s early childhood teachers who did not suspect he had dyslexia. She mentioned that both his pre-kindergarten teacher and his
kindergarten teacher had mentioned that Matthew had handwriting that was difficult to read. More importantly, if his early childhood teachers at the charter school had known about dyslexia characteristics, they might have suspected that he had dyslexia characteristics because of his speech delay and their concern that his handwriting was not legible. Michelle made this connection when Matthew was in third grade and she was attending parent trainings regarding the *Texas Dyslexia Handbook* (2018), which states that early childhood teachers should know which characteristics are indicative of dyslexia at a young age.

She mentioned that teachers needed to be trained in dyslexia identification. It is up to educators to learn to help all of their students. Furthermore, Michelle said that teachers need to keep in mind that all parents “don't have that opportunity [to stay home], they are working or [they] come home at eight or nine o'clock at night, and they don't have that flexibility that I have.” Meaning that some parents do want to provide support and help to their child but they are navigating and managing other obstacles such as having full-time jobs or caring for their other children.

**Dyslexia Friendly Front Office Staff**

Michelle was grateful that during Matthews initial identification in Texas at Mountainside Elementary, there was one member of the office staff who had a child with dyslexia as well, Ms. Jeannie. Michelle explained that she had an ally who had already been through the dyslexia identification process first-hand and was able to talk to another caregiver who had a child with dyslexia who was also an employee of the district. Although everyone at Matthew’s new school had been helpful, Michelle had no reason to not trust them all, and wanted to give the new school staff an opportunity to do right by Matthew. Michelle genuinely appreciated that this employee of the district had a different perspective on the entire process,
especially since this was the first time that Matthew had been in a public school in this district. Michelle said that she felt like she could trust Ms. Jeannie wholeheartedly. For example, instead of having to call several offices to locate the right person that she was looking for regarding dyslexia in the district or having to drive around the city in search of services, Ms. Jeannie gave her specific names and phone numbers, saying, “OK, talk to this lady. She’s very nice. She’ll give you information.” This is an example of one of the ways that school staff can facilitate caregiver’s experiences during the identification process. Caregivers can easily become frustrated or overwhelmed with so much information and misinformation when trying to coordinate services and find answers about their child’s new identification.

Compadrazgo, or coparenthood, “is a common feature of Catholic countries…It is based on the Catholic doctrine of infant baptism and at its core consists of three roles – parent, child and godparent, and three relationships parent-child, child-godparent and parent-godparent” (Killick, 2008, p. 321). This concept is one that I can apply to understand the feelings of kinship that Michelle described she had with the front office staff member. “The interpersonal relationships of compadrazgo are similar to that between family members and are bound by the same time rights and responsibilities as blood related family members” (Gill-Hopple & Brage-Hudson, 2012, p. 117). The connection that Michelle felt with this employee she saw every morning when dropping Matthew off at school also built her trust towards the school in general.

**Dyslexia-Unfriendly Front Office Staff**

Michelle realized that her experience with the front office ally Ms. Jeannie was unique. Generally speaking, the front office staff does not have a direct impact on the curricular interventions specific to students with dyslexia. However, Michelle believes that school staff should have a basic understanding of all of the different abilities in the school building.
I mean at least they can have an idea. That would be nice. I mean I think any parent who has a child with special needs will like the people who are there eight hours a day, five days a week, to have somewhat of an understanding of what is going on.

Furthermore, Michelle provided an example of an interaction that probably happens more often than not in the front office on a daily basis. “Sometimes they’ll talk to a kid and a kid looks at them like, “I don’t understand nothing what you’re saying, but I know you’re talking to me because I’m looking at you. But what did you just say?” Michelle was very passionate about having a community of educators and staff around her son that at least attempted to learn more about his different abilities. This was because when she was in this borderland community she really appreciated the close knit community, even though it was a large city. Michelle said that this community had a feel that was like a family and the culture of those around her felt as if everyone was looking out for the best interests of one another. This was an expectation that she thought caring educators should exude for not only Matthew but other children with learning differences. She did not want him to be dismissed or ignored and more importantly wanted the adults around him to be respectful and help him learn how to be an independent and successful child.

**Dyslexia-Friendly Administrators**

Michelle sincerely appreciated that the assistant principal, Ms. Griego at Mountainside was honest with her and told her she was still learning about dyslexia and was not very familiar with the characteristics. Although when Matthew was identified as having dyslexia characteristics, the assistant principal did say that she was glad to see Matthew was receiving through the dyslexia interventionist. Ms. Griego said, “I don’t know, I don’t want to give you
the wrong information, so I’m going to get educated first.” After that point, the assistant principal attended the last two sessions offered at the local BDC with Michelle. Michelle appreciated the dedication and effort that this administrator showed during the only year Mathew was at that school.

One of the other aspects that Michelle appreciated about the parent training sessions was that she got to experience what dyslexia was actually like through an activity that we did at the session. The assistant principal was present for one of the simulations. The simulation was an activity called the Experience Dyslexia Simulation Kit (International Dyslexia Association of Northern California, 2020) created by the International Dyslexia Association of Northern California. The simulation kit has six learning stations where participants experience different aspects of what it feels like to have dyslexia and is intended to be used for teacher and parent programs to help raise understanding of the challenges of people with dyslexia. Toward the end of one of our interviews Michelle assertively said:

Texas was wonderful [laughs]. I have to say I think Texas is really, um, the school system for kids with dyslexia. It’s really stepping up. Compared to other places, and I’m giving you a broad picture [because we moved two other times in one and a half years after that first identification experience in Texas].

Michelle felt that she was able to compare how she felt as she moved from one place to another that all follow the same special education and 504 laws. She was shocked that although the same law applies throughout each of the systems she took Matthew through, they were each completely different and did not honor the dyslexia in the same ways.
When the administrator attended these parent sessions along with Michelle, the administrator and the parent got to learn the characteristics of dyslexia alongside one another. Michelle explained that this experience, where the administrator sincerely was interested in refining her skills as an educator was something that impressed Michelle. Michelle expressed that learning alongside the campus administrator at a few of the the trainings offered by the local parent resource center, Borderland Disability Coalition (BDC) were beneficial and would not only help her to work with Matthew, but also the future students with dyslexia that the administrator would assist.

**Dyslexia Un-Friendly Administrators**

The advice that Michelle had for administrators as well as for those in charge of making policies and laws is for them to be mindful of what dyslexia characteristics are so that they can make informed decisions for all students based on that knowledge. That is, in their role as leaders, it is their responsibility to know about learning differences and to provide support that builds upon each child’s strengths in learning both academic content and in social and emotional skills.

She went on to say that it is “the principal [who] should have knowledge of it [dyslexia], 'cause that's the person who's going to try to get the funds for the programs, right?” Administrators need to be aware of what the specific needs of children with dyslexia have so that they can coordinate tailored programs for children with different abilities such as dyslexia. For example, when Michelle was in Puerto Rico, she and the other families wrote a letter to the superintendent to request that a program for students with dyslexia be purchased. The administration “denied it [the parents request for a dyslexia specific intervention program],
because they thought they had purchased a really good English reading program that it was suitable for everyone. So they were not going to invest in a specific [dyslexia program].”

Michelle felt that the rigidity of the education system in Puerto Rico, which was a school that was within the Department of Defense (DOD) system, fell short in providing specialized support for Matthew.

Overall she said that she would leave the following final thoughts with families who are new to the dyslexia identification process, noting that the initial identification process in Texas was a pleasant one. She said:

You should make the best... make the best out of it. We all can feel sad and depressed...

We all can feel upset and angry. And at end of the day, you end up being happy. I'm trying. Not every day is colorful, but hey – there are more colorful days than gray days.

Michelle constantly mentioned that she felt that her experience was specific to her, in that she had been able to look back and appreciate that the initial identification process went the way that it had for Matthew. This is something that resonated with me because when we consider critical disability theory, there are some families that do not have the same experience due to limited resources.

Analyzing Michelle’s Story with Critical Disability Theory

Michelle’s experience with the phenomenon of dyslexia identification provides a perspective of what it is like to navigate parenting a child with a hidden learning difference. This notion of a hidden disability suggests that individuals with dyslexia have something that is not within the expected trajectory of typical development (Colgon, 2016). The idea that impairment
and disability are intertwined is a major tenet of CDT. In the first superordinate theme in Michelle’s story, Surprise! Matthew is a Child with Dyslexia, Michelle was unaware that her son was struggling with dyslexia, perhaps due to the environment that was created at school and at home, neither of which placed narrow focus on requiring Matthew to decode words aloud or reading tasks. In an ethnographic study with 12 Puerto Rican caregivers who had children with disabilities, Harry (1992) analyzed their perspectives of disability constructs. The parents’ characterizations of different abilities included much broader boundaries of ability. That is, their perspectives frequently resulted in disbelief or shock when a label was applied to describe their child, such as learning disabled or emotionally disturbed. While it is not possible for me to generalize, I do believe that this finding of Puerto Rican caregivers is something that can also be applied to Michelle’s outlook on Matthew’s dyslexia. Michelle described herself as Puerto Rican, and time and again described that she had never had any indication whatsoever that Matthew was struggling with reading. However, Michelle was aware that he had been navigating other co-morbidities such as ADHD, this is what CDT challenges- the notion that physical disabilities or ones that are obvious are given more effort to remediate than ones that are invisible, such as his dyslexia. Matthew’s outbursts and determination to complete tasks in a methodological manner as he deemed necessary were ones that had been more obvious to Michelle and Marco. This was because the environment would demand some skills that would trigger or initiate some of the behaviors associated with his sensory processing disorder and OCD.

In a recent study, Woodcock (2020) detailed the experiences that she and five other mothers who were from diverse socioeconomic and ethnic backgrounds had as they navigated the dyslexia journey with their children in Massachusetts. One of the participants, a mother
named Anna who had a son named Manny noted that during navigating her son’s dyslexia, she said “Thank God, that I had the time, patience, intelligence and resources to help Manny.” Further noting that “many dyslexic families sacrifice everything they have to support their child” (p 1649). I think that this is something that Michelle described in detail throughout remembering her journey with the dyslexia experience in multiple school systems. Michelle explained that one of the things that was most beneficial to her as a mother with a child with dyslexia, ADHD, OCD and speech needs was that she was able to be home with him throughout each of the identification experiences as well as when they moved around. Thinking about the pandemic and how much it has changed her perspective of providing support to Matthew, Michelle says that she cannot imagine if the pandemic forces all of the schools to be shut for an extended period of time. She feels that the lack of interaction with his peers is something that has been detrimental for Matthew since socializing can sometimes be challenging for him.

Michelle’s determination to find a way to help Matthew with dyslexia via a medical lens, allows me to reflect on a sociopolitical view disability as discussed by Meekosha and Shuttleworth (2009). In the second superordinate theme of Michelle’s lived experience, Try Everything: Homeopathic, Medical, and Assistive Technologies, she described all of the ways that she was determined to find any assistance she could for her son with the dyslexia identification as she had in the past with his sensory, speech and ADHD needs. I believe that her constant consideration of how to provide resources that would ameliorate or get rid of his disabilities all together can be attributed to her professional background in medicine as a pharmaceutical technician. I do not mean medical in terms of medicine, although Michelle did medicate Matthew for about half a year during the time that he was nine and ten years old. She did try a few medications under the supervision and guidance of his psychiatrist; rather I think
that she believed that therapies such as neurofeedback, biomagnetic, and counseling were ways that she could help him overcome his diagnosed differences. The experience that Michelle had with the process of requesting the initial dyslexia assessment in the school in Texas (which was free) for her son from the education system and then later declining to have him assessed by a medical professional who was regarded as being able to treat dyslexia is an example of the medicalization of turning “non-medical problems” into pathological medical problems (Conrad & Leiter, 2004, p. 158). Michele mentioned that one of her frustrations was that different centers want to charge you a whole new fee. She explained:

One was $500 to reassess your kid even though you already have the testing done. It’s really frustrating. It’s like you feel you can’t do anything. The school has the program and not every school has it [a dyslexia intervention program. Because the school he was at before does not have that program [the charter school].

Michelle expressed frustration that there was not a consensus on one way to give him therapy or in regards to what assessment was better than another. In her perspective it seemed that each entity (school and various centers) required a new assessment. The one from the school trained professionals did not transfer to a new public school system nor did any medically trained professionals accept the school’s assessment. The center that Michelle describes in the quote above was a language clinic. This was a language clinic that I had visited after hearing other caregivers tell me that their child was making more progress at the center with new therapies versus the multi-sensory intervention programs in the schools such as Wilson.

I was asked to provide a training to the clinic’s staff about the dyslexia identification
processes in Texas schools by the owner of the clinic. This was a unique and interesting experience for me because I had seen in the literature that in the United Kingdom dyslexia intervention is primarily provided by speech language pathologist. This view of providing strategies and building on skills as related to speech was something that I had never heard of in the public school system where I worked in Texas. Moreover, the idea of having a speech therapist provide services for dyslexia in the public school system is not a common practice in the United States. Although a private speech therapy clinic was another option for Michelle to consider for Matthew, she refused to pay the fee to reassess him using their diagnostic assessments. This was primarily because she felt that if the school had already done the assessment and found that he had dyslexia characteristics, it was not necessary to do it again. In her opinion it seemed contradictory to have so many assessments that would all show the same results. However, Michelle was able to experience this disconnect when they moved to Puerto Rico and after Matthew went through another battery of assessments, the school psychologist said that he did not qualify for the special education services they had at the campus, and that dyslexia intervention was not a program they offered. I think that if Michelle had been in a city where there was access to a clinic which offered functional magnetic resonance imaging (fMRI) technology to diagnose Matthew’s dyslexia, she may have felt better about the “fact that he had something” that could actually be seen and diagnosed.

Finally, in regards to the educational opportunities that Matthew experienced when he was initially identified in Texas, I wonder what might have happened if he had access to teachers who were able to truly accommodate and integrate content across multidisciplinary subjects aligned with dyslexia instruction. Annamma (2018) states an idea that teachers situate dis/ability “as something to simply accommodate, not to organize lessons around” (p. 92). I feel that the
way that Michelle described Matthew’s experience with being identified in Texas with dyslexia was one that afforded him a teacher who organized lessons around his dyslexia rather than simply accommodating it. This is because his general education teacher had extensive training (at least 200 hours to become certified followed with 50 hours every five years in a structured reading program, with the Wilson Language Training Program). Therefore, Matthew was able to have access to both a specially trained teacher who met with him for 45 minutes at least three times a week to target language skills (phonetic components, syntax, decoding, and oral language). On top of that, he was able to return to his classroom and have a general education teacher who explicitly found opportunities to make connections for Matthew between his reading skills embedded within the content areas that he was learning.

**Intersectionality and Michelle’s Story**

I think that Michelle’s experience as a caregiver with multiple intersectionalities (Puerto Rican, always concerned about her second-language abilities, and an impending divorce where she will be losing Marco’s income) allows me to consider the experiences that he and his mother had during the initial identification in Texas and the following two moves. I cannot speak directly of Matthew’s experiences, since I had a second-hand account, however, Michelle did explain in detail how she felt each of the identification processes unfolded as they moved to a new education system. The use of an intersectional disability discourse as suggested by Connor (2006) and by Hernandez-Saca, Kahn, & Cannon (2018) allows me consider how this caregiver navigated her child’s internal and external feelings associated with his sense of self. Since Matthew had multiple diagnoses, Michelle explained that she was always aware of intentionally providing support for him that refuted the idea that his differences were negative or associated with stigmas. For example, Michelle described that although no teacher said directly that
Matthew was lazy, she felt that depending on how a teacher viewed ability, they made it seem that Matthew was choosing to not conform to their views of how a child should learn and behave in an elementary classroom. Ben-Moshe et al. (2013) states that the critical framework of disability studies makes clear that “disability is fluid and contextual rather than biological. This does not mean that biology does not play out in our minds and bodies, but that the definition of disability is imposed upon certain kinds of minds and bodies” (p. 210).

I can see how a fluid categorization of disability was evident in Michelle’s experience, because she had learned that dyslexia was hereditary and life-long. Michelle explained that Matthew was able to experience a system initially, when he was identified as having dyslexia characteristics in Texas, that integrated both the biological nature of dyslexia (which is neurobiological) and coordinated the context and environment in a classroom where his main teacher was a formally trained dyslexia interventionist who could weave dyslexia intervention and coping strategies together, using multi-sensory techniques in his daily classroom environment. On top of that, Matthew was receiving services from a second teacher who was currently a dyslexia interventionist and who was focused on targeting the exact needs that Matthew was exhibiting and needing more assistance with a formal program several times a week. Therefore, when she moved Matthew to Puerto Rico and found out that the system there did not acknowledge this specific learning difference, Michelle had to find new ways to ensure that her son would be successful in navigating his learning and behavioral differences without the supports that had been learning to use independently with scaffolded support from his general education and dyslexia intervention specialists within the public school. Ben-Moshe and Magaña (2014) put into perspective the rift between caregivers of people with disabilities as opposed to the experiences that people with disabilities themselves have. The authors state that the “major
differences lies in the fact that parents to not have the same opinions as their children” (p. 107). Keeping this in mind, it is important to consider the fact that I do not know exactly how Matthew felt when he moved from a school that was supportive of his unique abilities to one that did not even honor any of those abilities and outright said he could not qualify for any services. The intersectionality framework helps me understand how Michelle navigated oppression or discrimination based on Matthew’s abilities. As Matthew moved from the borderland community to Puerto Rico with relatives, Michelle had anticipated it would be a positive move for their family.
Chapter VII: DISCUSSION OF THE FINDINGS

The purpose of this chapter is to discuss the implications of this study. It begins with an overview of significant findings followed by consideration of these conclusions in light of existing research studies. After this, I consider the implications of my study for current theory and research in the field, as well as the limitations of my study. And finally, I discuss recommendations and suggestions for future research.

This qualitative study investigated how caregivers from minoritized backgrounds navigated the dyslexia identification process in a borderland community in Texas. I asked this question:

How do families from minoritized backgrounds in a borderland community in Texas experience the dyslexia identification process?

To address this question, I initially recruited participants from a local parent resource training site, Borderland Disability Coalition (BDC). The BDC is a non-profit that serves families in the borderland who have children with disabilities. Due to a limited response I also advertised my study at the Borderland Language Clinic. Ultimately there were three participants who met the criteria to participate in this study, Anna, Michelle, and Melissa. Using Interpretative Phenomenological Analysis (IPA), I analyzed each of their experiences individually and found their superordinate themes. In this discussion, I consider the similarities and divergences amongst their stories. These themes provide a lens into the experiences that caregivers in a borderland area in Texas had while navigating the ambiguous dyslexia identification process. After considering the way that I would frame this learning difference throughout this final analysis of my work, I decided upon following Annamma’s (2018) definition of the complexity
of the word disability. I will include a slash in dis/ability to address the ways dis/ability is not a thing to find and fix but a process. Annamma (2018) states:

That is, to be dis/abled is about the ways an environment is constructed and maintained in ways that support or hinder access. Being dis/abled is not simply a fact that people carry with them, but a fluid process dependent upon social context… Therefore, it is not that there are no differences between people, it is that some differences we imagine as so significant we must label, segregate, and remediate them. (p. 7)

All of the stories that the caregivers shared with me about their experiences included a multitude of factors that either challenged assumptions about, embraced, placated, or completed ignored how environments were arranged and impacted their child’s impairment of dyslexia. Taking into account that postmodern scholars of dis/ability studies want to challenge binary thinking, this study provides insight into the ways that caregivers identified and later navigated their children’s dis/ability in public schools.

**Overview of Significant Findings in My Study**

This discussion satisfies the function of a dissertation study as recommended by Rudestam & Newton (2001), as “drawing implications from the results of the study to the worlds of theory and practice” (p. 171). My study begins to fill the gap I found in the literature, namely, that caregiver experiences during the dyslexia identification process, particularly those from varied socio-economic and ethnic groups were missing from the extant literature. The significant findings were: (a) the route to identification varies significantly based on numerous factors that I will discuss below, and; (b) advocacy does not stop upon identification.
Route to Identification Varies Significantly Based on Numerous Factors

It appears through my participants’ experiences, that the pathway to how and when a child is identified with dyslexia varies significantly from child to child. How a child was identified varied in each of the three caregiver’s experiences. Two of the caregivers initiated the process after several years of advocating, because they saw their child struggling at home with reading. While one of them did not initiate the process because she had not realized he was struggling with reading. These findings suggest the amount of time that passed between initial concern and actual assessment varied between zero months (for the caregiver that did not detect any reading struggles) to 36 months. Figure 7.1 provides a comparative timeline.

Figure 7.1: Number of months it took between initial parent concern and final campus agreement to assess their child.

Parent-Initiated Identification Process

Two of the three caregivers who suspected an impairment felt the need to learn as much as possible about why their child was having difficulty in the area of reading. They did not necessarily know that the dis/ability, label or term would end up being dyslexia. In these two examples, teachers and administrators were consistently unaware of the characteristics of dyslexia. Both Anna and Melissa suggested that they were concerned that their children were struggling with reading and each of them asked the teachers for their professional opinions regarding their apprehension. In both caregiver experiences, the teachers in pre-kindergarten and kindergarten gave responses that blatantly discredited their concerns, failed to validate or
investigate the root cause of their concern, and persuaded the caregivers to simply “just wait “or “give it some time” before requesting a formal evaluation. This advice resulted in lost time for their children who could have been receiving reading interventions for dyslexia. This meant years of lost time that could not be regained for their daughters. Woodcock (2020) asserts that “We [practitioners in schools, higher education and/or clinical medical settings] can no longer shrug off vague symptoms” (p. 1651). This finding was suggested after conducting an authoethnography alongside interviewing five caregivers about their experiences with the dyslexia identification process. In Woodcock’s (2020) study, the caregivers mention an in-betweeness where it was difficult to have their child assessed because of the vague nature of identifying a hidden dis/ability such as dyslexia.

Ultimately, in my study, one child, Mikayla, was retained in kindergarten. After repeating kindergarten another time, she was identified an entire year later in first grade, as having dyslexia characteristics. Later on, in second grade she was also identified as needing support for ADHD characteristics and a math learning disability. While April, another child in the study was promoted from kindergarten to first grade without concern from the school system and was identified as having dyslexia characteristics later that year. Both of those caregivers mentioned that administrators had been either passive, very direct, or a combination of the two in their assertion that their child did not have dyslexia.

The entire point of having safety-net systems in place such as multi-tiered systems of support (MTSS) or response to intervention (RTI) is to have processes in place that improve the accuracy of identification. Systems such as these have a “lack of clearly defined intervention procedures” (p. 15). This in turn leads to confusion on how to provide support for children who are showing inconsistent or no progress. If processes toward identification were clearer for
teachers, then perhaps caregivers would not have to advocate so assertively. Caregivers sense of urgency to have their child assessed is so that their child can have equal access to learning. This access is what is outlined as a guarantee in a system that purports that the intent is to provide a Free and Appropriate Public Education (FAPE) to all children. More importantly, the tenacity these two caregivers showed as they advocated for their children is aligned to the idea in Critical Disability Theory (CDT), that everyone with a disability, should be provided equal access to curriculum and social opportunities. I assert that this idea should also include their families who advocate for them. This equal access in society and public schools is something that caregivers should not have to face discrimination for due to the fact that there is the hidden impairment or dis/ability of dyslexia within their child.

**School-Initiated Identification Process**

Upon identification, which was recommended by a teacher, the third caregiver became determined to learn and try everything that she could to support her child. In this finding of my study, the caregiver was surprised that the general-education teacher was able to detect dyslexia characteristics in her nine-year-old son. In this instance, Michelle was shocked because Matthew had already had three years of education at a local charter school. For those three previous years, the only thing that two of his three teachers observed about Matthew was that it was difficult to read his handwriting. Matthew’s kindergarten and first grade teachers’ concerns could have lead them to investigate if it perhaps was indicative of dysgraphia characteristics, which can be a comorbid dis/ability with dyslexia.

The *Texas Dyslexia Handbook* (2018) states that dysgraphia is best defined as a “neurodevelopmental disorder manifested by illegible and/or inefficient handwriting due to difficulty with letter formation” (p. 59). However, dysgraphia is a dis/ability that was recently
integrated into the 2018 edition of the handbook. Berninger & Wolf (2016) describe the process of handwriting as much more than a simple motor skill. Handwriting is a complex activity that involves not only physically moving fingers on a hand, but also multiple processes of language competency needed to complete the drawing, listening, repeating, and even use of eye movements.

This would mean that at the time Matthew was identified back in 2018, his previous teachers were not mandated to have been trained to detect this as a possibility. By the time Matthew was in third grade, his teacher realized he had dyslexia characteristics within the first month of school and asked Michelle to come in for a parent teacher conference only a few weeks afterwards. The bigger challenge to consider here in Matthew’s identification was that he was fortunate to have had a teacher who had already been trained in dyslexia multisensory intervention programs. If he had been in April or Mikayla’s schools, we can assume that he would not have been identified when he was, because he would have not had this highly specialized teacher. Michelle realized that she did not have to face the same types of oppression and discrimination from school staff that other families have had to endure while attempting to advocate for their child to be assessed.

**Advocacy Does Not Stop Upon Identification**

Two of the caregivers in this study expressed the exhausting nature of having to perpetually monitor whether or not the school was providing the appropriate special-education assistance for their children. Two of the three caregivers described being at Individualized Education Plan (IEP) meetings and realizing that their children were not getting the time they required for interventions in their schedule pages. Sometimes, they were surprised to learn that their children had been segregated from their peers so frequently. This led both of these
caregivers to refine their advocacy skills for their children and to demand that the school do more than they were to assist their children in integrated settings with their peers.

Michelle was the only one of the caregivers who moved to a new school district and had to navigate the problem of her son no longer qualifying for special education services. This process of first having a child identified and labeled as having a dis/ability in one area and then not in another area was very confusing for both Michelle and Matthew. Michelle described that Matthew was confused during the identification process and frequently mentioned being embarrassed once he moved to a new school system that said he did not have any dis/abilities.

All three caregivers expressed sincere unease regarding their children’s progress during the COVID-19 global pandemic. Each stated that they were advocating for their child to at least receive a basic education virtually. However, one of the caregivers, Melissa, was not as worried that the pandemic would make its way to the borderland when we had our first interview on March 11th, just as pandemic restrictions began to be enforced nationwide. Her concerns were not something she discussed in detail during any of our interviews, therefore, it was not a superordinate theme for her. When I asked why she was not worried about the pandemic becoming serious in the region, Melissa said, “It’s because us Mexicans don’t travel [out of the borderland area].” Her perspective about limited travel from people who identify as Mexican in the borderland area is due to the fact that Melissa and those in her social network did not travel very often. In fact, over the time that I have known Melissa, she had saved money and planned to take Mikayla and her son and aunt to Disneyland this past summer. The entire trip had already been paid for and she was devastated to have to tell Mikayla that the trip they had planned and prepared for over three years would most likely have to be cancelled due to the pandemic. After following up with her for a member check, she let me know that they did have to cancel the trip,
and that even though Mikayla would have finally been able to enjoy a summer without summer school, it would have to be done at home, under quarantine. At the time of the initial interviews, two of the caregivers still had a child receiving services for dyslexia and the other did not, as that family had moved the child to a private school. In our follow-up interviews, I discovered that the caregivers wanted my opinion about one key point: They all wanted guidance and reassurance that the pandemic would not cause their child to regress in reading. They asked if I thought the schools were going to open up by the end of the school year or by the beginning of the next school year. None of us had fathomed that school closures would have lasted beyond the early summer months. The pandemic is, without a doubt, an unusual time to be learning about how caregivers are navigating their advocacy experiences for their children who have dis/abilities.

Consideration of Findings in Light of Existing Research Studies

CDT is a theoretical framework that includes critical perspectives of Critical Race theory, Queer Theory, and Feminist Theory. Meekosha & Shuttleworth (2009) state:

The variety and degrees of their impairments and their intersection with other relevant social categories of experience demands a much broader and contextual interrogation of their restrictions. To that effect, critical disability studies draws from a much more eclectic mix of critical theories than earlier work in disability studies. (pp. 55-56)

While immersing myself in the literature, I found several definitions of CDT. Overall, this theoretical framework requires that scholars purposefully consider not only lived experiences of children and families affected by dis/ability, but to also consider their intersectionalities.

As I considered the three lived experiences of Anna, Melissa and Michelle, I wanted to ensure that I was using intersectionality responsibly, as Moradi & Grzanka (2017) suggest. Throughout my iterative analysis, I kept their challenge scholars in my mind, which is to
“expand analytic approaches to intersectionality research and evaluate research for its level of community engagement and social impact throughout the research process, as opposed to only scholarly impact, generalizability, or statistical significance” (Moradi & Grzanka, 2017, p. 25). Intracategorical complexity is the approach that I felt made the most sense to use when analyzing my data. This is an approach that falls between the intercategorical and anticategorical approach of intersectionality analysis. In intracategorical complexity, Moradi & Grzanka (2017) say the researcher “maintains a critical stance toward social categories, but recognizes their empirical and historical salience in the interest of exploring within-group variations” (p. 26). I felt that this was the most appropriate way to proceed. An intersectional perspective is one where the researcher “does more than examine various types of identity as independent of each other” (Roysircar, 2016, p. 13). Researchers should consider all attempts to not place individual or group experiences against one another, further adding caution when considering minoritized group experiences as more meaningful because they “deviate from the unmarked norm” (Moradi & Grzanka, 2017, p. 26). As I revisited the empirical literature, I came across many examples of families who were white, middle-class, and affluent who had experiences during the dyslexia identification process which listed similar themes to those the families from minoritized backgrounds that I was working with had experienced.

**Visual Representation of Adjectives of Experience**

I wanted to purposefully integrate and develop a creative way to spur conversations about each of the mothers’ perspectives and experiences. Therefore, I crafted several questions for my interview guide that asked caregivers to succinctly describe a sum of their personal experiences with the dyslexia identification process in Texas. By doing this, I challenged them to think about their entire experience and to use just one word or phrase.
Finding a creative way to show understanding was one of the skills I refined in my four years as a general education teacher, my next four years as a special education and dyslexia teacher, as well as in my two years as an assistant principal. During my time as a practitioner, I had to find creative ways to have my students answer assignments. This was challenging sometimes but it ensured that I was able to understand what they knew about academic content, processes, and arguments and rationale about what they were learning and understanding. Using graphic organizers and expression through art, technology and music, I was able to garner a better understanding of people’s ability and comprehension without relying on them to use text or print.

Bloom’s Taxonomy is a range of verbs that help educators in formative and summative assessments. There are six classification levels based on the use of verbs that provide concrete objectives for what is being assessed. Analysis is the fourth out of six levels in regards to the most complex type of thinking. I wove questions that reflected Bloom’s Taxonomy into the end of all of the interviews in hopes that it would give me a different understanding of their experiences with the process. I have included the chronological order I had planned on for each of the questions (Appendix E), and the entire interview guide had 19 questions. I decided to use order because I knew that we would have already discussed their own experiences. I hoped that they would have been reminded of experiences they may have forgotten, since several years had passed between the time of the process until the interviews. However, I want to note that depending on the way that each conversation unfolded, I did move some of the questions around if I it would fit in a particular place better, based on what the caregiver was speaking about. I asked the questions and hoped that it would provide them a frame to analyze their experience:
14. If you were going to use one word to describe the identification process of dyslexia in the public schools in Texas, what word would that be? 

17. What one word would you use to describe your child’s experience with this whole process? 

18. If you were going to use one word to let new parents know about going through this process, what would it be? 

Upon asking each of the questions, I gave them the time that they needed to pause and consider their experiences from their own perspective and the perspective of their child. I also wanted them to think about the advice they would give a new caregiver going through the process. 

Using word cloud generating software, I wanted to show a visual representation of the frequency of how often a word is used to describe something. In this case, I gave the words for each caregiver/child combination two different colors. I used black/dark grey to represent the caregiver experience and a light grey/white to indicate the child’s experience. I informed each caregiver that I had designed the study so that in the end I would also be able show them their word clouds as a visual representation of their experiences. When I asked each caregiver to sum up their experiences with a few words, all three caregivers had similar characteristics as they communicated with me. These characteristics included laughter, long pauses, hesitation and self-affirming words or phrases. Although I had intended for each caregiver to give me only only word, they all wanted to provide at least a few words or phrases to describe their perspectives about this process. 

Anna’s Word Cloud. Anna had the most difficulty of all three caregivers in condensing her experience into only one word. As soon as I asked her the question she chuckled and asked, “One word?” Anna’s word cloud shows that her most prominent word was stressful. This
caregiver’s experience with the dyslexia identification process was stressful and hard to navigate due to its ambiguity. The main word that came to mind for Anna about April’s experience was that the entire experience was overwhelming. In Figure 7.2, it is evident that although there were challenges involved with facing school staff that did not see April’s hidden impairment or dis/ability, she remained hopeful. Anna explained that she hopes other caregivers are able to learn from her experience and that they realize that although it is challenging, it is can elicit feelings of hope. The resilience that Anna found as an advocate for her daughter arose from having to resist teachers and administrators that refused to consider April’s multi-faceted intersections of dis/ability.

![Image of Word Cloud for Anna & April]

**Figure 7.2. Word Cloud for Anna & April**

**Melissa’s Word Cloud.** Melissa’s word cloud (Figure 7.3) shows that her primary word to describe the identification process was that it was a struggle. Her interview was the only one I could do face-to-face before the pandemic restrictions were enforced in Texas. I can still clearly
visualize her smirk, the smell of the too-sweet coffee combinations from the Starbucks at Barnes and Noble, and her eyes slightly rolling and looking away from me when I asked her the initial question which required that she tell me how she was doing, as a caregiver, especially with some strange pandemic sweeping across the world. Melissa always had a jovial yet honest perspective about the challenges that she was navigating when I conducted the interviews with her. However, this time she was concerned about her son because he had recently been identified as having epilepsy. She said it was a new challenge to navigate, since he was in high school and certainly did not want his mother hovering over his shoulder, worried about another unexpected seizure.

Throughout our interviews, she described time and again that it was not only difficult to have the school assess Mikayla, but it was also challenging for Melissa because her family members were persistent about their own opinions of what she should do as a single parent. The main words that came to mind for Melissa about Mikayla’s experience throughout the process were very hard. She believed that Mikayla felt that this process was very hard because it took several years from the initial time she was seen to be struggling until a label finally gave some legitimacy to the challenges she was facing. All of the pull-outs (separate classes during the day), endless tutoring, struggles to keep up with academic content and the standardized assessments, as well as the local school reading incentives (e.g., the school wide reading program) were challenging for her.
Michelle’s Word Cloud. Michelle’s word cloud, Figure 7.4, shows that there were several words she used most frequently. However, after returning to her transcript, I verified that main words she used were frustrating and a little scary. She said both things, but noted that “the easiest word is frustrating.” Michelle explained that it was a little scary because no parent ever wants to hear that there is something wrong with their child. The process was frustrating in that she had assumed that the process would be completed more quickly, which is why she went to Matthew’s pediatrician to see if there were any faster ways to get results. The process of waiting for the results were exhausting for Michelle. However, since she was able to reflect on the processes in three separate school systems, she realized that the process in Texas had been smoother and easier to navigate. Frustration was a sentiment that resounded still, as she moved to Puerto Rico and Alabama and found out that school systems vary greatly regarding their identification processes. The words that Michelle used to talk about Matthew’s experiences were that “the entire process was confusing.” In Texas, Matthew began to learn how to deal with his
new dis/ability identification and was learning how to navigate how the impairment could be navigated in different environments. When they moved to Puerto Rico and then Alabama, he still is learning how to cope with the oppressive ideologies and systems that do not honor his impairment.

Figure 7.4. Word Cloud for Michelle & Matthew

Advocacy: Caregivers searching for answers and help

Figures 7.2, 7.3, and 7.4 provide a distinct picture of these caregivers’ experiences with the dyslexia identification process on the border in Texas. The findings show that the caregivers’ main descriptors for their years of navigating the dyslexia identification process were: stressful, struggle, and frustration.

In a recent National Public Radio (NPR) series called “Unlocking Dyslexia”, parents discussed their experiences with the dyslexia identification process (Emanuel, 2017). The parents used phrases such as feeling that “it was really scary” to constantly encourage and coach my
child. Another parent said it was a “nightmare every night,” in regards to the continual challenges of trying to get the child to finish their homework.

I found a recent study that is the first I had come across that specifically considered the experiences parents have had during the dyslexia identification process in the United States. In a study based in Massachusetts, Woodcock (2020) discusses findings from an IPA study using the lens of CDT to understand the experiences that five mothers had with the dyslexia process in Massachusetts. Her findings show similar correlations to the terms that the caregivers in my study selected. The three superordinate themes in her study with a group of parents from diverse racial and socioeconomic backgrounds was that there is an in-betweenness or unclear definition about how to identify a reading dis/ability. They discussed that they perceived resistant behaviors among their children, along with endless emotional battles waged by parents, in order to fight for their children’s educational rights. The three terms that the caregivers in my study used to describe their experiences with the identification process in Texas were stressful, struggle, and frustration. The three predominant words caregivers used in my study are similar to the experiences that were found in Woodcock’s (2020) study. The overall experience of attempting to have a child identified with dyslexia characteristics is complex, nuanced, and filled with constant stressors to understand the process and advocate for assessment and interventions.

**How Dyslexia Is Framed and Why: Multiple Dimensions of Literacy and Ability**

As I was writing this, Tina Turner’s 1984 hit came on my Pandora radio station, and *What’s Love Got to Do with It?* played loudly in my headphones (Tina Turner, 1984). Looking at my proposed heading, *Literacy* made me automatically make a connection to wrapping my head around all of the things that I had been taught about literacy and the notion or myth of how it makes a society better. I have learned about literacy practices first hand from the perspective of a
former student in the K-12 system in Texas, and later as pre-service teacher and pre-service
administrator, as well as an early childhood instructional specialist in Texas. All of the literacy
practices that I was taught as a student, or required to uphold as an educator in Texas were
aligned to the state mandated curriculum, the Texas Essential Knowledge and Skills (TEKS).
The training I received as a Wilson Language specialist provided me a completely different way
of viewing literacy instruction that was aligned with multisensory instruction elements. My
views of literacy are also informed by my parent lens, since I have a daughter who attended a K-
8 dual language school learning Spanish, Mandarin Chinese, and English in a Texas public
school. Finally, I learned about literacy as a project manager and professional developer for my
regional service center, learning about literacy and all of the reasons educators should implement
certain “best-practices” that are research-based and would certainly produce “good readers.’

My views have changed and become more global yet again, now as a professor of literacy
and as a doctoral candidate. All of these experiences both in theory and in practice naturally led
me to wonder, “What’s Literacy Got to Do with It?” All of the caregivers in my study explained
how challenging it was once their child had been identified with dyslexia. They told me about
how they perpetually tried to be optimistic about their children’s ability to perform on state
standardized assessments.

These caregivers explained how relentless they were in their search for answers as to how
to help their children become successful in other areas not related to reading and literacy. They
were determined to not solely focus on the fumbles their children had had with navigating a
school system wrought with literacy standards in every single activity they completed in their
classrooms. “Literacy is a complex term covering a wide range of activities that differ from one
context or culture to another” (McDermott & Varenne, 2010, p 176). In each of their stories, the
caregivers found complex ways to challenge assumptions of what the school personnel had
determined to be limits of their child’s impairment of dyslexia. Anna, Melissa and Michelle
found opportunities for literacy to be a term that was represented in multi-faceted ways for their
children so that their dis/ability was supported at home with songs, audio-text apps, and
socialization opportunities. These caregivers wanted to ensure that their children saw themselves
as more than someone with an impairment affecting their reading. Instead, they wanted to find
ways to dismantle institutionalized barriers, and to access literacy in ways that were expected by
the school.

Foucault (1986) brings into perspective the emergence of biomedicine as a field of expertise
that represents power by organizing the way we consider and behave as related to our bodies and
those of others. Therefore, we can consider the ways that certain phenomenon and behaviors are
able to be designated as impairments. Power relations can be understood as related to who
decides what an impairment is and how it can be defined. The medical model of dis/ability is
most powerful, creating medicalized discourses which conceptualize and create learning
disabilities by classifying their existence based on social, cultural, and political influences.
Learning dis/abilities can be determined using varied approaches, and “local education agencies
are left to decide eligibility criteria independently” (Torres, 2017, p. 25). The fields of education,
medicine, and psychology influence the ways in which dis/ability is constructed as well as the
way that we think about and act in relation to the concept of learning disability.

Foucault (1995) used the concept of governmentality to refer to biopower, discourse, and
systems of normalization. The idea of governmentality has been discussed as the organized
practices through which subjects are governed. Tremain (2005) further describes Foucault’s idea
of bio-power or bio-politics as systems which have been created over the past two centuries to
ensure the welfare of the general population. These systems include a modern understanding or definition of a person with a dis/ability. Systems that have been created for normalization of the population include “asylums, income support programs, quality of life assessments, workers’ compensation benefits, [and] special education programs…” (Tremain, 2005, p. 5). Systems have been created by governments so that impairments are either ameliorated or removed. Nguyen (2015) provides a critique of biopower stating that “normative values of institutions are shaped by abelist ideologies and how our bodies are positioned in relation to the norms set out by global health and development institutions” (p. 17). The impairment that is dyslexia cannot be removed but depending on the environment that is around someone with dyslexia, the barriers of the dis/ability can be mitigated. Instead, the focus of the impairment itself shifts from something that needs to be cured to “removing the barriers that “create” the disability” (Cosier & Pearson, 2016, p. 2). I can see how in the three caregiver’s stories, each of the mothers suspected that their children would benefit from the removal of barriers that created their children’s dis/ability. All three of the mothers described that their children did in fact enjoy literacy for example, when their mothers read stories aloud at home, which eliminated the barrier of the child having to read independently. However, the moment that their child had to navigate text on a piece of paper and initiate strategies to read on their own, the caregiver was able to witness that something was not right and they immediately wanted to find help for their child. This idea that their child needed to be given interventions to fix their inability is related to the systems of power that are created through governmentality.

The notion of disciplinary power allows me to consider the ways that individuals are controlled via processes that can render a body “subjected, used, transformed an improved” (Foucault, 1995, p 98). The categories that are formed when comparing individuals to one
another create dividing practices of power. As such, it seems that these caregivers realized that their children’s impairments would be improved if they had access to assessment from the schools they attended. It was clear to me, as the mothers explained their experiences with the phenomenon of dyslexia identification in Texas, that they hoped their children would have access to interventions that would allow their child to navigate their impairment of dyslexia. These caregivers were certain that the school environment intensified their child’s dis/ability. The only way that their child would have access to specialized services, however, is if the school staff validated their concerns and agreed to initiate the assessment. This is where the divisive practices of power between the caregiver and school system occurred. Drawing on Waterfield’s (2019) explanation of the definition of identification processes for individuals with learning dis/abilities is one where “learning disabled individuals become learning disabled subjects through such dividing practices implicit with receiving a psychoeducational assessment to diagnose a learning disability” (pp. 14-15). Although two of the three caregivers were worried about stigmatization that might have occurred once their child was identified as having dyslexia, they perceived the benefits to outweigh the dividing practices associated with identification. The only caregiver who was not worried about the dividing practices associated with either identification or intervention upon placement into the program was Michelle. Her parenting philosophy was to try everything available to ensure that Matthew found success, even if that meant that he would be separated from his peers and go to another classroom.

While discussing the various models of disability is important for understanding how people with dis/abilities are treated in both school settings and the larger society, based on my findings I believe that the caregivers would have wanted a combination of both social and medical models. That is, they advocated for their children to have highly trained teachers who could provide the
explicit and multi-sensory instruction, while at the same time they wanted their children to have the opportunity to interact with their peers with an environment that respects their individual strengths and facilitates the specific abilities.

**Anna: “She’s Just Behind and Needs More Practice”**

In Anna’s experience, she had multiple opportunities to request that Anna be assessed for dyslexia. However, under the guidance of her daughter’s pre-kindergarten teacher, kindergarten teacher, and first grade teacher (who had had looped up and been her teacher two years in a row), she did not formally request an assessment at any of the ARD meetings she went to. The persistent suggestion to wait until more time had passed was something that Anna became very frustrated with. She did not understand how the school staff could fathom waiting until April fell farther and farther behind in reading in order to grant the assessment she had been asking for.

**RTI: Proposed Solution to the Waiting-to-Fail Model.** While the notion of Response to Intervention is one that seems to ensure that no children will be subjected to a wait-to-fail model, in Anna and April’s case, this is exactly what happened. Anna described that she met the Response to Intervention (RTI) specialist who was in charge of implementing further reading interventions for children who were not making progress on grade level standards. Anna did not understand how this specialist was supposed to prevent April from falling behind and ensure that April learned to read. This was because Anna had asked several teachers before to assess April, and Ms. Granado had presented April’s data to the RTI specialist at the start of the school year. If the RTI specialist was there to ensure all children were successful in reading, why would that specialist have requested more proof of data that April was continuing to fail for almost four months? McDermott & Varenne (2010) state that:
School performance has become integral to established political arrangements, and, by pitting all against all in the race for measured academic achievement on arbitrary tasks, school has become a primary site for the reproduction of inequality in access to various resources… the term LD [learning disability] has a political life that involves millions of people operating on little information about the social consequences of their work. (p. 174)

Anna was shocked that it took so long for April be assessed, even though as a caregiver she knew she had the right to request a formal assessment under special education law, for almost two and a half years. I think that April’s school performance was a primary site for the reproduction of inequality in access to various resources, as mentioned by McDermott & Varenne (2010). RTI is a model that is intended to identify children who have potential challenges with academic content and/or behavior. McDermott & Varenne (2010) provide an analogy to consider all of the elements that contributed to the identification of a learning dis/ability for a child named Adam in their research. The path toward identifying a learning dis/ability the authors assert, is made up of a multitude of different actors and systems that are involved in the “production of moments… to be recognized as having a learning problem” (p. 175). Educators are the ones that should be recognizing learning dis/ability, however even a child’s peers who realize that a child has a dis/ability create these moments. Peers can either notice the dis/ability, try and help their peer hide it, or ignore the dis/ability completely. What McDermott & Varenne term “the production of moments” (p.175) is also perpetuated by universities that grant teachers/administrators their degrees, tutoring centers who charge families and government agencies who fund some of these entities. This concept of the production of moments refers to the school environment which is created and perpetuates dis/ability through
socialization. McDermott & Varenne (2010) also have us consider another actor in this is culture. That is, children that either pass or fail standardized assessments. That means this is something that “most of the country is involved in” (p. 176). That is, it’s not just professionals who identify children who have learning dis/abilities.

Learning dis/abilities, in the view of the medical model, are inherent impairments which are located within a person’s body and are an outcome of biological or genetic factors (Hibbs & Pothier, 2006). The medical model view of ability is basically what is happening in the school system when one considers that children have to be identified in order to receive a highly specialized intervention. For example, two of the three caregivers had children who were in the Wilson Language Reading Program. This is one of a variety of programs that have been developed to explain what “many theorists, psychologists, and physicians [call] learning disabilities using a medical model, including Dr. Samuel Orton who is credited as being the key figure in the diagnosis and treatment of reading disabilities in the United States” (Torres & Barber, 2017, p 20). In Anna’s experience, the school was a system that did not identify April’s dyslexia. Rather, Anna herself spent years trying to convince the school that her daughter did have the dis/ability. April’s dis/ability meant that she struggled to navigate things like taking a spelling test and that she only way she could pass was to look around the classroom for cues as to how to spell the swords. Although April’s classroom teacher may not have noticed that she was barely passing reading, the scene at home during homework was completely different. At home, night after night, she would “cry and try to leave the table,” because she was not able to remain unnoticed as having challenges with reading. This reality is something that her classroom teachers, administrators, and RTI interventionist should have considered when Anna was explaining all of the characteristics she saw that might have been dyslexia. It is up to educators to
have the knowledge base that allows them to recognize when a caregiver is seeing a disconnect between what grades say in a classroom and what they are experiencing at home working with their child one on one.

**Melissa: “We’ll Take It”**

Melissa’s experience was similar to Anna’s initially, in that during pre-kindergarten and kindergarten, Melissa also brought her concern to the teacher and was told that Mikayla was “going to be okay.” Melissa’s experience quickly diverged from Anna’s in that by the middle of Mikayla’s kindergarten year, there were at-risk conferences happening. The problem here was not that she was identified as being in need of more intervention. Rather, the challenge was that nothing was done about it other than suggesting retention. In Anna’s experience, the RTI specialist was poorly informed about dyslexia. On top of that, the school did not have a system that identified April as a student who was struggling when she was in kindergarten. This is the opposite of Mikayla’s experience in a very large school district with benchmarks that needed to be met to indicate mastery of grade-level content in kindergarten.

**Retention and Progress: Who Gets Retained and Who Does Not?** In Mikayla’s example, she was the only child of the three who were retained in kindergarten. According to Kim, Losen & Hewitt (2010), there is a belief that students who are receiving special education services are imagined to be a shielded or protected group of students in schools. That is, some educators believe that once a child is in special education they cannot experience effects of disciplinary actions and that their access to particular services and instruction increases.

However, the reality is that children in special education are not protected from the negative consequences of an inadequate curriculum, biased disciplinary actions, and problematic pedagogy (Kim, Losen & Hewitt, 2010). Of the three caregivers I interviewed, Melissa’s
daughter Mikayla was the only child who was retained on the journey to discovering that she actually had dyslexia. Furthermore, she was the only one who was multiply minoritized in that she is Hispanic, as the other two children are, as well as black. This finding led me to wonder if she fell victim to an education system that retains black girls more than white and brown peers (Annamma, 2017). This unfortunate reality confirms what the extant literature already has shown that there is a higher possibility for a child to be retained or disciplined if they are a black female (Annamma et al., 2016; Cusick, Goerge, Bell & 2009; Martin & Smith, 2017; Ritchie, 2017).

In Endrew F. v. Douglas County School District, 580 U. S. (2017), caregivers challenged a Colorado public school due to the fact that their children failed to make progress there. The court ruled that public schools must ensure that only providing minimal progress for children in special education is not acceptable, and must provide a higher standard of education to them. In Melissa’s experience, it was very clear that the school did not do enough to identify her, and more importantly, she has not even had minimal progress after being identified. Melissa described the process of retention in kindergarten as “just awful” and after considering Mikayla’s lack of progress and the belief that she had of future success based on enrolling Mikayla in pre-kindergarten to have an advantage ended up not being a dream of hers as a caregiver which did not come to fruition. Melissa placed all trust in the school system and was at the mercy of their discretion. Melissa had hoped that Mikayla’s early entrance into public education would lead her successfully through each grade.

**Michelle’s Experience: Try Everything**

Michelle’s feelings about the identification process were different from those of the other two caregivers, as she initially did not have to advocate for testing. She expressed that the only reason Matthew was identified to begin with was not because she advocated for it. Rather, it was
his teacher who suggested that he may have dyslexia characteristics. In a recent study, Worthy (et al., 2018) found that dyslexia interventionists in Texas have a skill set of using authoritative language when making claims about a child’s dyslexia characteristics, identification and progress. The authors state, “The AD [authoritative discourse] of dyslexia and its institutionalization in policy has led to an unfortunate separation between dyslexia interventionists and other educators who share the goal of supporting students with reading difficulties” (p. 377). This authoritative discourse was something that I think is related to my data. I think that this authoritative discourse was what Matthew’s second grade teacher had used. He had only been in her class for a few weeks before she called Michelle and showed evidence as to why she believed Matthew was struggling.

Matthew’s third-grade teacher had been a general education teacher and then transitioned to being a dyslexia interventionist before she returned back to the classroom to be a third-grade general education teacher. Her ability to recognize the characteristics Matthew was showing in reading and math was directly related to her training. Dyslexia teachers in the Wilson Reading Program that Matthew received are required to have at least 90 of hours of training prior to ever working with a student. After a teacher has had the initial training, the program requires that they work in a practicum with one student for a minimum of 65 separate lessons. They must also be observed and evaluated under the direction of a master credentialed trainer. Michelle explained that she was surprised that Matthew’s teacher identified him as someone who may have had dyslexia characteristics within the first two months of school. In my opinion, his teacher being able to discern these characteristics was not a coincidence; a teacher who has this much specialized training is able to identify them fairly quickly and justify why they have identified them through an authoritative discourse.
Ambiguity of Label and Support at Home. Michelle stated that she did “not think he [Matthew] had it [dyslexia]” when his second grade teacher proposed the idea to her. After almost three and a half months of waiting, she found out he did have dyslexia characteristics. Matthew was relieved and shared that he “saw a light at the end of the tunnel” once she told him of the findings.

Unfortunately, a little less that 12 months had passed, when they had to move to a new town. After another battery of assessments, Michelle had to decide how she was going to tell him that now he did not have dis/abilities. Annamma (2017) describes dis/ability as fluid and multidimensional. This does not mean there are no differences among learners, but rather, it poses the question, “What meaning is brought to bear on those perceived differences?” (Baglieri & Knopf, p. 255). In other words, what did it mean to Matthew that he had dyslexia in one context not in another? Dis/ability is indeed socially constructed and based on multiple identity characteristics. They include environmental factors such as design and accessibility and the way a dis/ability is perceived. Michelle told me, “when he went to Puerto Rico, he was treated more like, "There's nothing we can do, you're [a] regular, normal kid." While I agree that dis/abilities are fluid and depend on a multitude of factors, as a former teacher, administrator, and now as a university professor, I cannot imagine how challenging this experience must have been for both the caregiver and child. Being told that you no longer have dis/abilities based on an assessment seems like it would be horrendous experience since it is almost as if a part of your identity has been removed from you. Even though the label was removed, Matthew still experienced the effects of the impairment of dyslexia as he navigated his daily school tasks and environment. For nine months in Texas, Matthew learned strategies and techniques directly associated with the Wilson Language Program from both his general education teacher (who had been a dyslexia
interventionist), as well as his separate dyslexia teacher. This situation is what Melissa had expressed to me as what she wished would happen for Mikayla – that her general-education classroom teacher had formal training in multi-sensory education and could find ways to integrate these techniques into all of the content areas, to include math, reading, science, social studies, and scaffolded support in learning to independently. She also hoped it would include self-regulation strategies and social/emotional interactions.

I feel that Michelle’s approach to navigating parenting Matthew through several rounds of assessment and providing verbal and physical support to him was something that is aligned with a DisCrit curriculum as proposed by Annamma (2018). Although the lens that is used for this framework is in regards to curriculum in a classroom, I can see how Matthew’s caregiver naturally embedded this approach in her parenting style. A DisCrit curriculum suggests that schools find ways to integrate topics that showcase and highlight individuals with dis/abilities into the curriculum. In Annamma’s study, ten girls of color participated and shared their experiences with discipline while also being in special education and belonging to multiply minoritized groups. One of the elements of a DisCrit curriculum is to involve movement and “plan for this in a way that would allow all bodies to participate” (Annamma, 2018, p. 148). Several of her participants described how challenging it can be to sit and learn all day without physical activity. A DisCrit curriculum also would integrate and build on the ways that “communities are multiply-marginalized through racism, ableism and other interlocking oppressions” (Annamma, 2017, p. 149). Although the DisCrit curriculum is intended for educators to consider their practices, I can apply this idea to Michelle’s caregiving philosophy. This is because it seems that Michelle has acted as a teacher for Matthew in this sense, providing multiple representations of individuals who have dyslexia and have overcome the challenges
associated with it. Michelle explained that she sought opportunities for Matthew to learn all that he could about dyslexia. Now that the pandemic has changed the way that education is being provided, Michelle said that it has been difficult, as she is no longer to provide Matthew with opportunities to move around and participate in organized sports.

**Denying Students Special Education Services**

The Department of Education Office of Special Education Programs (OSEP) investigated the validity of parent complaints after stories were written for the public via the series Denied by the Houston Chronicle (Rosenthal, 2016). OSEP held separate listening sessions across the state of Texas with educators (i.e., teacher’s assistants, teachers, administrators) as well as caregivers, and conducted a comprehensive review of processes and laws. The OSEP determined that there had indeed been a limitation or cap put in place in Texas public schools of 8.5 percent, and that it was intended to reduce special education identifications (DeMatthews, & Knight, 2019; Disability Rights Texas, 2019).

This means that school districts had attempted to minimize the number of children assessed for special education services, as well as the students identified and receiving services in special education to ensure that it was below the federal number. When specifically considering the dis/ability of dyslexia, Torres and Barber (2017) provide a social justice perspective about the Texas dyslexia identification process in To Be (LD) Or Not To Be (LD)? That Depends. Their analysis of the Texas identification processes considers the fact that state policy does not specifically agree upon what counts as a a learning dis/ability. Torres & Barber (2017) argue that the methods of determining its [learning dis/abilities] existence differ to such a great degree that a child can literally have a learning disability in one school and be ineligible for such services in another school. This is absurd; if LD really exists and if schools are
really going to teach all children, practitioners nationwide must come to some agreement about what LD is and how it is going to be identified. (p. 39)

Scull and Winkler (2011) found that Texas’ practice of not identifying dyslexia was a way to show declining numbers of special education students over a ten-year time span was a creative way of thwarting higher numbers and directly resulted in lower numbers of children in special education at the federal level. The authors accredit this decline mainly to an ambiguous identification process, resulting in granting individual campuses the right to make decisions as to whether to place a child under 504 or special education in order to receive services. The problem with having the solution of a special education cap at a national and state level is that educators and administrators are forced to make decisions regarding who gets assessed or let into special education and who does not. They also found that the overall population receiving services for a specific learning dis/ability in Texas was 3.8 percent in 2009-2010 as compared to 4.9 percent nationwide. Often times, these low numbers mean that the children with the most disruptive classroom behaviors (e.g., throwing items or yelling) may spur a teacher and administrator to have a child removed from that setting. In other instances, this may mean that families with some sort of perceived social or economic status may have their child assessed sooner than a family that does not have access to social or monetary resources.

For example, during my first year as a fourth grade elementary teacher in 2005, there was a student who unfortunately was a victim of a very rigid policy on standardized assessments and promotion to the following grade in Texas under a policy called the Student Success Initiative (SSI). My student, Imelda had been retained two times before in fourth grade and I, someone who was a new teacher, would be the third teacher she had had in a row, as she repeated the same fourth-grade curriculum. I found out as I got to know Imelda that she was not receiving any
special education services and that her little sister, Teresa, who was three years younger than Imelda was, had successfully entered and progressed from kindergarten through third grade and had joined her sister in fourth grade that year.

I felt horrible when I understood why Imelda had gotten into fights during lunch on the first days of school – it was because students in the fourth-grade classes made fun of her because her sister was ‘smarter’ than she was. Even more infuriating to me was that I later learned that these policies can be challenged by parents. All it takes is for them to come to the school and state that they want their child promoted. Some of my students who had failed the state assessment for the first time had parents who came to school and demanded an appointment with the administration to have their child promoted, even though they had not met the state requirement of passing all three state tests in fourth grade.

Imelda changed schools after being in my class, and she contacted me about five years later, by sending an email to the main office of the school. The technology specialist came into my room and said he had to relay an email message to “Ms. Owens.” Imelda wanted me to know that she was doing OK and that she was a freshman no. She shared that I had been one of her favorite teachers and that she missed me. Imelda, who was retained three times, and April, who was in special education but never identified as having dyslexia until her mother fought for her to be, both went unnoticed and unidentified by the school system.

Historically, the literature in special education states that the system is geared toward noticing children who are struggling in school as “a person with qualities to be discovered by agents of the school” (Varenne & McDermott, 1998, p. 215). This suggests that school staff are always on a quest to identify children who have dis/abilities. Reid and Valle (2004) state:
The very act of making decisions about which children deserve which resources for what purpose (i.e., determining the position of individual children within the educational system) constitutes the construction of meaning-making about how we conceive a free and appropriate education for all children. (p. 466)

What occurred in these scenarios is contrary to what would be expected to be done in special education when considering that the law specifies and represents a system that does not work as intended.

I actually was able to witness many caregivers’ concerns firsthand during a formal local listening session focusing on caregivers’ experiences with the cap on Texas special education identifications. At the time, I was working at the local regional education office, and the listening session was hosted at our regional office by OSEP along with the Texas Education Agency (TEA). The goal was to understand experiences caregivers had had in the borderland. The federal restriction was implemented to deter school districts from having an overrepresentation of students in special education, regardless of where they lived, their socio-economic status, ethnicity, or race. The cap was also put in place to ensure that not only were there too many children being identified with disabilities, but also to ensure that there was not too much money being spent on providing services to children with special needs. In the United States, the public school system is charged with educating all children, including children with all abilities. The education of all children, regardless of ability, is an admirable goal. However, the unintended (or perhaps intended?) consequence is that without funding, it is difficult for some schools to provide high-level services as they are delineated by the federal government.

It seems that not having funding, along with not having trained professionals educated about different dis/abilities is a direct consequence of restricting entry into special education.
This restriction makes it difficult for some children to get identified with a learning dis/ability and some families simply will give up, as the process has been made to be daunting. The cap was originally meant to ensure that school districts did not have the practices of funneling students into special education without actual academic, functional, behavioral, medical, or developmental reasons.

This lack of funding is evident in Anna’s story, because there was only one dyslexia specialist for the entire campus, and that teacher was already overwhelmed with more students than she had time to serve. Anna mentioned that it appeared that Ms. Short did want to help, but if April qualified for dyslexia, she might not be able to provide interventions until the following school year, as she already had too many students. In terms of Melissa’s story, Mikayla was working with three different teachers several times a week. All of the different resources that were being directed at her were something that Melissa said still fell short to actually help Mikayla make progress with tasks that required reading and writing. In Michelle’s case, Matthew was not denied entry into special education until he was reassessed and the school notified them that they did not have programs to serve him after he moved to a new school system outside of Texas.

This is frustrating. I experienced this personally, because when I was a special education teacher, the campus administrator had encouraged me to become certified to teach dyslexia in the district. At the time, I already had a full caseload of students who did not have dyslexia, and were receiving special education for other reasons. When I became the second dyslexia interventionist for the campus, it had been with the intention of only working with students who were in special education and also labeled as dyslexic. That is, I was not supposed to work with students who were receiving services via 504 and who were not in special education. Three years
later, I left that position, because I had been ‘creatively assigned.’ That is, I was basically working and getting paid for one job as a special education teacher and doing another job as a dyslexia teacher without pay. Working with students who had dyslexia were not only my students in special education; I also had students who were not in special education. My schedule was more than full, from the start of the school day to the end, without a conference period, which is required by law. I remember my administrator had reprimanded me, saying that I needed to build in my conference period by law. I asked her, “If I build it [a conference period] into my schedule, then who will serve my students during that time?” She responded that I was the only one who could make a decision about who would help them.

Special-education and general-education teachers are faced with ethical dilemmas such as these on a daily basis. With limited funds, it is simply not possible to serve everyone. Anna was relying on a system that boasts serving everyone and access for all, but that was not funded to do so. While I wanted to help all of my students, it was physically and mentally impossible some days for me to keep up with the demands of lesson planning for the four groups of students who had dyslexia. Those sessions which were each 45 minutes in length, four times a week, and I was also scheduling and preparing for ARD meetings for all of my students, dealing with unpredictable behavior interventions for some of my students who needed constant support in their inclusion classrooms, and facilitating more than 20 students in their inclusion classes in grades kindergarten through fifth grade. This meant that my students did not get the rigorous education they needed to meet their academic and social emotional or functional behavioral needs. When there is not a sufficient number of knowledgeable staff, students are the ones who suffer.
My Data and Implications for Professors of Education

The challenge of bridging theory to practice is an enormous undertaking. I think that colleges of education have an opportunity to contribute to a solution for dyslexia identification and the lack of clear guidance from state and national policies, as well as the problem of limited funding.

This would be possible if both preservice general and special education teachers received instruction in multisensory reading intervention strategies. If this approach were instituted, every teacher who enters into public schools would be able to provide intervention at a much younger age for learners who may begin showing characteristics of dyslexia.

This also has implications for administrator preparation programs, as administrators are the ones who will be at the RTI, 504, and ARD/IEP meetings. Ideally, these preparation programs could also be learning from current students with dyslexia and their families, to build on their understanding of what the dis/ability is and how to assist students, families, and communities. However, the state is involved with teacher education preparation coursework for both traditional preservice teachers, as well as for alternative certification license teachers, so this recommendation would also be for the state to consider when making legislative decisions.

Possible Solution to Conflicting Literacy Models for Upper Elementary Students

When I was working for the state agency in Texas, one of my responsibilities was to study new research in reading and literacy and present this information to educators in professional development sessions. I was charged with educating teachers on how to find ways to teach literacy, and they needed to understand how to teach reading and literacy in integrated ways, across multiple subjects, while covering the mandated grade-level curriculum – not the Common Core curriculum, as Texas has its own version, the Texas Essential Knowledge and
Skills (TEKS). Creating these trainings was both a joy and also a monumental, almost unsurmountable task. How is it humanly possible to cover all of the TEKS required in one academic school year, while also being mindful of and integrating each individual student’s needs, while also respecting their ability, language, culture, socioeconomic status, gender identity, and more? Furthermore, how would I find one program or philosophy that embedded and taught the teachers I was working with to integrate the ideological model of literacy and also what has been learned about highly structured and explicit multi-sensory teaching of reading?

One of the frameworks that I came across was a philosophy of teaching reading for upper elementary students is one that was published by the Bill and Melinda Gates Think-Tank, Intentional Futures called *Literacy and the Learning Sciences* (2015). In this 35-page guide, educators are provided with background knowledge about how to design literacy instruction that accommodates all learners. The authors a way to teach literacy based on current knowledge of how individuals learn and retain information about reading processes. This guide also considers integration of technology for students with dis/abilities, and the function of literacy in a society that relies heavily on technology. While this framework falls short in describing instructional or ideological practices for teachers to implement with children in early childhood settings, this is a model that considers how students with dis/abilities can navigate curriculum that becomes more challenging as they move into upper elementary. As children move into upper elementary grades, they are required to integrate readings strategies where they are reading to learn about concepts in subject areas such as math, science, and social studies. When I would mention this resource in my trainings, some teachers were visibly intrigued, and considered it to be a perspective they had not heard of before. While on the other hand, many other teachers completely disagreed with the ideas either verbally or via their body language. However, I would always ask them- if you are
using Siri or Alexa each day, you are already using assistive technology. I would challenge them to consider if they actually needed this accommodation due to an impairment or if it was simply to make their lives easier.

It was clear that they subscribed to ideologies that were aligned to an autonomous model of literacy in which all students who need to be able to read independently and with fluency in order to be successful in society. An innovative approach to teaching reading using multiple approaches is proposed in the resource called *Literacy and the Learning Sciences* (Intentional Futures, 2015). In my opinion, I believe that the literacy approach in this guide is more closely aligned with CDT. It not only considers how human beings acquire language and literacy, but it also allows for neurodiversity and individualization based on dis/ability and language. “Learning science can be applied in any content area and technology can be used as a tool to support learners across many contexts” (Intentional Futures, 2015, p 4). There is much that remains to be learned about literacy, and I am certain that debates about the best way to teach reading will continue as long as there are politicians invested in competing with other economies and companies trying to sell a product that will magically solve challenges such as meeting the needs of all students, while training all teachers to conduct interventions that help every child in their care.

**My Data and Implications for Pediatricians**

All three caregivers told me about going to their pediatricians during the identification process. This finding contradicts the practices of Texas public schools because if a caregiver brings in a doctor’s note requesting any assessment (ADHD, reading, etc), the school merely has to consider the request, but is not required to comply. One caregiver went the pediatrician for a doctor’s note, hoping that it would guarantee an assessment. Another caregiver sought advice
from the pediatrician about whether the decision to retain her daughter in kindergarten was a sound one, since her aunt who was a teacher, and mother who had been a daycare teacher, both adamantly disagreed with this decision. Finally, Michelle went to the pediatrician in hopes of finding a faster assessment, and that she was willing to pay out-of-pocket for it, since the school district said that the assessment would take at least three months to complete.

Although there is debate about which one specific assessment is best to assess children for dyslexia characteristics, two leading researchers in the field of dyslexia state that dyslexia is a “clinical diagnosis” (Shaywitz & Shaywitz, 2013, p 645). While this assertion may be true to an extent, this does not provide any solution whatsoever for practices of identification within the public schools. In public schools, families are told that their child has dyslexia characteristics and they are not given a diagnosis. This is because educators are not medical doctors and cannot provide a diagnosis.

Interestingly, I had the opportunity to work alongside a language clinic in the borderland area that has a philosophy that is more aligned with practices in the United Kingdom, where speech and language pathologists provide interventions for children with dyslexia. In Woodcock’s (2020) study with five caregivers, there was not any mention of the mothers seeking advice or justification from their child’s pediatrician. This is a finding from my study that was not discussed in the current literature of recent experiences specifically considering dyslexia identification in the United States.

Analysis of Data in Majority-Minority Borderland Community

The area where this study was conducted is a majority-minority community mostly comprised of Latinx people. It is difficult to say how the dyslexia identification process occurs in different regions. My research question,
How do families from minoritized backgrounds in a borderland community in Texas experience the dyslexia identification process?

elucidated findings based on each of the three caregiver’s experiences with dyslexia. Since two of the three caregivers had experiences in which their children were not identified with the learning dis/ability, it seems that this could be due to underrepresentation or misunderstanding of what the dis/ability is.

My positionality is that of both a former administrator in a K-5 campus and also as an educational researcher. I am constantly seeking to understand patterns, trends, or unlikely findings, and using data to improve teaching is something I am always eager to do. Therefore, I was eager to disaggregate each of the caregivers’ children’s campus data. In order to complete this analysis, I asked each of the caregivers to provide the campus names where their children were identified.

Using the Texas Academic Performance Reports (TAPR) (Texas Education Agency, 2020) which were formally called Academic Excellence Indicator System (AEIS), I disaggregated and compared each of the campus’ makeups to include:

1. Number of students at each campus;
2. Number of teachers who had more than three years of teaching experience;
3. The Demographics of the staff and students;
4. The Socioeconomic data of the student body, and finally,;
5. The State standardized assessment data.

April’s school had a population that was almost exactly100 percent Hispanic at the time she was identified. That means it would be challenging to disaggregate data to a point that would show an over-, under-, or disproportionate representation of Hispanic children who are identified
with dyslexia. In Mikayla’s school, there was a population within the school that was about 93 percent Hispanic, one percent black, and five percent white. Finally, Matthew’s school showed that about 60 percent of the population was Hispanic, 25 percent were white, six percent were Asian, four percent were mixed race, and two percent were black. That is, all of them went to majority-minority schools.

Based on national data of trends of minoritized children being either overrepresented or underrepresented in special education, I am left to consider that my data is indicative of disproportionate representation in special education. “Disproportionality is a critical issue, as it suggests discriminatory practices are being upheld in schools” (Torres & Barber, 2017, p. 79). With so many different intersectionalities of dis/abilities, race/ethnicity, and socio-economic statuses amongst all three caregivers, is difficult to pinpoint the exact reasons why some of the children in this study were retained while others were not, and one who was not in special education was identified sooner rather than later. Adding to the complexity of this disproportionate representation, where some children may be in special education and not actually need the services, may be due to the cap that the state subjected all campuses to follow, until OSEP investigated and demanded a revamping of the identification processes for special education in Texas.

All three campuses where the study participants’ children went had a significantly higher number of teachers who had been working for over three years. This year, the state average was about 85 percent. 96 percent of the teachers had more than three years’ experience teaching at these campuses. This is an important consideration, because teachers who have recently graduated from their university or alternative certification licensure program may not have as much experience navigating (a) the processes of identification; and (b) how to teach reading or
provide interventions, due to limited experience. The most interesting finding I discovered when doing this data disaggregation was the differences in each caregiver’s child’s campus regarding how many children in the were from low-income families. 90 percent of the students at April’s school were from a low socio-economic status (SES) family, 70 percent were from a low SES family at Mikayla’s school, while Matthew’s school had fewer than 20 percent of students coming from low SES families. What this data tells me is that there may have been more resources at April’s school that are funneled to campuses serving children from low-income home environments. Furthermore, it is likely that more highly qualified teachers work at schools in higher socio-economic areas.

**The Pandemic**

A second unexpected finding is that this work was conducted in an historical moment of the COVID-19 pandemic. It was a moment in time that impacted all of the caregivers I was speaking with, as well as the rest of the United States, and the world. Of course, I could not have anticipated discussing dyslexia interventions and advocacy during a pandemic. Therefore, some of the responses caregivers gave me about their overall experiences of advocating for their children were influenced by the pandemic. This was an unprecedented time for caregivers attempting to find services for their children. The participants knew that we would create a resource guide based on their experiences, to get information to future families going through the dyslexia identification process. Of course, that was my plan before the pandemic. Although I cannot gather with the study participants as I had planned, all three caregivers were still eager to create a resource guide for families in the region. It will have online resources and they suggested that I integrate their experiences into a video or audio format for families who are navigating the dyslexia identification process.
One caregiver, Michelle, even suggested that she could provide her experience of using the documentary *The Big Picture: Rethinking Dyslexia*, so that families could hear how it helped her teach her son what dyslexia is, how she used to inform her family members of what Matthew’s unique challenges with the dis/ability were and how it helped her “see the big picture” and realize that Matthew was going to be all right after so much uncertainty.

**Limitations of My Study**

**Timing**

One limitation of my study is that there was a very particular moment in time that impacted all of the caregivers I was speaking with, and that was the pandemic. This is a limitation because some of the responses caregivers gave me about their overall experience of advocating for their child were influenced by this very specific time and context – the pandemic.

**In-Person Interviewing**

The inability to meet in person for two of the three interviews may be a second limitation of my study. I was unable to meet with one participants because of social distancing restrictions of the pandemic, and for another participant it was not possible to meet in person because of (a) social distancing restrictions and (b) they were in a new state outside of Texas. IPA requires that participants share their personal experiences in detail, using rich descriptions and language to expand on their experience with the phenomenon (Noon, 2018). It is unclear if participants would have been able to get into a more detailed explanation of some of their experiences if the interviews had been done in person.
**Recommendation for Future Research**

**Training**

Future research should investigate the ways that educators are being trained about dyslexia, including both teachers and administrators. In an effort to systematically increase educators’ knowledge about dyslexia characteristics in Texas, House Bill 1886 was passed, which requires all educators with a teaching license to have at least eight hours of professional development in dyslexia interventions once every five years. One way that the state education agency was proactive about ensuring all educators had access to the same information and training as required by House Bill 1886 was by creating a statewide training called the Texas Dyslexia Institute. The aims of the state-created Texas Dyslexia Institute are very specific and delve deeply into what dyslexia is, how it affects different populations, including English language learners, along with how to identify children based on qualitative and quantitative data. The state created this five-part training, which I was one of many trainers selected to provide to teachers, along with other regional and selected school district representatives. The plan was for only the first of the five components to be required for every Texas teacher. Future researchers in Texas might explore the effectiveness of this institute, and more importantly, who is attending this training. Although having at least eight hours of dyslexia training once every five years is a new requirement for the state of Texas, there is a clause in the bill that states each school district can make decisions regarding how teachers are trained in dyslexia. This essentially makes the training hours discretionary, and makes consistency regarding how the dis/ability is identified in Texas a continual problem.

**Caregivers**

The second recommendation I make is to intentionally frame research around learning
more about caregiver experiences, specifically for families that are multiply minoritized and who are navigating dyslexia, not just learning dis/abilities in general. My positionality requires that I take into consideration the experience that I had as a sibling of a child who had dyslexia characteristics. My mother was a special education teacher and had a background in special education theory and practice, however, when her son was identified as having a specific learning dis/ability in reading, she had not really witnessed the impairment at home. I think this was because my little brother, such as all three of the children in this story, was able to find ways to “pass” as a reader in different literacy expectations at home and school. The notion of passing is a “deliberate attempt to pretend you are something you are not” (Devlin and Pothier, 2006, p. 15). My little brother is seven years younger than I am and I really did not understand that he had a hidden disability; he was able to complete rigorous academic tasks as long as the environment did not require tasks that emphasized his dis/ability. Even though our mother was a special education teacher, she did not have training in, or an understanding of the nuances of what different reading dis/abilities are; similarly, the special education teachers at my brother’s school did not either. In a socially constructed view of dis/abilities, my brother felt that the haphazard approaches the special education teachers were providing him in his separate class were not useful. After speaking with him recently about his experiences in K-12 schooling, he described that there were children who would snicker at his dis/ability and question why he had to leave to a separate classroom a few times a week. After several years of feeling like the separate instruction geared at re-teaching concepts in various subjects was not helping him, he and my mother advocated together to remove the label of reading dis/ability and he was exited from special education in high school. This is an example of how school systems may (mis)label or a child and provide interventions that are not aligned to the characteristics of their unique
impairment.

The most recent study I found had similar recommendations and was situated in Massachusetts (Woodcock, 2020). Woodcock’s study recognized this gap and also called for future studies specifically geared toward understanding the experiences of minoritized families with the identification process throughout the country. While there are studies that have been done about dyslexia and parenting, they are predominately from other countries, such as Australia (Delany, 2017; Leitão et al., 2017), Canada (Dyson 2007, 2010), Ireland (Beck, Hazzard, McPhillips, Tiernan and Casserly, 2017), and the United Kingdom (Earey, 2013; Riddick, 2010; Skinner, 2011; Skinner & MacGill, 2015). It is interesting that in these countries, more studies have been conducted that specifically consider the experiences caregivers have with their children who have the characteristics of dyslexia.

Conclusion

In conclusion, the principal implications of my findings were that caregivers found ways to navigate the dyslexia identification process in Texas by building their advocacy skills as well as becoming resilient when working with educators. They each were able to learn more about their child’s dis/ability of dyslexia by spending countless hours attending classes at a local disability information agency, the Borderland Disability Coalition (BDC). These three caregivers found solace in discussing their unique experiences with other caregivers at the BDC. They built advocacy skills and learned to demand equality and access for their child. Two of the caregivers in the study perceived that there was a disconnect between what the teachers were saying their child could do and what they actually were experiencing their child doing at home as they required their child to complete literacy tasks that intensified their impairment and dis/ability.
Practitioners should be mindful of finding a balance between validating caregivers opinions about their child’s progress and identifying potential dis/abilities. Kalyanpur, Harry, and Skritic (2000) state that service providers and school staff must take on the enormous tasks of advocating for children with dis/abilities because there are many caregivers who may not have the time nor skills to meaningfully participate in initiating advocacy. My findings indicate that these three caregivers were in fact able to find ways to make time to learn more about the dis/ability of dyslexia, navigate various intersectionalities due to their minoritized backgrounds, and become active members in their child’s identification processes. Barber, Shaw & Torres (2017) suggest that school systems find ways to empower families and make reasonable efforts to educate parents about their parental rights. They caution educators however, that

Not all parents enjoy the benefits of a strong education, and some parents may be intimidated by consent forms; highly technical evaluation reports; Admission, Review and Dismissal meetings; and other points of intersection between the parents and the school’s special education program. (p. 177)

I think that in order to incorporate caregiver’s perspectives of their child’s dis/ability, we must consider the fact that they do want to participate but sometimes we do not listen to what Woodcock (2020) termed as their contributions and *in-betweenness*. This *in-betweenness* can certainly inform what next steps we take in figuring out identification of dis/abilities based on their findings regarding their child’s progress. Caregivers come to our campuses with multiple intersectionalities that we have to learn to respect and make an effort understand.
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APPENDIX I: INFORMED CONSENT FORM

Study Title: Caregiver Experiences in a Borderland Community with the Dyslexia Identification Process in Texas

Principal Investigator: Angela Owens

I am a student at the University of Texas at El Paso in the College of Education. I am planning to conduct a research study, which I invite you to take part in. This form has important information about the reason for doing this study, what I will ask you to do if you decide to be in this study, and the way I would like to use information about you if you choose to be in the study.

**Purpose of the Study**
You are being asked to participate in a research study about parent’s experiences with dyslexia in public schools. The purpose of the study is to learn more about the experiences you and your family had as you interacted with the school system, specifically during the process of dyslexia identification. This study will provide information about the interactions, conversations, and experiences you had upon the identification of dyslexia and the experiences you had to have your child tested and identified for dyslexia. If you have more than one child who has been identified with dyslexia, you are invited to share that experience also, but each interview would take place at separate times so that you can focus on one experience at a time.

**What will I do if I choose to be in this study?**
You will be asked to remember the experiences you had before your child was identified with dyslexia, during the dyslexia identification process and after the process was completed. This will include sharing information about interactions you had with school personnel and family members. It will be an interview where you share your experiences one-on-one with the researcher, Angela Owens.

**Study time:** Study participation will take as long as you need to share your experience which may be anywhere from a total of 45 minutes to 90 minutes, depending on how much you’d like to share in detail about your family experiences with dyslexia identification.

**Study location:** Study procedures will take place in a face-to-face format at the place that you select as most convenient or can be done over the phone. You can select the face-to-face meeting areas in public areas such as the library, or if you prefer in the convenience of your home, or at The Children’s Disability Information Coalition located at 1101 E. Schuster.

I would like to audio-record this interview to make sure that I remember accurately all the information you provide. I will keep these digital recordings on my personal laptop and they will only be used by myself, the primary researcher. If you prefer not to be audio-recorded, I will take notes instead.
I may quote your remarks in presentations or articles resulting from this work. A pseudonym will be used to protect your identity, unless you specifically request that you be identified by your true name.

Furthermore, after your interview is conducted and I write it on a Word document, you will be able to look at it and verify that the contents are what you wanted to share.

**What are the possible risks or discomforts?**
To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

If during the interview you feel emotional or upset when answering some of the questions or sharing information, please tell the interviewer at any time if you wish to take a break or stop the interview.

**What are the possible benefits for me or others?**
You are not likely to have any direct benefit from being in this research study. This study is designed to learn more about the experiences that families have with dyslexia identification. The study results may be used to help other people in the future.

**How will you protect the information you collect about me, and how will that information be shared?**
Results of this study may be used in publications and presentations. Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used.

To minimize the risks to confidentiality, I will store the audio-recordings on my computer, access will only be for purposes of this study.

If I think that you intend to harm yourself or others, I will notify the appropriate people with this information.

**Financial Information**
Participation in this study will involve no cost to you. You will not be paid for participating in this study.

**What are my rights as a research participant?**
Participation in this study is voluntary. You do not have to answer any question you do not want to answer. If at any time and for any reason, you would prefer not to participate in this study, please feel free not to. If at any time you would like to stop participating, please tell me. We can take a break, stop and continue at a later date, or stop altogether. You may withdraw from this study at any time, and you will not be penalized in any way for deciding to stop participation.
If you decide to withdraw from this study, I, as the primary researcher will ask you if the information already collected from you can be used.

Who can I contact if I have questions or concerns about this research study?
If you have questions, you are free to ask them now. If you have questions later, you may contact the researcher at 915-780-5091.

If you have any questions about your rights as a participant in this research, you can contact the following office at the University of Texas at: UTEP Institutional Review Board (IRB) at (915-747-7693) or irb.orsp@utep.edu.

Consent
I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form.

Consent for use of contact information to be contacted about participation in other studies
Initial one of the following to indicate your choice:
______ (initial) I agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.
______ (initial) I do not agree to allow the researchers to use my contact information collected during this study to contact me about participating in future research studies.

___________________________
Participant’s Name (printed)

___________________________
Participant’s Signature

___________________________
Date

Consent form explained/witnessed by:

___________________________
Printed Name

___________________________
Signature

Date: _____________________    Time: ______________
Título del estudio: Experiencias de los padres con dislexia

Investigador principal: Angela Owens

Soy estudiante en la Universidad de Texas en El Paso en la Facultad de Educación. Planeo realizar un estudio de investigación, en el que lo invito a participar. Este formulario contiene información importante sobre el motivo de la realización de este estudio, qué le pediré que haga si decide participar en este estudio y cómo Me gustaría usar su información si decide participar en el estudio.

Propósito del Estudio
Se le pide que participe en un estudio de investigación sobre las experiencias de los padres con dislexia en escuelas públicas. El propósito del estudio es aprender más sobre las experiencias que usted y su familia tuvieron al interactuar con el sistema escolar publica, específicamente durante el proceso de identificación de la dislexia. Este estudio proporcionará información sobre las interacciones, conversaciones y experiencias que tuvo sobre la identificación de la dislexia y las experiencias que tuvo para que su hijo fuera examinado e identificado para la dislexia.

¿Qué haré si elijo estar en este estudio?
Se le pedirá que recuerde las experiencias que tuvo antes de que su hijo fuera identificado con dislexia. Esto incluirá compartir información sobre las interacciones que tuvo con el personal de la escuela y los miembros de la familia. Será una entrevista en la que compartirá sus experiencias uno a uno con la investigadora, Angela Owens.

Tiempo de estudio: la participación en el estudio tomará aproximadamente de 30 a 90 minutos, dependiendo de cuánto le gustaría compartir en detalle acerca de sus experiencias familiares con la identificación de la dislexia.

Ubicación del estudio: los procedimientos de estudio se llevarán a cabo en la ubicación que usted seleccione, una de las cuales puede ser en la Coalición de Información sobre la Discapacidad de los Niños.

Me gustaría grabar en audio esta entrevista para asegurarme de que recuerdo con precisión toda la información que proporcionó. Mantendré estas grabaciones digitales en mi computadora portátil personal y solo las usaré yo, el investigador principal. Si prefieres no grabarte en audio, tomaré notas en su lugar.
Puedo citar sus comentarios en presentaciones o artículos resultantes de este trabajo. Se utilizará un seudónimo para proteger su identidad, a menos que solicite específicamente que lo identifiquen con su nombre verdadero.

¿Cuáles son los posibles riesgos o incomodidades?
Según nuestro conocimiento, las cosas que hará no tienen más riesgo de daño que las que experimentaría en la vida cotidiana.

Si durante la entrevista se siente emocionado o molesto al responder algunas de las preguntas o compartir información, informe al entrevistador en cualquier momento si desea tomar un descanso o detener la entrevista.

¿Cuáles son los posibles beneficios para mí o para otros?
No es probable que tenga ningún beneficio directo por participar en este estudio de investigación. Este estudio está diseñado para aprender más sobre las experiencias que tienen las familias con la identificación de la dislexia. Los resultados del estudio pueden usarse para ayudar a otras personas en el futuro.

¿Cómo protegerá la información que recopila sobre mí y cómo se compartirá esa información?
Los resultados de este estudio pueden ser utilizados en publicaciones y presentaciones. Los datos de su estudio se tratarán de la manera más confidencial posible. Si los resultados de este estudio se publican o presentan, no se utilizarán los nombres individuales y otra información de identificación personal.

Para minimizar los riesgos de confidencialidad, almacenaré las grabaciones de audio en mi computadora, el acceso será solo para los fines de este estudio.

Si creo que tiene la intención de hacerse daño a usted mismo o a otros, le notificaré a las personas apropiadas con esta información.

Información financiera
La participación en este estudio no implicará ningún costo para usted. No se le pagará por participar en este estudio.

¿Cuáles son mis derechos como participante de investigación?
la participación en este estudio es voluntario. No tiene que responder ninguna pregunta que no quiera responder. Si en cualquier momento y por cualquier motivo, prefiere no participar en este estudio, no dude en hacerlo. Si en algún momento desea dejar de participar, por favor dígame. Podemos tomar un descanso, detenernos y continuar en una fecha posterior, o detenernos por completo. Puede retirarse de este estudio en cualquier momento y no se lo penalizará de ninguna manera por decidir dejar de participar.

Si decide retirarse de este estudio, yo, como investigador principal, le preguntará si se puede utilizar la información que ya se ha recopilado de usted.
¿Con quién me puedo comunicar si tengo preguntas o inquietudes sobre este estudio de investigación?
Si tiene preguntas, puede hacerlas ahora. Si tiene preguntas más adelante, puede comunicarse con el investigador al 915-780-5091.

Si tiene alguna pregunta sobre sus derechos como participante en esta investigación, puede comunicarse con la siguiente oficina de la Universidad de Texas en: UTEP Institutional Review Board (IRB) al (915-747-7693) o irb.orsp@utep.edu

Consentimiento
He leído este formulario y el estudio de investigación me ha sido explicado. Se me ha dado la oportunidad de hacer preguntas y mis preguntas han sido respondidas. Si tengo preguntas adicionales, me dijeron a quién contactar. Estoy de acuerdo en participar en el estudio de investigación descrito anteriormente y recibiré una copia de este formulario de consentimiento.

Consentimiento para el uso de la información de contacto para ser contactado sobre la participación en otros estudios
Inicial de uno de los siguientes para indicar su elección:
______ (inicial) Estoy de acuerdo en permitir que los investigadores utilicen mi información de contacto recopilada durante este estudio para contactarme sobre la participación en futuros estudios de investigación.
______ (inicial) No estoy de acuerdo en permitir que los investigadores utilicen mi información de contacto recopilada durante este estudio para contactarme sobre la participación en futuros estudios de investigación.

“Se me a dicho que mi participación en esta investigación es voluntaria, y que no seré penalizado ni perderé beneficios si me niego a participar o decidí no continuar en el estudio.

“Se me ha dicho que se me entregará una copia firmada de este documento y un resumen escrito de la investigación en inglés.

“Firmar este documento significa que el estudio de investigación, incluyendo la información arriba mencionada, se me ha descrito oralmente, y que acepto participar voluntariamente.”

_______________________________________________________________________
Firma del participante Fecha Hora

_______________________________________________________________________
Firma del testigo Fecha Hora

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APPENDIX 3: INTERVIEW GUIDE

The following questions will frame the open-ended interview, as parents answer questions about their experiences regarding dyslexia.

What has been your experience with the dyslexia identification process for your child?

Think of the word advocate; can you describe how you have had to advocate for your child?

Describe the system of support that you and your child depend on about dyslexia.

What are some of the examples of people or things that haven’t supported the “dyslexia?”
APPENDIX 4: SUPERORDINATE AND SUB-THEMES BASED ON EACH PARTICIPANT

(This template is only an example- the number of categories cannot be determined until the study is approved and participant experiences analyzed using an iterative approach)

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VITA

Angela Victoria Enriqueta Owens was awarded a Ph.D. in Teaching, Learning and Culture with an emphasis in Literacy/Bi-literacy. Her dissertation is titled Caregiver Perspectives During the Dyslexia Identification Process in Texas: PK-2nd grade during the Fall of 2020. Other degrees which Angela has been awarded include a Master’s in Education in Educational Leadership & Foundations (PK-12), a second Master’s in Education as an Instructional Specialist with an emphasis in Early Childhood Education, and a Bachelor of Interdisciplinary Studies with an emphasis in Early Childhood through Fourth Grade. Her areas of interest include educational equity in special education for learners and their caregivers, critical disability theory, teacher preparation as it relates to early childhood and elementary educators, integration of social justice topics using literature in elementary classroom settings.

Angela has served as a college instructor at the university and community college levels, as a project manager for the Texas Education Agency, an elementary school administrator, a special education teacher, general education teacher, daycare teacher, substitute teacher, and recreation leader for after-school programs for the Y.W.C.A. Her publications include:
