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How Children Understand Disability: A Qualitative Exploration

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HOW CHILDREN UNDERSTAND DISABILITY: A QUALITATIVE EXPLORATION

A Dissertation
submitted by

MEREDITH EDELSTEIN

In partial fulfillment of the requirements
for the degree of
Doctor of Philosophy

LESLEY UNIVERSITY
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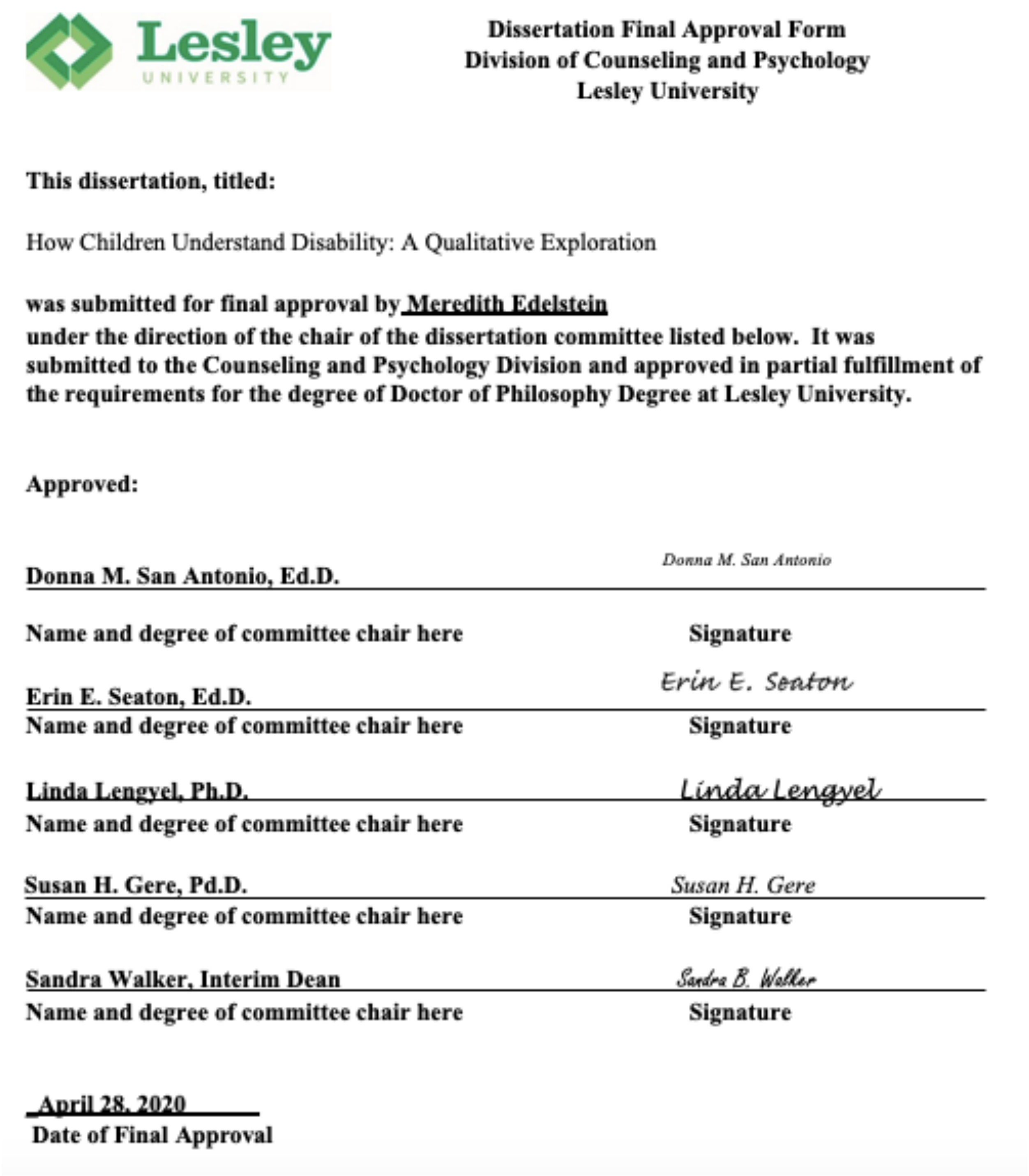

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was submitted for final approval by Meredith Edelstein under the direction of the chair of the dissertation committee listed below. It was submitted to the Counseling and Psychology Division and approved in partial fulfillment of the requirements for the degree of Doctor of Philosophy Degree at Lesley University.

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ABSTRACT

Disability research is broad in nature and covers a variety of experiences and conditions. Of critical importance in disability research is the delineation between the social and medical models of disability, and how these varying definitions inform one's understanding of disability and internalization of the meaning-making of living with disabling impairments. Research exists on the adult experiences and retrospective accounts of individuals with disabilities. However, missing from these studies is the voice of children with disabilities. While there is an awareness that decreased self-concept and stigma exist surrounding childhood disability, there is limited data that considers how children make meaning from their experiences related to disability.

This qualitative study compiles the stories of twelve children (ages eight through 12) who have been identified with invisible disabilities. Data consist of semi-structured interviews, drawings, and a storytelling activity. Findings show that four themes emerge from the many stories told by children. Namely, children interpreted their experiences in both positive and negative ways, indicating feelings of hardship, frustration, and sadness, but also opportunities to grow and foster resilience. Children defined disability in a flexible manner, acknowledging both the medical and social features of disability as they grappled to understand what it means to not be "normal." Participants were critical of the education system, both regarding how teachers reach their students as well as how the structures of school do or do not meet the individual needs of disabled individuals. Finally, participants could identify stigma and features of self-stigma or stereotype awareness, even if they do not have the vocabulary yet to name these structures explicitly. Implications and recommendations are provided to help educators challenge ableism and childism in the world of education.

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CHAPTER 1: INTRODUCTION

INTRODUCTION

In this dissertation, I explore how children experience and perceive their disability labels. When considering school-aged students and their demographics, basic statistics regarding disability are readily available. I can locate the following information regarding Massachusetts students: 860,320 public school students between grades kindergarten and 12 statewide; 154,696 identified with disabilities; 66% of students with disabilities graduate from high school; 62.3% of children with disabilities are White; 10.5% of children with disabilities are Black or African American; 20.3% are Hispanic or Latino; 3% are Asian; 0.3% are American Indian or Alaska Native; 0.1% are Native Hawaiian or Other Pacific Islander; and 3.6% are of two or more races (Data display: Massachusetts identification of children with disabilities, 2013; Enrollment of students with disabilities served under IDEA, 2014). Statistics reflect the severity, but not necessarily the intensity and quality of the disabled experience, or how children make meaning of being disabled. Statistics also neglect to demonstrate the growth and change that occurs as individuals learn about their disabilities. Gaps exist in regard to understanding the quality of the disabled experience and to understanding the experience of the younger population recently diagnosed.

In 1975, the landmark Individuals with Disabilities Education Act was passed, guaranteeing free, appropriate, public education for all children with disabilities (About IDEA, n.d.). IDEA was revised in 2004. Section 300.8 defines “child with a disability” as:

> a child evaluated…as having an intellectual disability, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance… an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services. (Section 300.8 Child with a disability, 2017)

Since its enactment, the Individuals with Disabilities Education Act has mandated that children between the ages of three and 21 receive free, appropriate, public education in the Least Restrictive Environment. Once enacted, 3,694,000 students were identified as disabled in 1976, with the key disability categories being emotional disturbance, hearing impairment, intellectual disabilities, other health impairments, specific learning disabilities, speech/language impairment, and visual impairment (Digest of educational statistics, 2016). When most recently measured in 2015, 6,555,000 students were identified as disabled, with autism, deaf-blindness, developmental delay, multiple disabilities, and traumatic brain injury having been added as disability categories over time. These statistics indicate that a large portion of our population is impacted by disability within childhood and adolescence alone. Given that special education law was not passed until 1975, the field of special education is still emerging. While the general concept of disability has been discussed and addressed in a myriad of ways over time, it wasn’t until 1975 that labels and public education determinations became essential to shaping the childhood experience of disability. Together, these numbers reflect the demographic impact disability has over the span of the nation and generations.

It was not until 1990 that rights were extended for all citizens in all locations. Both Section 504 and IDEA 1974 paved the way for the American with Disabilities Act to be passed, extending the prohibition of discrimination to all areas of public life, including jobs, schools, transportation, and any locations open to the general public (Davis, 2015). The ADA definition of disability mirrors that in Section 504: a person with a disability is someone “who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment” (A guide to disability rights laws, 2009). As activism moved toward legislation, the definition of disability shifted away from inability and toward impairment. This reflected an understanding that people experiencing impairments required rights but did not yet embrace the concept that disabilities are not always medical. Rather, disabilities are often reflective of a mismatch between a societally designed environment of ableism and the individual’s impairment.

The critical disability studies movement that started in the 1980s, around the time of significant activism and legislation for people with physical impairments, continues today by further analyzing the way different groups define disability and how these definitions inform rights or privileges (Garland-Thomson, 2019). Garland-Thomson states, “what counts as disability ranges across a broad spectrum of physical, motor, mental, sensory, behavioral, medical, and appearance conditions that restrict function, limit participation, and are understood as stigmatized forms of inferiority” (p. 12-13).

This highlights the need for researchers and activists to join together in defining disability, as these definitions shape the understanding of environments as well who has the right to design and access knowledge. Torres (2019) further stresses the need for disability activists to teach others about disability disenfranchisement, or the discounting of the disability experience in what is taught and shared. This should include the teaching of disability history and integration of disability rights into multiple disciplines across academia. Torres indicates these activist missions can take traditional roots but should also take advantage of growing social media platforms and other accessible technologies.

As is highlighted by disability history, much work has had to be done to overcome the predominant White male able-body narrative. There is still much work to be done to challenge this narrative and generate a more inclusive, empowering definition of disability and impairment. Further, this work needs to be done across generations so all people experiencing disability, from infancy to late adulthood can be treated with respect and dignity. This work can be done with the adult population, but it also needs to be done with the youngest members of our society in efforts to build confidence, empowerment, and future advocacy abilities, indicating the imperative nature of the proposed research. Further, the lack of children's voices in educational practices and guidelines reflects a strong need to understand and conceptualize how children perceive disability and its role in their learning.

EXISTING RESEARCH

A thorough literature review within this dissertation will explore the existing research regarding self-concept, disability, and childhood. Existing research on self-concept highlights predominantly quantitative measures to examine the relationship between disability and perceptions of self (Bear, Mink, & Manning, 2002). Findings regarding children with learning disabilities indicate decreased self-concept is most frequently observed within the academic domain (Gadeyne, Ghesquiere, & Onghena, 2004; Gans, Kenny, & Ghany, 2003; Kloomok & Cosden, 1994; Martinez, 2002; Rothman & Cosden, 1995). There is some variance in these findings depending on the severity of the disability (Rothman & Cosden, 1995; Martinez, 2002). There is also variance depending on the age of the students surveyed, with older students identifying decreased self-concept more often than younger children (Chapman, 1998).

Qualitative findings suggest the use of both adaptive and maladaptive coping strategies upon discovering the presence of a disability (Pestana, Rodis, & Boscardin, 2001). Namely, some individuals turn to community supports and relationships in efforts to adapt to their new understanding, while others may turn to substance abuse or other risky behavior. Other qualitative research highlights the difficulties of generating an understanding of disability given its nebulous and abstract nature (Cosden, Elliot Noble, & Keleman, 1999). Decreased self-concept has implications on the development of self-stigma in adults, particularly in scenarios where public stigma is high and in situations where one is able to “pass” or blend in with the nondisabled population (Corrigan, Watson, & Barr, 2006; Vogel, Bitman, Hammer, & Wade, 2013). While literature exists in some areas regarding disability and self-concept, there are significant gaps in the understanding of how *children* experience invisible disability (Corrigan & Watson, 2002; Evans, 2017). This has implications on how children are treated in school and community settings as well as how interventions are developed to support children in childhood in efforts to prevent maladjustment.

PERSONAL CONNECTION

Personally, I am diagnosed with a hearing impairment in my right ear. My disability was identified when I was eight. I remember feeling connected to family members who experienced a similar disability. I remember sitting in the kitchen and calling my grandmother to tell her I had the same disability as her, and how excited I was to explain my disability to my classmates. When I required assistive technology (an FM system and hearing aid), I felt privileged to store my materials in my teacher’s desk, where she would leave me special notes of encouragement. When I started middle school and found my assistive technology cumbersome, I still had the confidence and support of my peers that allowed me to self-advocate for my need for preferential seating and repeated directions. The narrative that went along with my disability was one that did not interfere with my self-concept.

When I was in my first year working as a school psychologist, I was on a flight while sick and nearly ruptured my left eardrum. I remember walking off the plane and realizing I could barely hear. The narrative changed. The next day, I walked into my job and attempted to conduct a psychological evaluation with a child with a communication impairment and found that I could not hear or understand his words. This time, I was confronted with disability as a life-altering event that could possibly cause the end of my brand-new, beloved career. Filled with anxiety, I went through hearing tests again and was able to determine that my hearing was only temporarily impaired in my left ear, and positively, updated technology allowed me to consider having a hearing aid that I could utilize regularly. Instead of always finding preferential seating, asking for people to speak loudly, or scrambling for repetitions, I could consider accessing a bypass strategy. When asked what kind of hearing aid I wanted, I indicated that I wanted the one that was purple. Not only because it’s my favorite color, but because it was a very obvious color against my brown hair. I made this decision because when I wear my hearing aid around the children I work with, I want them to see that my disability does not define me and that I accept it. I want them to ask questions and I want to be an adult who leans in when difficult conversations about disability emerge.

I am also a mother of a child with a disability. My five year old daughter is diagnosed with a communication disorder. As her parent, I have been tasked with finding her services and coordinating educational and private supports. More importantly, I am responsible for helping her understand her strengths and areas for continued growth. I am also responsible for helping her twin understand why her sister needs services, but also, how her sister wants to be treated so she feels human, valued and appreciated. Services not only prevent further difficulty, but they can also set a foreground of understanding for my daughters’ recognition of what it means to be a person with a disability in an ableist world. I play a role in how both my daughters develop schema related to disability, self-advocacy, and opportunity.

I am also a woman who is immersed in the lives of individuals with disabilities, particularly children, and their supporters. Over the course of my career, I have frequently been asked, “how do I tell my child they have a disability?” Behind this question are deeper, more complex questions: how is my child going to feel when I tell them they have a disability? Will my child feel changed? Is my child going to feel the pain I, as the parent, felt when I found out they have a disability? At its core, these concerns are steeped in worries about how a child will perceive their journey into our world filled with stigma, oppression, and fixed expectations.

With parents, I have answered these questions through further exploration of the label. Some parents will express hope that a label will help their child understand their struggles, while others will indicate they want their child to have realistic expectations. In each instance, the emotion of the diagnosis carries more weight than the definition of the label itself. When I have carried these explorations into discussions with children, again the emotion of being diagnosed carries importance alongside the actual name of diagnosis. Even the youngest children with whom I work have preconceived notions of what it means to be disabled and can see the differences between children who present with physical, apparent disabilities versus invisible disabilities (Evans, 2017).

In relation to my career as a school psychologist, a frequent and triggering statement used by evaluators or other school-based team members is “it doesn’t really matter what we call the disability as long as we plan appropriate services.” This is often said in efforts to comfort a parent or family member who is coming to terms with the eligibility identification of their child; however, I am always left discomforted by this statement. From my experience with children who are aware of their diagnosis, the label does matter because it captures the emotion behind the experience. It can have a great impact both on how the family interprets the child’s behavior as well as how the child makes meaning of his or her experiences.

My research seeks to fill this gap by providing opportunities to hear the voices of children as they learn about themselves alongside learning their diagnoses. More specifically, my research aims to develop an understanding of how children perceive their own disabilities within the critical period of mid to late childhood. This age is a key transitional time for children as they start to develop concepts of self and start to recognize who they are in relationship to others. Disability can impact feelings of self-worth, purpose, and value within society, particularly as children start to discover society's standards, pressures, and expectations. Furthermore, childhood experiences shape one's worldview and can set the foundation for future growth or stagnation. It is essential to understand how children perceive their own disabilities so other stakeholders can use information generated by children to support other children newly diagnosed. I argue that when children understand their disabilities, they are better able to access their learning environments and advocate in an appropriate manner. Further, giving children a voice at a young stage gives society the opportunity to better develop interventions that empower and encourage students instead of continuing messages of oppression and disempowerment.

RESEARCH QUESTION

The purpose of this research is to answer the following question: How do children in mid-childhood with an invisible disability experience being a child with a label? The goal of this study is to illuminate the childhood experience while also gathering data to inform recommendations for parents, teachers, and other stakeholders in the lives of children.

DEFINITION OF KEY TERMS

A term that will be frequently used throughout this dissertation is *invisible disability* (Corrigan & Watson, 2002; Evans, 2017). An invisible disability is a disability that is not readily apparent and thus allows an individual to pass as neurotypical, "normal," or part of a majority group (Bogart, Rottenstein, Lund, & Bouchard, 2017). Individuals who pass as "normal" may or may not experience feelings of stigma depending on a variety of factors, including their willingness to disclose, surrounding society, desire to fight for disability rights, and number of impairments (Bogart, Rottenstein, Lund, & Bouchard, 2017; Nario-Redmond et al., 2013).

I will emphasize that I put quotes around the word "normal," as this dissertation is centered around the framework of critical disability theory, which posits that impairment is not the main cause of difficulty for individuals with disabilities, and instead it is society that oppresses people with impairments and treats them as a minority (Baglieri & Shapiro, 2012; Brune & Garland-Thomson, 2013; Davis, 2002; Hehir, 2002; Lalvani, 2015; Oliver, 2004). Critiques of this model have indicated that impairments can have a significant impact on daily living, thus a disability label may not simply serve to oppress an individual, but also identify that the person experiences a condition that interferes with daily life (Oliver, 2004). This dissertation actively seeks to explore this nebulous concept of "normal" versus "disabled", particularly as it relates to how children see the world and experience their impairments.

When I refer to *childhood*, I am specifically speaking to the period of mid-childhood as conceptualized by Harter (2012) and framed by the identity development stage of Identity versus Inferiority, conceptualized by Erikson (Hamachek, 1988). Mid-childhood falls within ages eight and 10 according to Harter and between ages six and 12 according to Erikson. The decision to explore this age range will be further explicated within the literature review and methodology chapters of this dissertation.

When referring to *self-concept,* this is in reference to Harter's (2012) theory of self-concept. Harter defines self-concept as the development of self-representations and sees the development of self-concept as a continuous, cognitive process. Further discussion of Harter's theory is provided within the literature review of this dissertation. Harter's theory was selected to frame the concept of self-concept in that her theory is broad enough to encompass a wide range of behaviors and cognitions that influence self-concept. She also highlights the nature of development in the creation of one's self-concept, a consideration that is critical to understanding self-concept in children.

RESEARCH DESIGN

Qualitative research was used to reveal the experiences of children with invisible disabilities. The goal of qualitative research is to help understand how individuals make meaning from their experiences (Morrow, 2017). Specifically, this research uses a phenomenological approach and the philosophical framework of hermeneutics (Josselson, 2004; Marshall & Rossman, 2016; Wertz, 2011). Given this research orientation and the age range of participants, interviews, storytelling, and artwork were used to generate an overall understanding of how participants made meaning of their experiences. Data was analyzed through engaging in multiple readings of the data and comparison of themes revealed across case examples. Each participant was conceptualized as their own case, in efforts to enlighten the readers of the individual experience of disability. This then lead to a synthesis of findings across participants. Further details will be discussed in the research methodology and design chapter.

CONCLUSION

The next two chapters will set the foundation for the research process of this dissertation. First, relevant literature will be outlined regarding self-concept, disability theory, and stigma. When combined, these areas create a comprehensive picture of what research is and is not available when considering how children make meaning of disability labels. Following this chapter, I propose a methodological design that both moves to fill a gap in the research while also remaining sensitive to child development and disability theory. Finally, I conclude with a brief discussion of the long-term intentions of this research.

CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

The purpose of this literature review is multi-faceted. To better understand the history of disability and how society has perceived disability over time, models of disability will be explained and context will be provided to more critically examine the role of disability and the purpose of the label. The overarching theory of self-concept will also be defined. This will lead into a discussion of how self-concept – and its related topics such as self-worth and self-esteem – have been measured and described in disability populations. As disability is a potentially disempowering condition, a discussion of stigma will outline how researchers have defined stigma over time as well as how it has been studied in the context of disability. Finally, research regarding self-stigma in disabled populations will integrate the concepts of self-concept, disability, and stigma.

THE DISABILITY CONSTRUCT

Today, multiple models for disability exist and can shape the conversation regarding rights and adequate services. Different arguments can be made regarding what best serves the lives of individuals with disabilities depending on the definition of disability used. Furthermore, the potential of individuals with disabilities can be viewed in drastically different forms depending on the definition and lens used. The purpose of this section is to identify different disability models and provide the reader with an understanding of more critical ways of thinking about disability in efforts to better inform the analytic procedures used as part of this study.

The *medical model of disability* is most commonly known, with most citing definitions from the Americans with Disabilities Act to define the key characteristics of a person with a disability (Darling, 2013; Davis, 2015; Garland-Thomson, 2019; Nielsen, 2012). These definitions permeate into environments of schools and businesses, assuming that disability can be confined to a fixed portion of the population (Zola, 1989). Critiques have highlighted a variety of ways in which the medical model definition falls short of depicting the true experience of disability. In Zola's (1989) work, he notes that the medical model of disability will only work short term, as disability can impact all citizens, particularly as environments grow in complexity and diversity. For policies to fit growing populations, they need to recognize that the entire population is at risk for chronic illness and disability, and thus policies and practices should be designed to be universally applicable. Without this, citizens can fall through the cracks and suffer. Zola's work focuses primarily on physical disabilities; however, he brings to light the importance of recognizing that disability is not an isolated characteristic and has the possibility of impacting everyone, making it different from many other traditionally disempowered identities.

Critical disability activists and scholars overwhelmingly prescribe to the *social model of disability*. Namely, disability is the "fit of… impairments with the social, attitudinal, architectural, medical, economic, and political environment" (Zola, 1989, p. 401). In other words, it is not impairment that is the main cause of problems for people with disabilities. Rather, it is society that oppresses people with impairments and treats them as a minority (Baglieri & Shapiro, 2012; Brune & Garland-Thomson, 2013; Davis, 2002; Hehir, 2002; Lalvani, 2015; Oliver, 2004). As discussed by Lalvani (2015), disability studies is derived from Vygotsky's socio-cultural theory, "which emphasises [sic] the situated nature of all individual experiences and understands these as inseparable from the contexts within which they exist" (p. 380). This is essential to understand when considering children with disabilities, particularly as their education is built on the relationships that children build with teachers, schools, and curriculum. In other words: children – with or without impairments – are reliant on the context of their learning environment to make progress, and the behaviors that occur within their learning environment may be supportive but may also serve to disempower.

Critiques of this conceptualization are present in the literature. According to Oliver (2004), the social model discounts the realities of impairment, many of which have significant impact on day to day living. The social model also centers on the idea of being an "other," thus saying less about physical and environmental barriers and instead focusing on how culture values disability as a state of "otherness." Until recently, proponents of the social model have also had difficulties integrating other social divisions such as race and gender (Annamma, Ferri, & Connor, 2019; Oliver, 2004). Oliver posits that the social model is a tool, but should not be considered a well-developed theory, idea, or concept.

Thomas (2004) also critiques the use of the social model, highlighting that it does not acknowledge the bodily experience of disability. Namely, not all experiences can be explained by the presence of social barriers. Disability studies scholars should consider the psycho-emotional dimensions of disability. Thomas proposes the adoption of the UK's Union of Physically Impaired Against Segregation's 1976 definition of disability as a "form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (p. 25). Further, the fields of biology and medicine should not be given exclusive rights over the concept of impairment, allowing them to define bodily variation as impairing. Finally, if disability is to be theorized, then Thomas critiques that impairment must also be theorized and not left unevaluated: in other words, one cannot critique disability without holding a critical lens to the concept of impairment and multiple dimensions of this condition.

Parens (2017) discusses Glover's theory of binocularity, in which one uses multiple lenses to consider different facets of a person. Consideration of the person can be given to the person as both an object and a subject. When considering a person as an object, one may use more medical terminology, seeing disability as "good" or "bad," with clear delineations to its impact. A subject consideration may allow for the consideration of more social factors, meaning that the disability is not perceived in a valued manner as much as it is perceived as having an impact depending on the environment. As Parens discusses, those who use a binocularity approach to disability are able to consider the impairing factors of the disability that impact daily life while also considering the social lens, allowing for the flourishing of the disabled individual by embracing both the limitations and the ways disability enhance the human experience. This is an important consideration for the adults who work with children, namely educators, as it allows for a better understanding of how disability informs a child's identity development. Parens argument focuses on improving conversations regarding disability for the purpose of encouraging growth, thereby decreasing ableist tendencies and instead encouraging empowerment.

DISABILITY ACTIVISM

Over the course of history, disability activism has remained in the background of other movements, with the disabled voice often being ignored or assumed unimportant. It is the exceptions such as Helen Keller and Franklin Delano Roosevelt that have allowed disability to even emerge in historical contexts. When disability activism started to gain momentum, it was often the privileged citizens with disability – i.e. white, male, middle class – who voiced their needs and fought for equal rights. Families of the disabled, such as the Kennedys, were also able to use their able-body status to advocate. Voices of intersectionality continue to work for rights both of the disabled and other marginalized populations (Annamma, Ferri, & Connor, 2019). The voice that is not readily heard in modern disability theory is that of the child with disability. This may be because there have been adults able to advocate for children; or it may be due to societal assumption that children's stories do not need to be heard or considered in the writing of historical accounts. The hegemonic voice continues to posit that children do not know what is best nor do they have the foresight to understand what the capitalist society requires to stay afloat. While advocates like Freire (1970), hooks (1994), and Kozol (1991) have argued for the need to include children in the construction of education and knowledge, this has been the exception and has been seen by society as too radical to be plausible. Additional discussion and research with children needs to be conducted to fill this void and to provide insight on how disability theory can inform younger generations who will eventually enter into roles of leadership and advocacy.

SELF-CONCEPT THEORY

The purpose of this section of the literature review is to describe the theoretical underpinnings of self-concept and develop an understanding of how self-concept is conceptualized. This conceptualization will then be discussed from the lens of middle childhood. The research regarding self-concept within disabled populations will then be synthesized and will include an analysis of methods of measurement.

Harter's Theory of Self-Concept

Building on the early work of James, Gergen, and Piaget, Harter's theory of self-concept identifies the development of self-representations as a continuous and cognitive process (Harter, 2012). Harter's work provides an in-depth discussion of how self and self-concept has been defined over the course of psychology's history. While many theories regarding self exist, Harter's theory is grounded in many of the historical thought patterns regarding self and integrates historical perceptions alongside modern interpretations. Furthermore, Harter provides a developmental lens to the understanding of self-concept in that she outlines the progression of self-concept definition and the influencing factors that inform how self is impacted in different stages. For the purpose of this research, Harter provides a theoretical framework that proves useful in understanding how the self emerges in mid childhood as well as how societal and relational factors influence this growth. As this research seeks to evaluate the relationship between self, labels, and experience, Harter's theory is helpful in the organization of findings and conceptualization of the developmental process.

Self-Concept Development in Middle Childhood

For children, the development of self is specific and unique. Development of the self is limited due to the argument that children have cognitive limitations and approach information in a concrete manner (Harter, 2012). Harter indicates development is so rapid in children and so influenced by a multitude of factors that development of the self has a chaotic pattern instead of following a clear pathway.

According to Harter (2012), the period of middle childhood falls between the ages of eight and ten and is flanked by early childhood and late childhood/pre-adolescence. As children age out of early childhood, they move away from concrete, behavior-based representations of the self and toward more cognitively complex representations. Self is most often described using competency driven language, i.e. children describe themselves by identifying where they succeed or where they fail. Descriptions of self are particularly driven by peer relationships, especially those of children of the same gender. Harter (2012) notes that this period of childhood represents the “pinnacle of gender segregation” (p. 60). This is also the period in time where children shape their own autobiographical memories and are apt to dictate what is remembered from important experiences. This leads to an ownership of narrative, as well as an increase in self-agency and self-efficacy.

Regarding cognition, more complex abilities emerge in the areas of memory, linguistics, and problem solving in middle childhood (Harter, 2012). Children move from the period in which they are just discovering the general concept of self to being able to identify specific individual characteristics of self more readily and in more complex ways. Due to these developments, children are better able to generalize their isolated skills and personal experiences to higher level concepts. For instance, a child will be able to identify repeated academic successes as being indicative of an intelligent self. Children are also able to hold both positive and negative attributes simultaneously, shifting self-perceptions from a place of cognitive dissonance to a place of integrated understanding. The same construct can be applied to emotions: children in middle childhood are better able to recognize that multiple emotions can occur simultaneously, or different types of emotions can occur with the same group during different times. This skill development takes time and does not emerge fluently until the end of middle childhood and just before early adolescence, although sometimes this development occurs later. It can also be heavily influenced by social interactions and self-evaluation in relation to peers or relevant stakeholders.

Cognitive development also brings about vulnerabilities within self-processes. The ability to hold onto multiple values simultaneously is highly sensitive throughout this period of development. According to Harter (2012):

> The ability to be able to construct a global perception of one's worth as a person represents a major developmental acquisition, a milestone, as it were, in terms of a shift from mere domain-specific self-perceptions to an integrated sense of one's overall self-esteem. However, other cognitive-developmental acquisitions can serve to lower the valence of this global perception of self, leading to lowered self-esteem (p. 64).

Harter's discussion of self-concept theory provides a conceptual framework to help understand the childhood developmental processes in middle childhood. There are areas of Harter's theory, however, that neglect to discuss in detail the impact that race, class, gender, and ability can have on the development of self-concept. Harter highlights the "cultural self" as a developing factor that can emerge in middle childhood, but this concept encapsulates the broad understanding that society is heterogenous. This leaves the discussion of self open to a wide breadth of influences to consider. This broadness means that societal privilege and social oppression are not explicitly considered in how they can influence the self in positive or negative directions. Additionally, Harter uses the language of pathology to describe certain experiences that may result in decreased self-concept. Namely, she identifies societal influences leading to the presentation of false-selves as a pathological behavior and does not provide consideration that a false-self may serve to protect oneself in an oppressive environment. Despite these considerations, Harter's theory is useful in considering the developmental stage of middle childhood and how sensitive this period is to both previous experiences as well as to the development of future strength or weakness. For the purpose of my research, Harter's theory is broad in its definitions of self-concept while also encapsulating the developmental features of childhood that will need to be considered as the childhood perspective on disability is explored. The broadness of Harter's theory leaves room for exploration of how factors intertwine and inform growing self-esteem, rather than confining the development of self-concept to concrete, isolating stages.

Piers, Shemmassian, and Herzberg

While Harter depicts the developmental theory of self, Piers, Shemmassian, and Herzberg (2018) provide theoretical assumptions in their description of self-concept that can be used to understand the construct more generally. In their discussion of the theoretical underpinnings of self-concept, they posit the following six assumptions: first, self-concept is phenomenological in nature and cannot be directly seen as much as inferred. Second, self-concept is both global and specific. Third, self-concept is relatively stable. It is situationally dependent in children, but becomes more stable over time, with some areas of self-concept being more difficult to change than others. Fourth, self-concept can be descriptive, but it can also be evaluative. Fifth, self-concept is different in various developmental stages. Finally, self-concept helps to both organize behavior as well as motivate it. Together, Piers, Shemmassian, and Herzberg's assumptions are accessible, despite their lack of developmental discussion. It is also important to understand Piers, Shemmassian, and Herzberg's assumptions, as their quantitative tool – The Piers Harris Self Concept Scale – is frequently utilized throughout the literature.

In summary, self-concept theory has grown and changed over the course of psychology's history. What has remained consistent is the understanding that self-concept is an integration of many factors and is greatly impacted by relationships with others and the messages set forth by influential individuals or groups. Self-concept is an important feature of the human's psychological development and can greatly impact behavior, motivations, and emotions. Applications of self-concept theory and measurement of its processes are extensive; however, there are still gaps in certain areas of the literature regarding self-concept as it relates to disability and childhood identity development.

SELF-CONCEPT APPLICATIONS

Quantitative Studies Regarding Learning Disabilities and Self-Concept

Significant amounts of quantitative research have been completed regarding the self-concept of students with learning disabilities. Meta-analysis of articles using quantitative tools have indicated there is a significant difference between children with learning disabilities and children without disabilities (Bear, Minke, & Manning, 2002; Chapman, 1988). Significantly lower scores were indicated for students with learning disabilities particularly in the academic self-concept, with some studies indicating this finding as more prevalent in older students (Chapman, 1988). Lower self-concept was commonly noted for students placed in a non-remedial setting. Bear, Minke, and Manning (2002) found that children with learning disabilities viewed themselves less favorably than non-learning disabled children in global self-worth and the specific domains of academic, social, and behavioral competence. The researchers also found that there were no gender differences of self-worth. It is noted that there is no mention of other factors that can impact self-concept, namely socioeconomic status, race, and language proficiency, by either meta-analysis.

A preponderance of the research illustrates that academic self-concept may be low while other domains remain average or higher (Gadeyne, Ghesquiere, & Onghena, 2004; Gans, Kenny, & Ghany, 2003; Kloomok & Cosden, 1994; Martinez, 2002; Rothman & Cosden, 1995). Learning profiles have an impact on the level of self-concept. Full scale IQ and math achievement show a positive correlation with the self-perception of a learning disability. Self-perceptions of ability, writing competence, behavior, and social acceptance also positively correlate with global self-concept (Rothman & Cosden, 1995). Students with high global self-concept and high academic self-concept, as well as students with high global self-concept and low academic self-concept, score higher on reading achievement than students in the low global self-concept and low academic self-concept (Kloomok & Cosden, 1994). In other words, students with a higher rating in either academic self-concept or global self-concept are likely to show better reading skills than students where both areas are decreased. Similarly, students with general low achievement scores demonstrate poor self-concept alongside challenges with attention and academic motivation (Gadeyne, Ghesquiere, & Onghena, 2004; Gans, Kenny, & Ghany, 2003). When split out by subtype of learning disability, students with both reading and math disabilities report the lowest levels of global self-concept and academic self-concept (Martinez, 2002). Students with just a math disability or just a reading disability have similar global self-worth scores compared to non-disabled students.

Qualitative Studies Regarding Learning Disabilities and Self-Concept

Limited research is available regarding the qualitative experiences and self-concept characteristics of people with learning disabilities. That which is available relies on the life stories of adults or older children with limited interpretation, relying on the reader to take meaning from the depicted experiences. Many of the stories speak to similar experiences: participants spoke to feeling like a slow learner who presented with anxiety in the classroom (Pestana, 2014; Rodis, Garrod, & Boscardin, 2001). For adults with learning disabilities identified later in life, they highlighted feeling frustrated and stupid throughout school experiences, with feelings of relief when their learning disability was finally identified. Adults have shared that as children, they were less able to verbalize the experience of their disability but could describe they “just knew” they were disabled or were informed by trusted adults, mainly teachers (Cosden, Elliot Noble, & Keleman, 1999). Pestana, Rodis, and Boscardin’s (2001) work indicated that substance abuse was frequently used as a coping mechanism for managing stressors later on in life related to disability, while Cosden, Elliot, Noble, and Keleman (1999) indicate that they used communicating with others about their disability and looking for places of self-growth as coping skills.

Learning Disabilities and the Consideration of Race, Class, and Gender

While the quantitative literature frequently considers race, gender, and ethnicity constructs in their research design (Bear, Minke, & Manning, 2002; Gans, Kenny, & Ghany, 2003; Martinez, 2002) minimal research has been completed regarding the intersection of these factors with self-concept. Some research has revealed differences in self-concept in girls versus boys (Kulshrehtha, 2016; Mano, Jastrowski Mano, Denton, Epstein, & Tamm, 2017). Statistically significant differences have been identified between physical self-concept in boys versus girls, with boys reporting higher levels of physical self-concept. Temperamental and moral self-concept was higher in girls (Kulshrehtha, 2016). However, this sample did not include participants with disabilities, making it difficult to generalize these findings to a more specific population. In looking more specifically at differences between genders and self-concept in children with comorbid Attention Deficit Hyperactivity Disorder (ADHD) and Learning Disability, Mano, Jastrowski Mano, Denton, Epstein, and Tamm (2017) found that while there were gender differences in emotional/behavioral problems and gender differences in reading problems specific to this population, emotional/behavioral difficulties do not directly cause the reading problem. This brings up the importance of intersectionality in identification of disabilities, predominantly the over-identification of some students and the under-identification of other students based on race, class, and gender. Treating race, class, and gender as constructs instead of variables can greatly change the perspective one has on how disability identity is formed and understood.

Together, studies of learning disabilities and self-concept highly emphasize the use of quantitative measures and concrete constructs to describe a nuanced process, and additionally neglect to place gender, class, and race at the forefront of discussion. This leads to a missed opportunity to examine intersectionality as another contributing factor to the development of self. This also fails to consider how power and oppression can constellate in a drastic, life-altering manner, particularly during mid-childhood where the concept of self is developing through the influences of countless factors. Moving forward, this gap highlights the need to develop research that considers intersectionality of phenomenon rather than the intersections of disability type and demographic construct.

Disabilities Outside a Specific Learning Disability

Compared to the learning-disabled population, considerably less research has been conducted on the self-concept and experiences of other disabilities outside a specific learning disability. This means that disabilities like autism, ADHD, anxiety, and medical conditions are not always represented equally in the data. This lends to a difficulty in synthesizing that which has been researched since the existing studies explore self-concept in such a variety of ways that they cannot be readily compared. Wei and Marder (2012) sought to identify the developmental trajectories of self-confidence and importance beliefs in the academic, social, and self-image domains for students with disabilities between the ages of eight and 17 and to determine if developmental trajectories differ between students with LD versus 10 other disability categories, as well as how they differ by gender and race/ethnicity. Using the Special Education Elementary Longitudinal Study data set, the authors found that patterns of self-confidence were similar across groups around age eight: these factors then declined during the remainder of elementary school, then returned to increasing upon entering a later developmental stage. The nature of the disability was a relevant factor, specifically showing that children with social disabilities such as Autism or an Emotional Disturbance present with lower levels of self-confidence. There were significant female advantages in the majority of outcome measures, with academic importance values presenting as similar to male ratings. The authors briefly brought attention to the over-identification rates of minorities in special education by highlighting that minority students did not always have lower self-concept despite overidentification. However, their discussion falls short as it does not further discuss this relationship. This study frames questions of self-concept in relationship to different population characteristics effectively in a quantitative manner, but given the expansive data set, the authors are unable to provide meaningful information that can be generalized to direct work with students in applied settings. While their recommendation to target academic skills prior to directly addressing self-concept skills is reasonable, the data to support this recommendation is questionable given the wide breadth of data collected and analyzed. This study again exemplifies that quantitative data can provide an overarching snapshot of the population of children with disabilities, but it does not give in-depth, rich descriptions of the lived experiences of these individuals. Gathering this information would fill a research gap and enlighten consumers of the experiences of children.

Communication Impairments

Qualitative research has indicated that those with communication impairment labels experience both positive and negative identity attributes related to being labeled (Edmonds, 2012; Lyons & Roulstone, 2016). Lyons and Roulstone (2016) uncovered themes of desired identities and undesired identities in 11 children between the ages of nine and 12 with primary speech and language impairments. Participants identified desiring identities that reflected positive evaluation from others; competency; being perceived as “good”; and being socially attractive to peers. Participants indicated a dislike of being labeled by others, as this made others perceive them as different and potentially undesirable. Edmonds (2012) discovered similar themes when conducting retrospective interviews with four adults with childhood dyspraxia. All participants had negative school experiences and their self-esteems were negatively impacted by the perceptions and labeling by others. What was not always celebrated was the high level of creativity and empathy demonstrated by these students. These researchers exemplify how qualitative research can reveal important information regarding the disability experience and can stretch the conceptualization of what it means to be disabled.

Autism

Research conducted with autistic populations revealed similar patterns of both positive and negative attributes associated with the label (DePape & Lindsay, 2016; Jackson, Skirrow, & Hare, 2011; Kelly, 2005; Mackay & Parry, 2015). Sense of self was often underdeveloped or reflected a narrower lens related to special interests and decreased theory of mind (Jackson, Skirrow, & Hare, 2011; Kelly, 2005). Some respondents indicated feeling different based on the barriers presented in everyday life (Kelly, 2005) while others felt having the label of autism helped them find relief and acceptance (DePape & Lindsay, 2016). DePape and Lindsay (2016) in particular made efforts to synthesize and integrate qualitative research about the lived experiences of individuals on the Autism Spectrum using a meta-analysis. Analysis of existing literature revealed four themes permeating qualitative research: perception of self, interactions with others, experiences at school, and factors related to employment. Findings relevant to the research question stated above include the discovery that responses to diagnosis varied depending on the person queried. Some found a sense of pride within diagnosis, while others were indifferent. Feelings of acceptance and relief were indicated if diagnosis provided answers related to behavior. However, feelings of devastation and helplessness were also discussed in relation to having a lifelong disorder. A discussion of unique interests and important coping skills were also included within these themes. These findings are useful in reminding stakeholders that diagnoses can be both powerful and disempowering. Still, this research focused on adults and neglected to consider the power labels can have to the childhood experience. Further research is needed to capture this phenomenon.

In some research, measures of the perceptions of autistic behavior indicated that autistic individuals perceive their autistic traits related to restricted interests as hobbies or as mere reflections of self (Jackson, Skirrow, & Hare, 2011; Mackay & Parry, 2015). Meanwhile, the perceptions of non-autistic individuals suggested that autistic behaviors reflected decreased awareness of the social world and ritualistic behaviors with little meaning. The research on autism made strong attempts to capture the lived experiences of autistic individuals. However, results were presented in an ableist lens; for instance, highlighting behaviors as odd or unusual when compared to individuals without disabilities. Priority was also given to the neurotypical interpretations of lived experiences over understanding the autistic interpretation. In other words, the method by which this research was presented assumed the reader would be neurotypical and likely be able to exert power over people identified with autism, indicating the privilege inherent in the neurotypical status. Research that is sensitive to the phenomenon of disability should highlight the power in the experience of the disabled, not just how the experience differs from what is valued and celebrated in society.

Intellectual and Developmental Disabilities

Jones (2012) and Foley et al. (2012) aimed to give voice to children and adolescents with intellectual and developmental disabilities. Both studies explored the way social supports helped these participants navigate their labels and how they perceived their labels within their social environments. Findings indicated that having strong relationships with family is a key factor related to empowerment. Foley et al. (2012) further discovered common themes between participants and what they saw as protective or hindering factors to healthy well-being: good friends, strong family, coping mechanisms, and healthy personal growth and development were frequently discussed when participants were asked about what contributed to their overall well-being. Anxiety related to school and school experiences negatively impacted overall well-being.

Research Implications

In summary, the existing literature reveals important information regarding disability and self-concept, but there are still areas that are yet to be unpacked or discovered. First, the majority of research uses quantitative measures. This type of information is helpful in determining wide scale patterns and statistically significant differences but leaves out the voices that have experienced feeling different or othered. Second, research is thorough regarding learning disabilities, but is lacking in its discussion of other disabilities. This leaves a significant portion of people with disabilities out of the discussion of how one’s self-perception is impacted by the presence of a disability.

Literature review also exposes a lack of consideration for the full developmental spectrum. Participants across the identified research ranged between later elementary school and adulthood. While some disabilities may not be identified until these later times, others may be identified in students from the early childhood population or characteristics of disability may be observed within this developmental stage. The existing literature includes retrospective discussion of childhood experiences, thus describing the experiences once processed with higher-order cognitive skills or contextualized (e.g. Edmonds, 2012; Pestana, Rodis, & Boscardin, 2001). More research is needed to display the childhood voices regarding childhood experiences of disability because it will allow for better intervention planning and developmentally sensitive diagnostic approaches to disabilities.

One final observation regarding the existing literature in this domain is that the research on learning disabilities and self-concept appear to have experienced two bursts over time. Specifically, these bursts occurred in the mid 1990s and the early 2000s, often being conducted in California. Research on invisible disabilities outside the specific learning disability diagnosis is minimal. New research needs to be conducted to update how disabilities are understood and interpreted by children of this generation. Disability definitions in the Individuals with Disabilities Education Act were revisited in 2004 (Individuals with Disabilities Education Act, 2017) and the Diagnostic and Statistics Manual – Fifth Edition was released in 2013 (DSM-5: Frequently asked questions, 2018). Harter updated her theoretical conceptualizations of self-concept in published text in 2012. The existing research is quickly becoming outdated and reflective of past practice. New research must be conducted to fill this gap and update the understanding not only of how self-concept develops in children with disabilities, but also how children perceive the process of being labeled disabled and integrate it into their concept of self.

STIGMA

The previous sections of this literature review have addressed the history of disability, existing definitions of disability, self-concept theory, and the measurement of self-concept in disability populations. At the crossroads of these subjects is the consideration of how stigma has developed over time, how it is conceptualized, and what role it can play in the lives of individuals within oppressed populations. The purpose of this section of the literature review is to provide the reader with an understanding of stigma, and in particular how societal stigma can transfer into self-stigma, impacting the way a person perceives oneself and fosters self-worth.

Stigma Theory

Goffman's (1963) work explores the concept of stigma across visible and invisible populations. As one of the original works regarding stigma, Goffman seeks to expose the socially designed concepts that help foster categorization. Specific to disability, Goffman discusses the concept of visibility and how this is a crucial factor to developing the social identity that is then interpreted by outsiders. For invisible conditions, such as mental illness and learning disabilities, the idea of passing is defined as when a stigmatizing affliction is unknown to others, which can be both a desirable and challenging feature of disability. As indicated by Goffman (1963), in-group and out-group attitudes can also interfere with the development of identity in relation to the stigmatizing condition.

Around the same time, Paul Hunt (1966) directly speaks to the issue of stigma in his work discussing the experiences of the disabled in London at the time. Hunt outlines the inadequacies of social services in Britain, focusing on the lack of financial support provided by the government despite recent legal actions through The Disabled Persons Employment Act. Within the text, additional authors speak to how lack of services is challenging, but the quality of relationships is what is most impacted by disability. Multiple essayists indicate that family relationships are marked by protectiveness, superiority, aloofness, or revulsion (Townsend, 1966). These relationships impact the ability of the person with disabilities to feel normal or be part of normal society, indicating self-stigma along with the stigmatization of society (Townsend, 1966; Darling, 2013). Hunt is cited as stating, “disability, like intelligence, is more a matter of degree than of kind. It is more a relative than an absolute condition. If this is correct, then our conception of human diversity has merely to be extended beyond the customary limits” (Townsend, 1966, foreword). Similar to Goffman, Hunt and colleagues approach a topic novel to the time given the lack of public discussion regarding disability and stigma. However, the essayists use the lens of those with disabilities to explore stigma, providing an authentic discussion of how stigma informs day to day living and self-perception.

Disability studies scholars including Jeffrey Brune, Rosemarie Garland-Thomson, Susan Schweik, Tanya Titchkosky, and Heather Love (2013) have reflected on the contributions of Goffman and Hunt in efforts to modernize the discussion and critique of stigma. Scholars note the importance of Goffman’s (1963) work as setting a foundation for discussing stigma. His discussion of relationships highlights the understanding that disability and other impairing conditions are understood within the context of relationships. However, Goffman’s perspective is primarily negative and does not focus on the positive possibilities inherent in relationships, such as advocacy and empowerment. Goffman additionally uses an ableist, normalcy lens that lessens the importance of the disabled experience instead of recognizing that disability identity helps resist stigma. Within the forum, Heather Love (2013) notes that Goffman has recently been dropped from the Disability Studies Researcher and new questions have arisen as to whether Goffman has a place within the disability studies perspective given his focus on normalcy. In many ways, Hunt sets a better foundation for disability studies as he uses more inclusive language and highlights binary distinctions that do not necessarily fit the disability experience; in other words, Hunts is able to identify gradients or variants to disability that impact experience and make it nuanced. Hunt further argues that stigma is not a challenge to a person; rather, it is a challenge to society and its ability to function inclusively. Love (2013) indicates that Hunt is a better model in many ways for disability scholars, but his work is often shadowed by Goffman’s reputation and role as the originator of stigma discussion. In whole, disability scholars agree that Goffman’s work should be considered because he addresses the process of categorization and how people can become inferior or feel inferior within society, but the work should be used selectively when applied to disability.

Self-Stigma

The research on self-stigma takes classic definitions of stigma and applies them to the idea of self and identity. For the purpose of my research, it is important to understand the underpinnings of self-stigma, including how it develops and how it informs behavior. In particular, self-stigma has implications on how self-concept develops as it incorporates hegemonic culture alongside the internalization of societal oppression. Research on self-concept of children with disabilities is likely to unpack and explore how children hear society's messages and internalize them, either positively, negatively, or a combination. The following sections of this literature review explore a wide breadth of dimensions regarding self-stigma, including how self-stigma informs disclosure, self-stigma in family members of individuals with disabilities, and the development of self-stigma in children.

Scholars identify that self-stigma is made up of similar constructs to societal stigma, including the presence of stereotype, prejudice, and discrimination (Corrigan & Watson, 2002; Darling, 2013; Siebers, 2004; Watson & River, 2005). Stereotype within self-stigma theory is a negative belief about the self. Prejudice is the agreement with this belief and having a negative reaction to it. Discrimination is the behavioral response to prejudice, which presents similarly to learned helplessness or maladaptive behaviors (Corrigan & Watson, 2002; Watson & River, 2005). In many people, the process of self-stigma development may follow a similar pattern to other disempowered populations and result in righteous anger (Corrigan & Watson, 2002).

Further complicating this model is the consideration of visible disabilities, such as physical impairments or the presence of obvious adaptive devices, versus invisible disabilities, such as high functioning autism, anxiety, attention deficit hyperactivity disorders, or specific learning disabilities. In the case of invisible disabilities, there is also the layer of hidden stigma (Corrigan & Watson, 2002). Hidden stigma occurs when a person with an invisible disability has not yet been diagnosed or has not yet developed an understanding of their disability but is aware of the stigma placed on their presentation. Research is mixed as to whether hidden stigma has a stronger or weaker effect on self-esteem. On the one hand, self-stigma may lessen given that the disabling condition is not readily apparent to others. However, someone with an invisible disability may have more difficulty identifying others within their disability group, thus making it harder to access the protective factor of group identity (Corrigan & Watson, 2002; Darling, 2013). According to Siebers (2004), many with invisible disabilities select to "pass" as "normal", particularly as society has varied representations of disability, including those generated by the masquerading of disability in popular culture. Examples include characters on television shows with exaggerated characteristics of autism, such as the character Sheldon from *The Big Bang Theory*, or intense anxious behaviors, such as the character Monica from *Friends*. In these instances, society develops hyperbolic stereotypes of invisible disabilities. Individuals with these conditions may select to hide their conditions through passing, or instead take on these stereotypes and masquerade them as an act of rejecting oppression (Siebers, 2004).

When stigma invades self-esteem, it follows a specific process (Corrigan, Watson, & Barr, 2006). During the first step of stereotype awareness, the individual must be aware of the stereotypes present regarding their condition. This awareness can start in early childhood: the understanding may not be explicit, but with social awareness comes the awareness of social norms and practices (Corrigan, Watson, & Barr, 2006). Following stereotype awareness, the individual must agree with the stereotype, a step known as stereotype agreement. This leads into self-concurrence, or the internal agreement that one's disability profile matches that which is believed within stereotype. The subsequent step is the self-decrement stage, where the individual's self-esteem is impacted due to the belief in the stereotype. Significant correlations have been found between stereotype agreement, self-concurrence, and self-decrement (Corrigan, Watson, & Barr, 2006). However, the relationship between stereotype awareness and the other three levels of the model have not been statistically significant. It is essential to consider this finding. It is imperative that we understand how stereotype awareness and explicit intervention against bias can prevent self-decrement and decreased self-esteem. In order to take a proactive approach to decreased self-esteem, we need to consider individuals at their earliest developmental stages so we develop a healthy awareness of stereotype and advocate for alternative narratives. However, research on self-stigma in children is deficient, as there is a large gap in developmental awareness and child advocacy.

Stigma and the Disclosure of Disability

Much of the research evaluating stigma, self-concept, and disability is focused on the self-esteem of individuals and how it changes depending on the acceptance or rejection of stigma. In general, researchers have identified that the higher initial public stigma that an individual holds for a specific population, the higher the subsequent self-stigma (Corrigan, Watson, & Barr, 2006; Vogel, Bitman, Hammer, & Wade, 2013). An individual may be aware of stigma or stereotype and may even agree with the stereotype, but that does not necessarily mean it will be internalized (Corrigan, Watson, & Barr, 2006). It is not until the individual sees the stereotype within themselves that self-stigma may develop. In their evaluation of stigma as a barrier to recovery for individuals with mental illness, Link, Struening, Neese-Todd, Asmussen, & Phelan (2001) identified low self-esteem was not be a significant problem for the 70 people studied who experienced mental illness. However, the majority of respondents suggested that people with mental health conditions are likely to receive rejection and turn to withdrawal as a means of coping. For respondents experiencing decreased self-esteem, baseline measures of devaluation due to discrimination and measures of withdrawal strongly predicted self-esteem at both six- and 24-month measurement. It is notable that quantitative study with predominantly White, male participants has been used to generate these findings. Thus, while related factors can be identified as being significant statistically within a narrow band of the population, their intensity and severity of internal impact are yet to be defined, both within privileged and disempowered groups of people. The intensity of the human experience of self-stigma as well as the moments at which individuals start to believe stereotype and devaluate themselves need to be evaluated if we are to understand this concept fully. Further, as righteous anger can become a feature of self-stigma (Corrigan & Watson, 2002), narratives need to be heard in efforts to understand the disability experience alongside other experiences of stereotypes or oppression.

Specific factors are more likely to increase the acceptance or rejection of stereotype as well as the likelihood of an individual to disclose their disability, inviting the stigma of others. Individuals with invisible disabilities “manage stigma by either ‘passing’ as majority group members or identifying with their minority group” (Bogart, Rottenstein, Lund, & Bouchard, 2017, p. 553). As indicated by Bogart et al., recognition of stigma was a strong predictor of whether or not someone self-identifies as disabled. Increasing number of impairments and severity of disability was also a significant predictor of disclosure, as well as a predictor of advocacy behaviors (Nario-Redmond et al., 2013). People with strong disability identification were more apt to fight for disability rights. People with visible features to their disabilities were also more apt to advocate. While newly diagnosed individuals may experience more self-stigma, increased appreciation of the disability appeared to emerge with the increasing length of time with the diagnosis. Those who were more secure with their disability were less likely to support strategies aimed toward overcoming or minimizing disability (Nario-Redmond, Noel, & Fern, 2013). Again, these findings were found within primarily groups of White, male, adult participants. Further, respondents in these studies were limited to the use of rating scales. Respondents were not given the opportunity to voice their experiences and capture the emotion behind advocacy, disclosure, and living with a disability in an ableist society.

Evans (2017) is one of the few who makes a qualitative attempt to describe the disabled experience and its relationship to societal stigma and disclosure. Evans interviewed three men and nine women between the ages of 29 and 54 to examine the experience of individuals who have made active efforts to resist assimilation into society's expectations of normalcy. Evan clearly describes her study as one that depicts the White experience of acquired impairment given her sample. Based on responses, Evan identified that significant efforts to minimize attention to impairments are made in work settings and social situations. While disclosure of an impairment can be powerful in relationships, the impairment may be discounted if the individual is able to self-manage. The majority of respondents reported concerns of burdening others while also experiencing frustration when outside people forget their impairment. This can force the individual to downplay their impairment. In other instances, participants highlighted a pressured feeling to disclose. Evans places this analysis also within the ableist United States, highlighting that the cultural expectation of the U.S. is different from other countries and populations, which makes the disabled experience potentially more disempowering than in populations where disability is accepted and not contrasted against normative cultural constructs. Evans is explicit in her discussion of disability and the resistance of stigma; however, her sample is not representative of many experiences, as she notes in her methods. Evans gathered White individuals with bachelor's degrees or higher levels of education to complete her study, a group that lacks diversity. More research is needed to examine the experience of self-stigma across populations that include broader races, ethnicities, and ages.

Parental Experiences of Stigma

Research conducted with parents highlights both perceptions of parents regarding stigma as well as the parental experience of affiliate stigma or self-stigma. Across research, parents indicate that stigma plays a powerful role in the lives of children with disabilities (Corrigan, Buchol, Michaels, & McKenzie, 2016; Manago, Davis, & Goar, 2017). This informs both how parents advocate for their children, as well as how parents perceive self-advocacy. Manago, Davis, and Goar (2017) qualitatively investigated as to whether parents stand up to stigma or back down when confronted by it. They found that parents evoked both the medical and social models of disability depending on the situation. Interestingly, parents more often invoke social components rather than the medical components of disability when advocating. They indicated equal rates of deflecting stigma and challenging it. Data suggested this is true for parents of children with visible as well as invisible disabilities. Corrigan, Bucholz, Michaels, and McKenzie (2016) investigated parental perspectives on whether or not children should disclose their mental illnesses to others. Findings indicated the beliefs that there are benefits to disclosing as it may help to change stigma, reduce stereotype, make things better at school or work, bring relief to self, boost self-esteem, and help families understand one another. Participants were more likely to be concerned with outcomes for middle and high school adolescents versus younger children. Responses also indicated that those people who endorsed high rates of stigma believed disclosure comes with more costs, such as the loss of support and decreased opportunities.

Parents are also vulnerable to experiencing their own self-stigma related to their personal experiences as a parent or as a member of the disability community. Mikami, Chong, Saporito, and Na (2015) used rating scales and coding of parent-child interaction behaviors to determine how the stigma of parents influences parental behavior toward their child with Attention Deficit Hyperactivity Disorder. They found that a higher rate of affiliate stigma reported by the parent was predictive of a higher rate of parental negativity toward their child during interactions. Greater stigma also predicted poorer social functioning of the child. Eaton, Ohan, Stritzke, and Corrigan (2016) looked at the qualitative experience of self-stigma in parents with children under the age of 13 that have mental health disorders. Interview data revealed several key themes. Namely, parents indicated having a “good parent ideal,” in which they identified the characteristics they wanted to have to be considered a good parent. Parents were aware of external stigma and the outcomes of it, which at times led to the internalization of stigma and the generation of self-doubt. Finally, parents grappled with refuting self-stigma, identifying it as a relevant factor to meeting their definition of the good parent. Chan and Lam (2018) additionally highlighted these themes through quantitative research, indicating that increased self-stigmatization is significantly correlated to decreased life satisfaction, caregiving gains, caregiving burdens, and increasing depression.

An influence on the parent perspective is the teachers who educate their children. Parents and teachers often have different mindsets regarding disability and how to support children with differences (Lalvani, 2015). In a qualitative study looking at the similarities and differences amongst adults in their perspectives of educating and raising children with disabilities, Lalvani found the theme of labeling as a feature of stigma to be consistent in the perspectives of both parents and teachers. Parents often responded negatively to labeling or wanted a particular label because of a favorable stigma related to specific diagnoses. Teachers were more positively minded about labeling, seeing it as helpful for academic planning. Parents saw removal from the classroom to receive services as more stigmatizing, while teachers felt that stigma has decreased over time and that removal is critical to instruction. Together, responses indicated that teachers subscribed to the medical model of disability, locating the disability within the child, while parents' definition of disability included a discussion of impairment versus context, and how the two interplay to create disability. The discussion of labels is salient to the researching of childhood experiences with disability. Children who are aware of their label are likely to have a perception of the label that then informs their behaviors and colors their experiences. In order to understand the phenomenon of childhood disability, labels must be explored and further conceptualized to illuminate their impact and role on the child's self-concept.

Research regarding parents is helpful in understanding the emotional backdrop to decision-making process for children. However, literature is limited regarding cultural factors and their impact on self-stigma. This is an important area of consideration, given the significant differences in child-rearing across the cultural, racial, and ethnic landscape. Furthermore, there is minimal research regarding the way parents communicate with children about disability and then translate the child’s values to the educational and parental decision-making process. Finally, the majority of research examines self-stigma in parents of children with mental illness. This neglects to include the parents of populations of children with other forms of invisible disability who also experience stigma and decreased self-concept. Additional research is needed to capture these narratives in efforts to better understand the trajectory of stigma leading to self-decrement and decreased self-esteem.

Childhood Experiences of Stigma

Minimal research exists regarding the childhood experiences of self-stigma. In a meta-analysis of the research regarding stigmatization and self-perception of youth with Attention Deficit Hyperactivity Disorder, Bussing and Mehta (2013) found that there are common types of stigma experienced by individuals regardless of age. The first type of common stigma was public stigma; this is the general stigma held by society toward people with disability. The second type of stigma was courtesy stigma, otherwise understood as ways in which people interact with the disabled population in efforts to appear courteous and helpful, but instead create disempowering interactions. The final type of stigma across studies was self-stigma; however, very minimal research could be found regarding this area, thus limiting the discussion of its impact.

Within the limited research regarding self-stigma in children, results indicated that experiences of stigma were consistent with findings related to self-concept and self-esteem (Chan, Chan, Cheng, Chow, Tsang, Lee, & Lin, 2017; McKeague, Hennessy, O’Driscoll, & Heary, 2015). In a study conducted in Hong Kong with a homogenous population of children, self-stigma was higher in children with specific learning disabilities, resulting in decreased quality of life when compared to children without specific learning disabilities (Chan et al., 2017). When qualitatively investigated, retrospective accounts of adults with attention deficit hyperactivity disorder and/or depression indicated themes of feeling and being different, responding negatively to peer stigmatization, and selecting to disclose carefully and judiciously in efforts to protect oneself from increased stigma.

While these two studies made attempts to consider the experiences of children, the lack of research within this domain highlights a desperate need to talk to children, particularly the newly diagnosed or identified, in efforts to learn about how self-stigma develops and how children interpret being disabled in today's society. It is critical to talk to diverse groups of children with disabilities: this will help fill the gap regarding children while also providing opportunities for participants to process stigma and develop protective mechanisms to combat stigma and advocate for themselves over time.

CONCLUSION

The intersection of self-concept, disability, and stigma is complex. When broken apart, research provides moderate insight into each individual component. When measured quantitatively, research highlights decreased self-concept across disabled populations. However, the methodology used to reach these findings is narrow and limiting. Research focuses primarily on self-concept as a measurable concept that can be summarized by rating scales developed in academia. The nature of rating scales is that they are restricted and have their basis on scripted questions. The advantage of this structure is that the data derived can be quantified. Quantified data can be compared.

Quantified data can be assigned value. If the goal is to compare, judge, and isolate thinking to one form of truth, then the existing research on self-concept captures the positivistic interpretation of how people with disabilities measure their self-concept. If the goal is to understand, enlighten, and explore the diversity of experience, then the research is non-existent. This is especially true for disability populations outside of specific learning disabilities as well as marginalized populations who have been seen in the research as independent variables instead of valued members of society. Furthermore, the research on self-concept in middle childhood aged children is minimal, despite theorists such as Harter stating that middle childhood is a complex part of the growth between childhood and adolescence and where the cognitive capacity of children shifts from concrete to complex.

The construct of disability over time also needs to be critically analyzed when developing this research question. Throughout history, disability has been seen as a condition that limits a person's ability to contribute to society. This has been conflated with other human conditions and it has taken significant advocacy for our society to identify that disability is not only present, but it has the possibility of impacting all individuals at any time. The work of modern disability studies has made strides in changing the way we view disability. Namely, scholars (e.g. Brune & Garland-Thomson, 2013; Torres, 2019; Zola 1989), have separated out the difference between impairment and disability, leading to conversations about how social conditions can be changed to create more inclusive and supportive environments. The work that has been done has been completed by physical disability activists and has been critiqued as not encapsulating the pain or distress that does come with having an impairment. Therefore, there is considerable room for discussion and debate regarding what disability actually means for invisible impairments. Furthermore, children are not yet part of this discussion. Until they have a seat at the table, the experiences of younger generations experiencing impairment will be excluded from the disability studies model.

The research on stigma highlights the ongoing difficulties people with impairments face when confronted with unsupportive environments. Theoretical models reflect the possibility for individuals to internalize societal stigma if they recognize the stigmatized behaviors in themselves and agree with their negative evaluation. Parents and teachers have had the opportunity to voice their concerns about stigma toward their children’s impairments. They have also had the opportunity to voice their own experiences of stigma. Adults have been asked to reflect on previous experiences of stigma. The primary themes of research indicate that higher stigma leads to negative emotions and people who are highly aware of societal stigma are aware of its impact on marginalized individuals. Still, the research ignores the first person voices of children. Perhaps this is because adults want to protect children from stigma, or they believe children are too naïve or young to understand it. But if adults don’t provide the opportunity for children to have these difficult conversations, they will not be prepared to confront stigma and other forms of oppression as they grow and become more independent.

Research does not occur in a vacuum and is not exempt from social influence. The aforementioned studies indicate a mindset towards one way of thinking. They suggest the continuation of the ableist and adultism lens. A significant gap exists in the literature as it lacks consideration of the opposite lens which focuses on the embracing and empowerment of impairment. It is this observation that leads to my research question: how do children in mid-childhood with invisible disabilities experience being labeled? Qualitative research that examines the disability experience from the child's perspective will allow future researchers alongside future advocates to recognize what children need to feel confident and secure in their identities. In the next chapter, I will discuss the methodological design that can be used to fill this gap in the research.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

INTRODUCTION

The goal of this study was to illuminate the childhood experience of having a disability label while also gathering data to inform recommendations for parents, teachers, and other stakeholders in the lives of children. This section will discuss the research methods utilized to answer this question and shape future decision making, namely the use of qualitative research, phenomenology, interviews, and thematic coding.

METHODOLOGICAL DESIGN

Qualitative Research

This study utilized qualitative research techniques in efforts to generate an understanding of the childhood experience of invisible disabilities (Evans, 2017). The purpose of qualitative research is to help understand how people make meaning of experiences (Morrow, 2007). Qualitative research uses language as a tool to "glean meanings that are not otherwise observable and that cannot be gathered using survey or other data-gathering strategies" (p. 211). Qualitative research is reflective in nature and allows for exploration of the minutia of social and cultural experience, providing the opportunity to discover meaningful layers underneath the presenting behavior (Agee, 2009). Further, qualitative research acknowledges the presence of personal perspective, bias, and experience and outlines procedures to account for these factors. This study aimed to generate understanding of the childhood experience of invisible disability, meaning that quantification is less important and, rather, the words, voices, and meaning-making of children are in the forefront of exploration.

Phenomenology

Phenomenology was most appropriate for exploring the experiences of children and disability diagnoses. As a branch of qualitative inquiry, phenomenology seeks to uncover the essence of an experience or phenomenon and attempts to elaborate on how people exist in the world by illuminating the self within an experience (Moustakas, 1994; Wertz, 2011). According to Ricoeur, (1981), "the most fundamental phenomenological presupposition of the philosophy of interpretation is that every question concerning any sort of 'being'… is a question of the meaning of that being" (p. 74). For this reason, phenomenology was selected because this study specifically seeks to understand the "being" and the "meaning of being" specific to disability.

Phenomenology has its roots both in philosophy and psychology. There are multiple ways of thinking about phenomenology, including transcendental phenomenology and the hermeneutic approach (Josselson, 2004; Marshall & Rossman, 2016). In Husserl's transcendental phenomenology, the goal is to entirely separate pre-knowing or pre-understanding in efforts to understand the underlying phenomenon of the experience (Moustakas, 1994). Through a method known as "bracketing," one is able to "see what is, just as it is, and to explicate what is in its own terms" (p. 41). This is particularly important when listening to children, given that adults approach their listening to children from a perspective both of their own childhood experiences as well as how they process child behavior as adults. Further, Husserl posits that "it is logical in its assertion that the only thing we know for certain is that which appears before us in consciousness, and that very fact is a guarantee of its objectivity" (Moustakas, 1994, p. 45). Specific to this study, phenomenology appreciates that what children are sharing is their reality and from their consciousness, versus gathering data and placing greater emphasis on surrounding factors that may not be readily conscious to the participants.

Phenomenology is additionally built upon the philosophical framework of hermeneutics (Wertz, 2011). The hermeneutic circle is the process by which one breaks apart a phenomenon to analyze it by its individual parts and then synthesizes it to discover new meaning (Josselson, 2004). This process involves multiple deep readings of information and intense involvement with the text. Different from Husserl's work in transcendental phenomenology where all known information is bracketed, Gadamer's (1975) work with contemporary hermeneutics acknowledges that individuals approach new information from a place of one's own understanding of the world, a place he defines as the horizon of understanding. This horizon is comprised of one's prejudices, which are both positive and negative. According to Gadamer, it is impossible to truly bracket one's understanding: instead, one must engage in a conversation with the text by conducting several readings paired with reflection and analysis, leading to eventual enlightenment of the phenomenon. Given its consideration of how the world can be socially constructed and there is not one "truth" to the human experience, Gadamer's work appropriately mirrors the goal of this research. Namely, this research sought to develop an understanding of the disability experience, from the multiple perspectives of children.

Phenomenological research with children is particularly unique given that the person conducting the research has already experienced childhood, resulting in a well-developed forestructure of understanding (Danaher & Briod, 2005). In using phenomenology with children, "[t]he experiential threshold to a child-as-child is discovered through remembering and re-imagining childhood's life-world: the world as directly meant and immediately experienced" (Location 5229). In other words, one must suspend their own personal experiences while also recalling the essence of childhood as they engage with the data. The researcher must hold the child's subjective experience in the forefront while simultaneously recalling what it is like to be a child, so interpretation is done with respect and honor to the experience of what it is like to be little while also acknowledging there is no one "truth" to childhood. Specific to this research, the use of hermeneutics was essential to integrating experience with data, while also recognizing the multiple lenses by which the data is analyzed. It allowed for the delicate balance and appreciation of the fragility of the child's emerging sense of identity as well as the recognition that these understandings are within a development continuum and not necessarily fully developed yet. Furthermore, hermeneutics and phenomenology respect that there are features of identity that children may not directly speak to given their developmental stage, such as the intersectionality of race, class, and gender with disability, but this methodology still illuminates the importance of that which is conscious to the participant.

Epistemological Stance

As a researcher, I view the construction of knowledge from a constructivist-interpretivist stance. I subscribe to the idea that one's construction of reality is within the mind of that individual (Ponterrotto, 2005) and a universal definition of "truth" is unattainable. An individual is able to gain understanding through reflection and spiraling analysis of information in efforts to unearth one's truth within an experience. Furthermore, I hold that values and mindsets are generated through social interactions within the community, and thus it is impossible to separate or remove the influence of surroundings (Gergen, Josselson, & Freeman, 2015). With children, the construction of knowledge is especially socially driven given the power differential between children and adults (Freeman & Mathison, 2009). For children, I believe the social process is more vital to the spiraling internal process of generating understanding and definitions of self. For this reason, I look at work with children more specifically through a social-constructivist lens given the developmental vulnerabilities within this age range.

Reflexivity and Positionality

I am a woman who experiences multiple disabilities and who has developed much of her self-concept around the discovery of what disability means in our society, particularly for women. As highlighted in the introduction, I was labeled disabled when I was eight with a hearing impairment and had to quickly develop self-advocacy skills in order to best serve my needs in the classroom and in the community. I am also a woman who is immersed in the lives of individuals with disabilities, particularly children. In relation to my career as a school psychologist, I have had the honor of being beside children as they have learned of their label. In the counseling sessions following this discovery, I have seen children grapple with what it means to be different from their peers or different from societal expectations. Some children respond to the label with relief, while others find it a painful piece of information to internalize. Each child is different, but what is consistent is that the label means something. Together, these experiences have lead me to be passionate about this subject, both based on my personal meaning making a well as professional experiences.

PARTICIPANTS DESCRIPTION

Age

Recruited participants were between third and sixth grade. This decision was anchored in two developmental theories. This age stage is reflective of how Harter (2012) frames the mid-childhood stage in developmental discussion of self-concept development. While this research focused on self-concept, this age range was also selected based on Erikson's (1968) work regarding identity development. Erikson specifically highlighted the ages six to 12 as the years of the Identity versus Inferiority crisis, during which the sense of self begins to blossom and children start to discover what excites them, where they succeed, and what it takes for them to persevere (Hamachek, 1988). Children between six and seven were excluded as part of this study given the likelihood they will not know their diagnosis and will just be entering the process of learning their strengths and weaknesses. Further, six to seven is lower than the Harter (2012) definition of mid-childhood and is at a different developmental understanding of the concept of self. Also, while Harter only defined mid-childhood as between eight and ten, students up through sixth grade were included given their close proximity to the mid-childhood range and ability to reflect on recent events.

Disability

In efforts to narrow down criteria regarding disability and education, participants were expected to provide information regarding the child's disability identification and the corresponding educational classification provided in a public-school setting. As this research focused on the experience of invisible disabilities, the following disability categories were considered: Autism, Communication Impairment, Emotional Impairment, Health Impairment, Neurological Impairment, and Specific Learning Disability. Students presenting with visible Physical Impairments, Sensory Impairments, and Intellectual Impairments were not considered given the visible features inherent in their disabilities. The classification of Developmental Delay was also not considered, as the federal definition of this disability suggests the presence of weaknesses that a child will grow out of over time with intervention, versus the more fixed definitions of the other disabilities (Special education definitions and related links, 2018).

Documentation and Understanding of Disability

The parent or guardian of the participant was asked to provide a copy of the child's Individual Education Program. The purpose of its provision was to confirm the presence of a disability as well as to provide a general framework of how the disability impacts the child at school. Namely, the IEP was used to provide demographic information including what services the child receives in school, who comprises their school-based team, and what goal areas are addressed through services. Child participants needed to have been told of their disability and know the name of their disability. Participants also needed to be familiar with the word "disability." These criteria were essential to this project as this study directly sought to understand how children understand concepts like labels and diagnosis/identification. This expectation was explicitly stated in recruitment information as well as within informed consent. The purpose of these criteria was to ensure the children participating could speak directly to the idea of a label as well as the concept of having a disability, rather than needing to frame interview questions in a nebulous fashion.

Gender

Both males and females were recruited for this study. Only cisgender males and females were recruited in efforts to minimize the influencing factors on self-concept development. More specifically, it was predicted that children who have transitioned or who are initiating their transition at this age range will be engaged in processing what it means to be transgender and this is likely to impact self-concept alongside other experiences. Further, given that this subject is disability and children are open to persuasion, exclusion of transgender individuals was also purposeful as to reduce the likelihood that a transgender child misinterprets questions to reference their gender as a disability.

Race, Ethnicity, Social Class, and Community Setting

No specific criteria were set regarding these demographic indicators of participants. As the researcher, the community from which I was likely to recruit from is predominantly suburban, middle class communities that are primarily White. This was likely to impact the diversity of participants. While it is a goal to recruit as diverse a sample as possible in efforts to capture the diversity of human experience and intersectionality of constructs, it was expected that the diversity of participants would be limited due to the small sample size and the accessible community. Further, the goal of qualitative research is not necessarily to generate a broad sample, rather it is to dig deeply into specific experiences.

SETTING

Children are heavily influenced by the setting in which research is conducted (Freeman & Mathison, 2009). Participants were offered several options for interview location. The first option was conducting the interview in the home setting if the parents felt comfortable with this option and if reduction of distractions could be achieved. A second option was my office, which is located in an office building and designed to be child-friendly with access to toys, art supplies, and age-appropriate seating. A third option was a neutral location such as a local library. 11 children selected to participate in my office, while one child was interviewed at home.

RECRUITMENT AND SAMPLING PROCESS

Initially, ten children were recruited for this study. However, more males than females initially responded to the research announcement and thus IRB approval was requested to increase the sample size to 12, in efforts to have a balanced number. In the end, six girls and six boys participated in this study.

Recruitment information was disseminated in two ways. First, a social media posting was used to recruit specifically from my social network. This included friends, but also included a significant number of educational professionals such as teachers and school psychologists, as well as parents with whom I socialize based on the age of my own children. It was the intention that some snowball sampling would occur if my social connections were comfortable reaching out to friends who have children with disabilities. Second, participants were also recruited by carefully sampling through my professional contacts and providing them with an email explaining my study. The same script was used for the social media post and the email (Appendix D). To further support transparency in the recruitment process, a Google Form (Appendix E) was created that outlined the informed consent of participants and allowed possibly interested individuals to share their contact information. The Google Form was password protected and could only be found if the person was provided the direct link. The only person able to access the responses was myself. The Google Form was deleted once recruitment was completed.

CONSENT PROCESS

Given the nature of interviewing children, certain criteria was outlined for the guardians of participants (Appendix B). Guardians had to consent in writing to their child participating in an interview without the guardian present. Guardians were asked to remain nearby and an interview location agreed upon by both guardian and interviewer was selected. Guardians were provided scripts to use in explaining the purpose of the interview. The goal of providing scripts was to reduce children's confusion over the purpose of the study and what they were expected to share. Given that an adult researcher's role can be perceived as one of higher power (Marshall & Rossman, 2016), it was important to attempt to limit other adult influences when entering the interview arena. In addition to parental consent, children were asked to provide verbal assent (Appendix A). As part of their participation, children were given a gift card of 20 dollars.

DATA COLLECTION

Interviews

Interviews were the primary method of data collection in this study and were expected to last approximately 60 minutes. Children are often not used to being asked for their views or opinions and are often used to being disregarded (Greene & Hogan, 2005). For this reason, special attention was given to how interviews were conducted and how children were addressed both verbally and non-verbally. All recruited participants were interviewed in a style most appropriate to their learning style and given the age of the participants, significant time was dedicated to rapport building and clear explanations of the purpose of the research (Josselson, 2013). This time included talking about personal interests, playing games, or engaging in child-directed art or crafts. Interviews had an open agenda (Murray, 2003), with the intention of gathering information about the child's perception of disability, child's perception of their own disability, perception of others with a disability, definition of self, and long term self-vision. Semi-structured questions were generated in advance to create consistent lines of discussion and later thematic analysis, but follow up questions were generated in the moment in efforts to further thinking or deepen understanding (Appendix C). Interviews were audio recorded using a password protected device (laptop) and transcribed.

Artwork

As a part of this study, children were asked to complete a drawing that depicts a time where the child has felt disabled (Appendix C). Drawing and discussion took between ten and 20 minutes. Before children communicate through language, they learn to rely on symbols and pictures in their surroundings to describe experiences and explain phenomenon (Freeman & Mathison, 2009; Veale, 2005). Pictures are multi-dimensional, demonstrating parts of human experience that can be verbalized but also parts of experience that are too complex to put into words. They also allow for a less pressured method of communication, as drawing does not have a similar time pressure to it as the interview process. As a form of data, drawings may be considered somewhat difficult to interpret; however, drawing is unobtrusive and can allow for a different exploration of the child's reality (Creswell & Creswell, 2018). For this study, children were asked to draw and then describe the scenario in the drawing. Follow up questions occurred depending on the images depicted and the descriptions provided.

Storytelling

The process of telling stories is another method by which children can describe their experiences in an indirect manner (Veale, 2005). Storytelling allows for the sharing of vulnerable information through a more protected lens because the story can be told about someone else. Similar to drawing, storytelling is highly child-driven and does not contain the same pressure as the interview process. It allows children to provide some interpretation to their experiences, giving them a role similar to member checking or data analysis (Green, 2017). It is also an opportunity to incorporate humor and creativity, which are likely to increase rapport and thus strengthen validity. For this study, children were asked to tell a story about a child with a disability that included a beginning, middle, and end. The story should also give information about how the child in the story is thinking and feeling (Appendix C). This activity took approximately ten minutes.

Memoing

Once the data collection with children was complete, I wrote reflections and notes in the form of memos to better capture some of the nuances of the data collection process, including notable emotional moments, influencing scenery, and my own emotional reactions or thoughts that occurred during the process. The purpose of these memos was to allow for as rich data collection as possible as well as to explicitly identify my own lens or bias throughout the phenomenological process. After memoing, I used the data collected to generate an individual story for each child, taking the time to break apart their responses into individual themes and generate initial analysis of each individual child.

Pilot Exercise

For the pilot study, I conducted an interview alongside drawing and storytelling with one male individual identified with dyslexia. The purpose of this pilot was to check the nature of the questions being asked to determine if they are effective in generating an understanding of the childhood experience of disability. The process also built confidence in the selection of drawing and storytelling as supplements to interview data. The pilot also provided important feedback to the consent process and the general understanding of the study from a child's perspective.

DATA ANALYSIS

Procedures

Phenomenological inquiry relies on the analysis of themes uncovered throughout the data and an iterative approach in efforts to generate understanding and enlightenment (Patton, 2002; Wertz et al., 2011). This was done over the course of multiple readings of the data. First, areas of thick description were pulled from the data for thematic analysis. This was followed by a conversation with the data via memoing, story writing, and re-reading of the data, engaging in a hermeneutic circle and uncovering meaning within the language. The process allowed for phenomenological reduction so that details were reduced and the essence of the experience was revealed (Danaher & Briod, 2005). Phenomenological analysis with children again relies on the unique interaction between the researcher's own childhood memories and the child's disclosure of meaningful life moments (Danaher & Briod, 2005). When the child shares about his or her experiences, the phenomenological understanding that occurs relies on the "awaken[ing of] the awareness of actual childhood" (location 5363). To aid in the data analysis process, the computer program MaxQDA was used for coding and organization of themes.

In addition to engaging in this hermeneutic process with interviews, stories and pictures were analyzed to further illuminate themes. Stories were read in a similar manner to interview data. Coded themes from stories were independently analyzed from the interview data, but then also compared to interview themes to look for similarities, contradictions, and confirmations. Drawings were analyzed through a step by step method of coding (Creswell & Creswell, 2018). Verbal descriptions of drawings were coded similarly to interview data. To examine the actual visual imagery, drawings were uploaded into MaxQDA and details were coded with the similar coding approach used for interview data.

VALIDITY CONSIDERATIONS

Validity

Data was gathered in a variety of methods to ensure triangulation of information in addition to the triangulation of sources (Fossey et al., 2002; Greene & Hogan, 2005). Namely, in addition to interview data, I collected data through the use of drawings and storytelling. These methods allowed for the deepening of understanding as well as inclusion of multimodal data. Furthermore, I followed my meetings with children by writing memos and other self-reflections in efforts to acknowledge my own position and to assist in phenomenologically analyzing my data accurately. This reflective process further ensured there has been reflection of the ethical considerations of this study.

Marshall and Rossman (2016) note that there are increasingly “calls for including children’s and youth’s perspectives as relevant and insightful in learning more about aspects of their words” (p. 161). The purpose of their involvement is to capture children’s voices so they can be involved in processes such as program design, intervention creation, and policy making. While children are considered a vulnerable population, this research sought to find methods to support children in a manner meaningful to them as they foster their identity. Questions were purposely included to allow children to voice their opinions regarding adult perspectives on disability and what supports are either supportive or detrimental to their development.

Validity considerations regarding adults can be generalized to younger age groups and should be considered more critically when thinking about children. For example, it may be confusing or difficult for a child to understand repetitions of the assent process, or they may feel more obligated to continue given the power dynamic and age difference between the researcher and themselves, thus compromising the validity of the data. It is also highly expected that the data collection process may ebb and flow more rapidly, given the more fluid and spontaneous nature of children. In their early development, children place different value on relationships with adults and see the relationships in a more black and white manner (Garbarino et al., 1992). Thus, children may have more difficulty processing the quality of the researcher-participant relationship and need firmer limits or boundaries regarding the adult’s role and connection to the child.

Reliability

Given that this study is qualitative and relies on the sharing of meaningful experiences and memories, it relies on children telling their truth and being open to the conversation. I spent the time to build rapport with the children I interviewed so they felt comfortable discussing their experiences and would be more apt to answer truthfully and meaningfully. This was also meant to assist in increasing the trustworthiness of the data (Marshall & Rossman, 2016).

Due to my personal investment and interest in this subject, I also relied on peer debriefing (Marshall & Rossman, 2016) to reduce personal bias and to help identify what areas may have been missing or given less attention. Member checking (Marshall & Rossman, 2016) is likely to be ineffective with a childhood population, but regular checking for researcher comprehension was used to ensure reliability.

Generalizability

The concept of generalizability suggests that study results are applicable to a wider group of people over a broader period of time, thus qualitative research is not always designed to be or meant to be generalizable in the traditional sense (Patton, 2002). Lee Cronbach in particular suggested that "social phenomena are too variable and context bound to permit very significant empirical generalizations" (p. 582). This research, therefore, was designed with two goals in mind. First, the research design for this study was purposeful to allow for future researchers to use this design as a model when conducting research with children. The methodological design of this study is meant to inspire new ways of thinking and studying childhood experience. In this sense, while the findings of this research may be illuminating to stakeholders, it is the also intent that the methodology can be used in the future to further allow for the exposure of childhood experiences.

Second, the goal of this study was to be meaningful for the participants because their voices are being heard. This goal also applies to readers, who will hopefully be moved to change their thinking or mindset toward childhood experience of disability. As told by Patton (2002), Stake suggested that this type of meaning could be described as "naturalistic generalization," meaning that "the 'vicarious experience' that comes from reading a rich case account can contribute to the social construction of knowledge that, in a cumulative sense, builds general, if not necessarily generalizable, knowledge" (p. 583). In sum, while this research is not generalizable according to traditional definition, this research has the potential to resonate with a number of individuals seeking opportunities to learn more about the childhood experience of disability.

ETHICAL CONSIDERATIONS

A key area of ethical consideration is the central focus of children within this research project. The principle of beneficence addresses the importance of doing no harm with research subjects, yet given developmental differences of children, they may be more vulnerable to internalization of the interview experience as negative or harmful (Marshall & Rossman, 2016). Erikson's Identity versus Inferiority stage highlights that children are increasing their metacognition exponentially (Hamachek, 1988; Garbarino, Stott, & Faculty of the Erikson Institute, 1992). Additionally, Harter (2012) highlights the cognitive processes of children in mid-childhood as emerging and typically concrete. This may intertwine with the child's experience as a research participant, meaning they may place meaning on the research process differently and more sensitively than an adult would, given differences in life experiences.

Further, Garbarino et al. (1992) posit that "children with disabling conditions and learning disabilities have a particularly difficult time regulating self-esteem during middle childhood" (p. 32). However, historically children have been seen more often than not as possessions of adults, with mindsets slowly shifting over time to acknowledge the rights of children (Garbarino, Stott, & Faculty of The Erikson Institute, 1992). This has led to the slower embracement of children's perceptions and attitudes toward the world.

This research purposely sets out to move this attitude forward and embrace the power of children's voices.

Participation in this study did present possible harm to the child; however, this harm was considered minor and could be addressed using appropriate procedures and strategies. It was predicted that some of the questions asked in this study may be uncomfortable for children who have not considered the questions before. This may have resulted in emotional distress or feelings of emotional discomfort. This process may have also been tiring to participants, who may not have been used to having long conversations with adults. To address these concerns, I put significant time into the rapport building portion of interviews and also regularly checked in to determine how the child was feeling about the interview. Children could take breaks whenever necessary and their parents/guardians were asked to be readily accessible in case additional comforting was needed. Children were also reminded regularly that they did not have to answer every question or participate in every activity.

Another possibility was that children participating in this study would start to consider negative features of their disability and internalize societal stigma that was alluded to in many of the questions asked during the interview. To address this concern, language was carefully considered in the framing of the interview questions. Also, while some researchers may approach the interview process in a neutral, blank slate fashion, I intended on approaching children in a developmentally sensitive manner that included explicitly pointing out if I felt the child was starting to internalize stigma and allowing our conversation to explore that, both in service to the child as well as in service to the data collection process. Conversely, talking about a disability could also be seen as an empowering experience, as this space is not always available to children, and thus this study can also be considered an ethical responsibility of researchers when they consider the design of a study.

CULTURAL CONSIDERATIONS

Diversity Considerations

Suzuki et al. (2007) refer to the feeling of "culture shock" (p. 301) when collecting data and learning about a new population. Shifting to the culture considerations of this project, it is highly likely to experience culture shock when exploring the topic of disability, age, and identity while also considering cultural features. As a White, heterosexual woman, I experience privilege despite having disabilities and thus am likely to have a different perspective on disempowerment than my subjects. Namely, my racial profile has not been an area of consideration as I have reflected on my disability's possibility for disempowerment.

Further, much of my vocational experience has been within a suburban, mainly White community, so I have not had to confront certain intersections as I have navigated the themes of this research in my work. In efforts to prepare for the cultural shock that may have occurred when these issues arose in the interview process, I relied on my reflective nature and maintained awareness of my inner dialogue. This awareness would lead me to asking meaningful and sensitive questions when necessary that further the understanding of how cultural factors interplay with disability and self-concept.

As a school psychologist, my attitude towards cultural considerations is best captured by Cardemill and Battle's (2003) perspective on conversations regarding race and ethnicity:

> [w]e believe that having open conversations about race and ethnicity is one way for therapists to more fully incorporate diversity issues into their work. Demonstrating a willingness to engage clients in these dialogues can promote an environment of trust and understanding that will ultimately help the treatment process. (p. 278)

While race and ethnicity were not the central focus of consideration in this research, they are part of the overarching conversation of privilege. It could be easy to sit back and not put the topic of other empowering or disempowering features on the table; however, to fully understand the complex dynamics of my chosen subject, I needed to remain open and transparent with child subjects as well as their parents. I also needed to consider their trajectory in relation to their racial identity development (Tatum, 2003) when framing questions of race. Together, these considerations highlighted that I prepared to grapple with what was shared with me in interviews and saw this cognitive work as an opportunity to lean in and learn more, knowing that intersectionality is a piece to understanding the disability experience.

Stakeholder Considerations

As it is inevitable that I would encounter discussion of schools in my interviews, another area of cultural consideration was the presence of stereotype threat (Jordan & Lovett, 2006). In efforts to unpack this concept, I needed to consider how discussing school in relation to race and gender could inadvertently result in the emergence of stereotypes that the child has learned about her culture, gender, and disability. These themes were not often explicitly stated, thus I needed to consider if I name this for the child, as I would in a therapy session, or instead follow the interviewee to see where this information leads.

Knowing that many participants may share that a parent informed them of her disability, another area of ethical consideration was to remain neutral regarding how parents have shared messages regarding a child’s experiences. Parents may have their own values regarding disability based on their own upbringings and experiences, which may emerge in discussions with children. Consideration was given to how that language influences a child’s development, as well as the intent of that language. Parents approach all intersections of child-rearing with limited road maps: this research may hopefully empower children in their identity development but may also help parents in their journey as well, knowing that raising a child is hard work, unpredictable, and life altering.

In summary, the ethical considerations of this study included many stakeholders with their own opinions and experiences. The nature of hermeneutic phenomenology is to acknowledge one’s lens throughout the process and engaging with the data in a manner that allows for enlightenment and a newfound understanding of human experiences (Moustakas, 1994). For this reason, the hermeneutic process is, in of itself, an ethical process when executed in a thoughtful and critical manner. The methodology outlined in this section has been carefully considered in efforts to maintain a high level of ethical execution.

CONCLUSION

There are multiple intentions to this research. For the participating children, I hope their experiences within the interview and data collection process will serve as an opportunity for them to explore who they are and who they want to become in a safe, supportive location. It is my intent that our interactions will be positive and inspiring, not only for myself as the researcher, but also for the child who disclosed such meaningful, powerful experiences. I hoped to see children feel empowered the way that I was when I was able to speak about my disability to my family and classmates.

For families, I hope their child's participation in this research implicitly signaled how important their children are to our world. The ableist world often neglects to celebrate the work of families who engage tirelessly in the development of their children so they can function to their highest potential. It is easy to forget what families have endured. I hope that allowing children to speak about their experiences gave a chance for positive family decisions to be illuminated and felt deeply. I also hope that this research allows for future recommendations that can support families in their journey.

Finally, for myself, I hoped this research would provide me the opportunity to fulfill how I envision the role of a school psychologist in the life of a child. A school psychologist does not simply test, counsel, and consult. At the core of the job, a school psychologist supports, celebrates, and embraces each child they encounter for their individual strengths and areas for growth. A school psychologist can set the expectation that a child has a place in our society where they can thrive. A school psychologist advocates for children, not simply based on what testing shows or best practice says, but because they listen to children and care about their needs and desires. This research sought to give children the attention needed to define what it means to thrive as a child with a disability.

CHAPTER 4: INTRODUCTION TO FINDINGS AND ANALYSIS

INTRODUCTION

The purpose of this section is to present the findings of the twelve interviews. Firstly, the children's biographies will be presented. The goal of including their biographies is to provide information about who these children are as individuals, rather than only focusing on the data collected from their words. As research with children often neglects to highlight individuality, the biographies are designed to instead celebrate and embrace these children as unique people.

Following the biographies, a discussion of how children construct disability will be provided. Within this section, children will describe how they came to learn of their disabilities, what these disabilities are, and how they understand the concept of normalcy as they grapple with the concept of difference. The goal of this chapter is to highlight where children fall within the continuum of medical versus social model of disability and to illuminate what children have internalized about the disability construct.

The next chapter investigates how children make meaning of having a disability. Within this chapter, more individualized stories and experiences are presented in efforts to display what is meaningful to children. These stories are what have had greater impact on the participating children and have helped to form impressions of what the future looks like as well as what can be learned by having a disability. The goal of this chapter is to provide qualitative information that can't be well grasped by quantitative measures of self-concept.

The third analysis chapter of this section explores how children encounter and manage stigma. Within this chapter are discussions of how children grapple with visibility and disclosure, as well as how self-stigma starts to develop. Due to the extensive time children spend in schools, as well as the many stories of stigma within schools, a discussion of the education system is provided within this chapter. Further, discussions of resistance and resilience are provided in this chapter in efforts to show how children cope as they develop an understanding of what it means to be a person with a disability within an ableist world.

Finally, this section concludes with a brief discussion of how this data can be integrated. A brief review of how the disability experience plays out for parents will be provided in efforts to draw a comparison between how children make meaning differently and thus a model is not easily conceptualized. Data will also be compared to the current models of disability to illuminate where current definitions fit the experiences of children and where the models fall short.

A brief note regarding the role of children's voices in this portion of the dissertation: the children who told these stories selected their pseudonyms and picked out what details were essential for inclusion in their biographies. Each biography and many of the stories included in analysis will include details that may not seem important to the adult reader, but are vital to the child's representation of who they are and how they perceive themselves. You will not only learn about the diagnoses and characteristics of ADHD, Anxiety, Autism, Leri-Weill's Syndrome, Madelung Deformity, Social Pragmatic Communication Disorder, Dyslexia, Cerebral Palsy, Specific Learning Disabilities, and Dysgraphia. You will also learn about what it's like to walk in the hallways of school. You will hear about what it's like to ride the bus. You will hear what it's like to feel connected to family and friends. You will hear about why it is important to be a vegetarian. You will hear about woodworking, bugs, bunnies, ASMR, sports, books, cosplay, and theatre. You will hear about superpowers and strengths. Most of all, I hope you hear and take to heart that each child is on their way toward self-discovery in a world that silences part of their individuality. This is their chance to be heard.

CHILDREN BIOGRAPHIES

Bunny

Bunny is a White, eight year old female who is currently in third grade at her local suburban public school and is supported through an Individual Education Plan. She lives with her mother, father, younger brother, and pet bunny Flash. Bunny was excited to come to her interview, having heard that she would get to talk about her interests and would receive a gift card for her participation. Bunny's interview was scheduled for 6:00 p.m., but she bounded in with the energy of a newly awake child. She smiled widely when I noticed and commented on the sparkly bunny on her shirt. Bunny's biggest passion is bunnies. She loves learning about them, spending time with them, drawing them, pretending to be them, and writing stories about them. When I asked her to pick her pseudonym, she screamed, "SUPER BUNNY SPARKLES!" Bunny also loves cats, although with a slightly decreased level of passion when compared to her feelings towards bunnies. She would like to be a veterinarian someday. Bunny participates in gymnastics and enjoys doing flips off the tumble track in the gym. Bunny also attends a weekly occupational therapy group and social skills group. Bunny's biggest frustration at school is having to do sudokus. Bunny is diagnosed with Autism and ADHD.

Rose

Rose is a White eight year old girl who is currently in third grade at a suburban public school and is supported through an Individual Education Plan. Rose lives with her mother, father, and two dogs. She enjoys playing soccer on her local town team as well as playing with her friends in the neighborhood. She feels lucky that many children in her neighborhood are close to her age, so she always has peers to play with. In school, Rose enjoys art class, particularly when the class works with watercolor paints. She dislikes math because it is difficult for her and physical education because she becomes frustrated when other students are cheating at games. Rose's favorite part of school is the special equipment that only her classroom has access to. Each student has a special yoga ball for their chair and has access to fidget toys. Rose takes this privilege very seriously, as she knows that she can lose her ball chair if she bounces or plays too much. Rose's biggest fear is that due to her disability, she may be required to repeat a grade. Rose was quiet at first as we started talking, but as soon as she got to describing the ball chair, she lit up and was ready to share about her school experiences and interests. Rose is diagnosed with Dyslexia and ADHD.

Tyler

Tyler is a White, nine year old, fourth grade boy who currently attends a private school for children with language based learning disabilities and is supported through an Individual Education Plan. Tyler's parents selected to place him at this school. His family is currently negotiating his placement with the school district. Tyler is an athletic and energetic individual who enjoys any opportunity to engage in friendly competition. He plays football, golf, baseball, and basketball. He is also hoping to try out BMX and is saving up his money to buy a dirt bike. Tyler is a creative builder and maker. He loves to build using leftover lumber from projects and finds enjoyment in knowing the history of the many tools his father allows him to use. He is especially fond of using the lawn mower, drills, and leaf blower. Tyler lives with his mother, father, little brother, and dog. Tyler captured the meaning of phenomenology when he commented, “I feel like you know these questions, you’re just asking ‘em because you just want, you want, like you know these questions, like you want to have nothing in your head, but you want to like, learn everything.” Tyler had me smiling and laughing when I asked him if there was anything else he wanted to add at the end of our interview, and he loudly shouted into the recording device, “She knows the answers! Just give her the doctorate already!” Tyler is diagnosed with dyslexia and ADHD.

Izzy

Izzy is a nine year old White girl who currently lives in a quiet suburban town with her mother, father, older brother (Bob), older sister (Samantha), dog, cat, and fish. Izzy currently attends the local public school and receives educational services through an Individual Education Plan. She is in fourth grade. Izzy enjoys school. She loves math and is enjoying learning more complex multiplication. Her favorite special is art. She also loves participating in the school play and is growing eager for fifth grade so she can be in the school’s culminating play for the oldest students. Outside of school, Izzy participates in her local theatre group. She is currently playing the steward in *Into the Woods*. She also participates on a swim team and is planning to start soccer. She loves spending time with her friends, making people laugh, drawing, painting, and using gimp. It is also important to Izzy that people know she has a deep passion for animals. This includes sustaining a vegetarian diet in efforts to protect animals. Her favorite animal is the panda.

Izzy was the most hesitant of participants to engage in the interview, initially questioning if she wanted to talk about her experiences. While she waited for her sister and brother to complete their interviews, Izzy and her mother found the book *All Birds Have Anxiety* in my office and read it together. This inspired Izzy to participate, and she went from feeling nervous to feeling courageous to share her story. Izzy is diagnosed with Leri-Weill's Syndrome, Madelung Deformity, and anxiety.

Louis

Louis is a White, nine year old male who currently receives home tutoring through his suburban school district. Louis lives with his mother, father, younger brother, and two golden retrievers. He has a nanny who spends time in his home regularly and who Louis speaks about as though he is family. Louis is passionate about gaming. He owns an original Nintendo, Super Nintendo, Nintendo Switch, Wii, Playstation 4, and a gaming computer. His favorite games are Legend of Zelda, Wild, and Minecraft. Louis also loves to watch television, with his preferred shows varying depending on his mood. When I arrived for the interview, Louis was in the middle of watching anime on an upstairs computer. He was the only child I interviewed who was interviewed at home. Louis had a unique sense of humor and was quick to engage in word play or intellectually superior humor. He loved calling me out on the use of double meaning words or idioms. Of all the interviews, he provided me with the best sentiment of all: "the first book I ever read was *Green Eggs and Ham.* It's a story about a vegetarian who just wants to be left alone." Louis is a vegan and is passionate about caring for animals and the environment. Louis is diagnosed with Autism, ADHD, and anxiety.

Kylie

Kylie is a White ten year old girl who is currently in fifth grade and is supported through an Individual Education Plan. She lives with her mother, father, and twin sister. She also has three dogs. Kylie currently attends the public school in her urban hometown and enjoys classes with different teachers for each subject. Her favorite subject is math, which is also her strongest subject. Outside of school, Kylie enjoys karate. She is currently a red belt. Kylie also recently started gymnastics, which she is enjoying, and is working on using the monkey bars at recess. Kylie has a dry sense of humor and a quick wit. While at times her responses were brief, the emotion and sense of sarcasm was thick and meaningful. It was hard not to smile when Kylie told her stories or gave her opinions. Kylie is diagnosed with Cerebral Palsy, ADHD, and dyslexia.

Samantha

Samantha is a White ten year old girl who currently resides with her mother, father, older brother, younger sister, dog, and cat. Samantha lives in a small suburban town and attends fifth grade in a multi-town public elementary school. Samantha is an active child who participates in several afterschool activities. She is most passionate about theatre. She is involved with the town’s theatre group and is currently playing Rapunzel’s prince in *Into the Woods*. Samantha also loves to read. She has read the entire Harry Potter series and is working her way through the books for a second time. At school, Samantha loves art, music, and physical education. She does not like library because she has to sit for most of class and take notes, when she would rather be picking out books and moving around the library. Samantha also dislikes math because her school has changed its academic schedule and is requiring an increased math load this year. Samantha has four close friends, both from her neighborhood and school. Samantha was interviewed on the same day as her two siblings (Bob and Izzy), and was the most eager to participate. She has reflected on her own disability experience with her family, but is now ready to share her story with the world. By the end of the interview, I wanted to give Samantha a big hug and say, “you are amazing.” Samantha’s interview was emotional and intense, and gave me further confirmation that this research is vital to helping children. Samantha is diagnosed with Leri-Weill’s Syndrome, epilepsy, and ADHD.

Stan

Stan is a 10 year old white boy living in a small suburban town. He lives with his mother, father, and sister. He attends a private therapeutic day school and is supported through an Individual Education Plan. He came to his interview with his mother, well equipped with a snack in hand and a curious desire to explore the interview room. Stan took in the space, looking around while he listened to an explanation of the study. When asked if he had any questions about the study, Stan looked at me in the eye and simply asked, “what’s your favorite kind of bug?” From this point forward, Stan was the expert in the room, and the area of focused expertise would be nature. Stan also regularly asked about nearby locations where bugs could be found and asked to play games throughout the interview. He was very interested in engaging around some of the preferred activities of children: games, favorite subjects, and drawing. If we had the time, I know I could have learned so much about nature from Stan. Stan is diagnosed with Autism, ADHD, and anxiety.

Tex

Tex is a White, ten year old female who is currently in the fifth grade at a charter school. She lives primarily with her mother, older sister, and younger sister, but also spends time with her father on the weekends. Tex receives support at school through an Individual Education Plan. In school, she loves art and reading. She likes some of her teachers, but in general finds teachers scary because they can be strict. Outside of school, Tex is a girl with an eclectic set of interests. She enjoys drawing, namely doodling rainbows and stars or blending colors. She rides horses at a nearby stable. She loves an anime show/manga/video game entitled *Danganronpa*, which she prefers to call DR because of the complexity of the name. She recently attended Comic Con, where she cosplayed as a Danganronpa character. She described this experience as absolutely phenomenal and was excited to wear her costume again for Halloween. Tex loves her friends and describes them as "goofy." Tex has a beautiful smile and a pleasant demeanor that made her someone I enjoyed spending time with. She was engaging and content to share about her life and what she has learned so far. Tex is diagnosed with ADHD, anxiety, and a specific learning disability in math calculation.

Bob

Bob is an 11 year old White boy who currently lives in a quiet suburban town with his mother, father, two younger sisters (Samantha and Izzy), dog, and cat. He attends sixth grade at the local middle school, where he receives school support through an Individualized Education Plan. He is actively involved in local sports, participating in tackle football, skiing, lacrosse, and swimming. He plays the trombone in the school band. Bob's strongest area of interest is technology. He has a computer and a phone and is currently working on programming the several Alexa devices in his house to communicate with one another. Thus far, he has been able to program the devices so he can turn on the televisions from any room in the house. Bob also enjoys spending his time working with Legos. He has made up a superhero character and designed a home base for him alongside a story line about the character's many adventures. In school, Bob enjoys his science class. He also enjoys math, particularly because the math curriculum is designed to allow "kids [to discover] on their own, [rather] than the teacher standing over the board making you learn." While he enjoys the class content, he "despises" math homework because it is extensive now that he is in middle school. Bob is diagnosed with dysgraphia, ADHD, and social pragmatic communication disorder.

Caleb

Caleb is a White 11 year old boy who is in sixth grade. He currently attends a private day school specializing in the utilization of Applied Behavior Analysis. Caleb has attended this school for one year. Caleb lives with his mother, stepfather, and older sister. He also sees his biological father regularly. Caleb enjoys drawing, particularly cartoons. He likes to watch television, but is more interested in watching YouTube videos about how to build objects and how to complete projects. He also likes ASMR videos, which depict the crushing or destruction of objects to create interesting sounds. We shared an excited fondness of watching iPhones and iPads being crushed in metal shredders. Caleb also likes technology and owns a Nintendo Switch, phone, and chrome book. On video games, he enjoys exploring levels that other children have created or exploring different worlds. He also enjoys simulator games, which give him a chance to use his wireless mouse. Outside of his interests, Caleb has a robust group of friends and enjoys spending time hanging out. He participates in karate and is currently working on his red belt. Caleb regularly seeks out opportunities to talk about autism and advocate for people with his disability. Caleb is diagnosed with Autism and ADHD.

George

George is a 12 year old White boy who is entering sixth grade in a suburban public school and receives support through an Individual Education Plan. George came eagerly to the interview, excited to share all his knowledge and experiences. He has a big smile and a joyful tone to his voice, as though everything is a little exciting and a little fascinating when he says it. As described by his mother, “George likes to help people.” In the classroom, he is a leader and a role model. George lives with his older brother, mother, and father. George is an active boy with many interests: he loves to play sports and enjoys going to physical education at school. He loves social studies and history, particular the Revolutionary War. George describes himself as a child who enjoys “getting more information in his head.” He aspires to be a social studies teacher so he can have summers off, as well as an engineer. He is currently exploring how to invent a flying car and has plans to patent his design once it is complete. George is diagnosed with dyslexia.

For ease, the following chart is provided to guide readers in recalling salient information regarding each participant.

Table 1

Participants

Pseudonym	Age	Race	Known Diagnoses	School Setting
Bunny	8	White	Autism; ADHD	Public school with an IEP
Rose	8	White	Dyslexia; ADHD	Public school with an IEP
Tyler	8	White	Dyslexia; ADHD	Private school for children with LBLD with an IEP
Izzy	9	White	Leri-Weill’s Syndrome; Madelung Deformity; Anxiety	Public School with an IEP
Louis	9	White	Autism; Anxiety	Home tutoring program
Kylie	10	White	Mild Cerebral Palsy; ADHD; Dyslexia	Public school with an IEP

Samantha	10	White	Leri-Weill's Syndrome; ADHD	Public school with an IEP
Stan	10	White	Autism; ADHD; Unspecified Anxiety	Therapeutic school for children with autism with an IEP
Tex	10	White	ADHD; Anxiety; SLD (Math Calculation)	Charter school with an IEP
Bob	12	White	ADHD; Dysgraphia; SPCD	Public school with an IEP
Caleb	12	White	Autism; ADHD	Therapeutic school for children with autism with an IEP
George	12	White	Dyslexia	Public school with an IEP

CHAPTER 5: HOW CHILDREN DEFINE DISABILITY

INTRODUCTION

A significant portion of interview questions centered on how children construct the concept of disability and how this relates to their overall identity. In the literature, explored definitions of disability include the medical model of disability as well as the social model of disability. The medical model, which is most utilized in institutions like schools, businesses, and therapeutic settings, indicates set disability characteristics that create an othering of individuals experiencing symptoms (Darling, 2013; Davis, 2015; Garland-Thomson, 2019; Nielsen, 2012).

Meanwhile, the social model of disability is eagerly endorsed by critical disability activists and scholars, positing that disability is the function of an impairment oppressing an individual within the dominant culture due to dominant practices and procedures (Baglieri & Shapiro, 2012; Brune & Garland-Thomson, 2013; Davis, 2002; Hehir, 2002; Lalvani, 2015; Oliver, 2004; Zola, 1989). Both these models have been created by and subscribed to by the adults. The collected data in this study illuminates a third model of disability that will be discussed at the conclusion of this section of the dissertation.

NORMALCY

It is difficult to discuss disability without conceptualizing what children mean when they say “normal.” There is no clear rubric that exists for normalcy, yet children seemed to suggest there is a clear sense of what is and is not normal. While no direct questions were asked about “normalcy,” the words, drawings, and stories of children gave meaning to what it means to be outside the norm.

“Normal,” In Words

Four children (Louis, Tex, Bob, and Caleb) specifically used the word “normal” to describe peers and non-disabled individuals. From the perspectives of these children, there is a distinct difference between normal and disability, but it is an abstract concept to conceptualize.

The phrase “other kids” was used by Bunny, Louis, Izzy, Samantha, Rose, Kylie, Tyler, and George. Most anecdotes were similar to the following, stated by Kylie: “I think [my diagnosis] just answered everything. That’s why I do things differently than other kids, why I get more frustrated, that stuff.” Tyler put it in this manner: “Dyslexia is when you, like look at words differently than other kids. I mean, I don’t know how other kids look at words, but I know how I look at words.” When children used the phrase “other kids,” they were primarily describing the symptomology of their disabilities and how they placed them in a division from peers.

All twelve children spoke to the idea of being “different.” Importantly, the emotional attributes related to being different were variable. Some children, like Kylie, Tyler, Louis, and Samantha, suggested that it is negative to be different. Meanwhile, Caleb, Tex, Bob, George, and Bunny suggested positive features of being different, adding to their descriptions of different words like “unique,” “not bad,” or “special.” Still others, like Rose and Stan, seemed to still be developing an emotional appraisal of the concept of “difference.” Together, the word “different” appears to be prominent in how children are informed about disability and how they shape their understanding of it, but the use of this word is variable and abstract, suggesting that perhaps the lexicon for difference needs to be expanded.

Neurotypical

Louis directly spoke to the concept of normalcy in his descriptions of what it means to be "neurotypical." In several instances, Louis suggested that he went from being "NT" to being autistic, as though a switch was flipped when he was four years old. When Louis was struggling to identify more abstract features of Asperger's, I changed the line of questioning:

> M: So what do you think it's like to be neurotypical?
>
> L: Less intelligent.
>
> M: I mean, I'm willing to say I'm probably not as smart as you. So I'll own it.
>
> L: My special place on the spectrum, academically I advance academically faster.
>
> M: So part of being neurotypical is not being as smart as people who are not neurotypical?
>
> L: Yeah, not advancing as rapidly.
>
> M: Are there other things that you think of when you think of neurotypical?
>
> L: Being more socially adept.

Louis also shared several other insights about neurotypicality. From his perspective, he was neurotypical up until age four:

> I get what it's like to be neurotypical because I used to basically be neurotypical. I used to basically not be affected by this. And then it started showing up as I got older. So I also know what it's like to be neurotypical… it was boring.

So, Louis can understand the neurotypical experience, but NTs are unable to understand what it is like to have Asperger's because they don't have it. Louis also communicated a subtle air of superiority in his descriptions of Asperger's, suggesting that the neurotypical experience holds minimal value when compared to the unique, fascinating, and possibly strange characteristics of Asperger's. Louis's father also pointed out that Louis attended a public school through first grade, during which he was in regular classes with "the NTs." Louis responded to this by saying merely, "and it was terrible." For Louis, neurotypicality is truly the norm; however, it doesn't mean that it is a stimulating or fascinating experience.

"Normal," in Pictures

Both Tex and Kylie selected to include the concept of "normalcy" into their drawings. Tex describes having ADHD as being more exciting than normal people. She also indicated that she feels like she is all over the place, which is different from others without ADHD. Kylie selected to draw a picture of herself feeling frustrated about something. She put this picture directly next to an image of her sister, who Kylie says "doesn't have any problems," to show that her sister is not having a similar reaction. Like how children compared themselves to "normal" in their verbal definitions, the concept of "normalcy" emerged through imagery as well.

Figure 1

Tex's Drawing

Figure 2

Kylie's Drawing

"Normal," in Stories

During the storytelling activity, George, Tyler, Caleb, and Tex alluded to the idea of normal as they described a character with a disability. Similar to their definitions about their own experiences, their stories varied in emotional attributes. George, Caleb, and Tex focused on how normal isn't necessarily the preferred or optimal condition. Tex, for example, told her story as follows, noting that it is unclear if normal is right or not:

> There was a princess named Ms. ADHD, who told him where to go and who to speak to and what to do in life. And then he said, I don't know if this is right or not. And then she said, well, you're a different person and that's fun. The End.

Her story suggests that the experiences of children with disabilities are real and powerful, but they don't necessarily take away from the person's value or ability to connect with others.

Meanwhile, Tyler's story exemplified the intensity that comes along with feeling different:

> So, once upon a time there was a guy named Joe. Now, his birthday was coming up and his friends bought him tickets to a reader theatre…Joe had dyslexia. So, his friends were big, big, big readers and they loved reader's theatre. And he went to the reader's theatre and was like, "oh. no. I can't read!" A bunch of thoughts came into his head. I'm just going to be sitting there an hour, I can't sleep because my friends are going to think I'm like, a book snoozer, like every time, the second I look at a book I start falling asleep, so I'm just gonna sit there for an hour, like this (head in hands) doing nothing… So he tried reading, and the thing was, you had 10 minutes on each page. So even if you were done, you could pull your phone up, but you had to have all sound off and wait until the next page.

> Um, and he just sat there, it took him like 15, 16 minutes like, to like… he couldn't finish a page… He completely said nothing. So he didn't tell his friends because, but next year, I mean a year later, they bought him a ticket to a reader theatre again because they thought he liked it so much. And he told his friends he had dyslexia. And his friends were like, "WHAAAAAT YOU'RE SO STUPID AND DUMB!" And then he went inside and cried for the rest of his life. And he went into hiding and died because he didn't want to buy food. So yeah. That's the end.

In Tyler's story, he speaks to the need to keep his disability hidden because it could be – and is - processed negatively by peers. Tyler also speaks to some features of his disability that are more oppressive than others. Namely, the speed at which one reads, the books one can select that are at one's respective reading level, and the emotional exhaustion required to engage in reading. He directly lays out the feelings of stupidity that have accompanied a dyslexia diagnosis and suggests that even fun activities are tiresome and embarrassing when they are related to reading. He also highlights the feelings of loneliness and isolation that can come with a disability.

PERCEPTIONS OF DISABILITY IDENTIFICATION

Responses were mixed when children were asked how their disabilities were identified. As alluded to earlier, multiple children indicated that identifying disabilities involves a medical process. Seven children stated that doctors identified their disabilities. Of these seven children, several stated that the doctors simply labeled it, while others indicated that the doctors ran medical tests to identify the disability.

Seven of the children identified sensing that something was different about them prior to learning of their diagnoses. This is parallel to retrospective accounts of individuals with disabilities, who felt like they “just knew” or could tell they were disabled prior to learning the label (Cosden, Elliot Noble, & Keleman, 1999). For Bob, Tyler, and George, they observed that certain academic subjects were difficult, which eventually led to testing and receiving a diagnosis. Tyler and George also noticed a change in the support they were receiving at school. Rose recalls sitting with a teacher, who was counting the number of errors she made while she was reading and thinking “What did I get wrong?”

Louis and Caleb indicated that they sensed behaviors that indicated they had autism prior to receiving diagnoses. In Louis’s words:

> M: Okay, how do you think adults figured out you have a disability?
>
> L: My brain.
>
> M: Your brain?
>
> L: My brain. It acts very strange.
>
> M: Ok, but do you think adults noticed something about you, or like they ran tests…
>
> L: I noticed something that was strange.
>
> M: You noticed something strange, okay.
>
> L: No, people noticed something was strange. And I was diagnosed with something strange. I was diagnosed with the thing that would correspond to my behavior.

Together, these responses suggest that children are well-aware of the construct of normalcy and how they do or do not blend in, even without initially knowing their label.

The Moment of Discovery

Half of the participants did not recall the exact moment at which they learned of their disabilities. For the children who did remember learning of their disabilities, some recalled entire stories, while others remembered only bits and pieces. Tyler's memory was the most vivid:

> T: Mmmm, like in first grade my mom had me do testing and they said I had dyslexia. But when I first found out, I was in the car and I heard something [on the radio] about dyslexia and I was like, "Dad do I have dyslexia" and he said yes. So that's kind of how I found out.

Initially, Tyler did not have a big reaction to this moment. From his perspective, he accepted the information and moved on. As work demands increased, however, Tyler started to internalize the concept of being different and started to notice how far behind he was compared to his classmates. When I asked Tyler what he thought the meaning behind all of this is, he started to talk about contemplating life and wondering why he is alive. While Tyler didn't make the explicit connection, I took this moment as a glimmer of how Tyler is trying to conceptualize what it means to struggle. While the label was simple at first glance, over time Tyler has started to attempt to connect struggle, label, and purpose. Throughout his interview, he sounded frustrated and discouraged, causing me to think that these thoughts lay heavy on his conscious and self-concept development.

Izzy also remembers the exact moment that she and Samantha were diagnosed with Leri-Weill's, as they were in the doctor's office together when the label was first stated. For the other participants who vaguely recall the moment of discovery, they were able to provide small details. Kylie, for example, remembers that she learned of her disability in January because it was just after the holiday season, after everyone had been busy and stressed about the holidays. Caleb remembers he was on the couch. Bob remembers he went through his testing on a Monday. Together, these children suggest that it can be important to think about how a disability is explained because the moment may encode as an essential memory for that child's identity. While the details may not all be vivid, the suggestions of memories that these children provided give a sense that there is something emotional in the experience of being told you are disabled. This is what encodes this moment into memory in a meaningful manner. When adults are planning on telling children of their disabilities, these stories highlight the need to be judicious and considerate of how the message is delivered, including how a disability is framed and either described as disempowering or empowering.

Level of Functioning

George, Tyler, Caleb, Kylie, Rose, and Bunny all expressed some kind of awareness about their level of functioning compared to other "normal" children or other children with disabilities. George seems to have an unconscious rating system to determine who has disabilities "worse" than him. Within the group of students with whom George receives academic services, George describes some children as having dyslexia "worse than him," which often results in their emotional stress. He has observed students crying and becoming stressed out when they don't understand something. George is proud of being a higher performer than his peers and considers himself more connected with a student who performs at a similar level than him.

For Caleb, it is important that he be identified as having “high functioning autism,” which means he is able to verbally communicate and has learned to regulate his behavior and emotions using coping strategies. He sees himself as being very similar to children who are identified as “normal.” Caleb puts high value on his ability to verbalize, which he sees as providing him opportunities to communicate with “normal people,” explain his needs, and advocate for what he sees as right and wrong. Two of his closest friends also have autism, and he sees them as high functioning because they “know how to communicate stuff.” Comparatively, Caleb is surrounded at school by children who he identifies as having “low functioning autism.” From his perspective, low functioning autism behaviors consist of hand flapping, having meltdowns, being nonverbal, and making noises. He notices that the teachers at his school regularly restrain certain students that he perceives as lower functioning.

Tyler and Rose, meanwhile, feel like their disabilities are not as impactful as other disabilities, namely those involving interfering behavior and dysregulation. Tyler compared his disability to autism, indicating that autism is much more difficult and impactful long term. Rose identified a group of children in her school who seem to have much more difficulty because they are in a special classroom and appear to have tantrums all the time. These two children suggest that their disabilities are not as severe or that they are better able to navigate the world because of the skills they have been able to develop.

Kylie and Bunny spoke about being less able to do something than peers their age. For Kylie, she is highly attuned to the fact that she becomes increasingly frustrated or angry in situations where her sister and peers do not escalate. This makes her feel like she cannot do certain things as well as others. Bunny's definition of autism also alludes to being at a different level from other people. Namely, "I don't think as well as other people." These two children suggest that part of having a disability is recognizing what is harder for oneself compared to others. This is not necessarily part of the neurotypical experience, in that children without disabilities may not live with this type of tension or cognitive dissonance on a regular basis.

Purpose of a Label

Kylie, Bob, George, and Louis spoke to the purpose of labeling and how they feel about their labels. For these four participants, they find having labels to be helpful so children can be understood and receive what they need. For Kylie, she felt relieved when she learned her label:

> M: What was memorable in that moment? Were you happy, or sad, or confused?
>
> K: I was just, ok, now I finally have an answer for why I get more upset from other people, or why it's harder for me to walk.
>
> M: Mmm. So it answered some questions.
>
> K: It answered a lot! And why I have to go with special teachers for testing, like [for] MCAS.

Bob had a similar response to learning his labels:

> M: Okay. Um, how did you feel in that moment when you found out about the social communication pragmatics and the dysgraphia? Do you remember how you felt?

> B: Um, I really don't know. I was either happy about it, because I finally know what I have. I'm pretty sure I was happy because I know what I have. And I can actually get help for it.

George spoke to the purpose of his label when he was asked if he would change the name of his disability if he could:

> I kind of like the name dyslexia because it, it puts its, it’s talking about the mind – lexia I think? That’s what, and it shows my problem, and dys- shows that it’s a problem, so it tells everybody that you need to fix this and this kid needs help a little bit.

Finally, Louis sees labels as useful for understanding others. Because he so frequently used the term “neurotypical,” I selected to ask him what he thought of the term “neurodiversity.” This term was coined by Judy Singer and Harvey Blume in the late 1990s. Singer developed this term as an alternative to the term “disability” in efforts to celebrate difference and emphasize the neurological differences between autistics and the dominant culture (Silberman, 2015). Louis namely focused on how labels provide information to other people, suggesting that while disability may be a term of disempowerment, conversely a label could be helpful if you are prescribing to the idea that difference from the dominant culture should be celebrated.

These four children suggest that labels can be a useful tool for helping children understand their behaviors, if the information provided is accurate and helpful in fostering an understanding.

HOW CHILDREN CONSTRUCT THEIR OWN LABELS

Each child participating in this study had unique ways of defining their disabilities. Notably, approximately three quarters of the children initially could not recall the name of their disability, instead responding with phrases like, “I don’t know what it’s called, but it means I learn differently.” Every child indicated that having a disability makes them “different”, either by using the word “different” or a phrase like “not like other kids.”

When asked to be more specific, children often identified certain tasks being “hard” or were able to identify individual symptoms of their disabilities. For Rose, Kylie, Tyler, and George, they similarly labeled having dyslexia as “looking at words differently than other kids.” Rose specified that it makes “math and reading hard for me.” Similarly, Samantha, Caleb, Bob, Rose, Tex, and Kylie spoke of how having ADHD makes it “hard to focus,” “I have a low attention span,” or “emotions are a problem.”

Defining autism proved more complex for Caleb, Stan, Bunny, and Louis. Louis did not provide a specific explanation of what autism entails, rather he indicated that autism is a set of behaviors on a checklist. Bunny stated, “I don’t think as well as other people and stuff like that.” Stan responded “I don’t know” to questions about what autism means.

Caleb explored the diagnosis of autism through several examples and stories, showing how children can make meaning of a label. Caleb initially grappled with how to define autism:

> I don’t really know, I mean it’s like, no one’s ever really asked me that. I don’t like, no one’s ever explained to me what that is, it’s just like, it’s not

> like a bad thing. I feel like, I think it means I just like, need a little extra help with stuff. I don't know.

Caleb also mentioned picking at his nails and feeling nervous. He was able to add more to his definition of autism when asked about the other children at his therapeutic school:

> I'm what they call high functioning autism, so I'm verbal and I can look at people when I talk. Like my friend, who's in the transition class or whatever it's called, he doesn't look at people when he talks to them. So that's like, how… my mom said there are signs, like you know, if someone has autism. And it just means they need a little extra help on learning skills and stuff to, maybe not get frustrated that easy, or like, kind of learn how to say full sentences, you know? And [5 years ago], I even admit this, I was horrible, I was like, throwing fits and stuff. Now I have the skills to be like, ok I'll just ignore that. Get that out of the way. You know?

Together, Caleb's sense of autism is that individuals with this disability are "very unique." That is why it is important to Caleb that he shares his experiences and story. From his perspective, the autistic experience is so unique that it needs to be contemplated on an individual basis, rather than grouping people together.

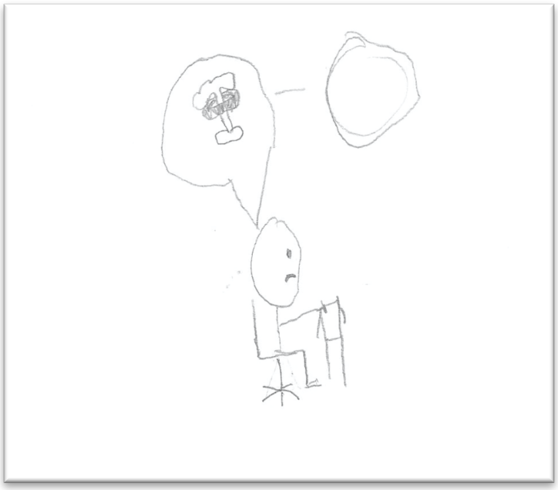
Medical definitions also emerged as part of the discussion of labels. For Kylie, Izzy, and Samantha, they identified cerebral palsy, epilepsy, and Leri-Weill's as medical conditions. Kylie defined cerebral palsy by explaining that one side of her body is stronger than the other side. Both Izzy and Samantha referred to Leri-Weill's as a growth hormone disorder. Samantha identified that epilepsy is a condition in her brain that results in seizures. Several children also referred to visiting doctors as part of the disability identification experience, associating disabilities with medical settings. The medical language children used seem to serve the purpose of understanding, concretely, the features of disability, which fit with the predominant societal approach to disability.

Drawings: Making the Invisible Visible

For many of the children, they were better able to describe their disabilities when asked to draw what it is like to have their disability. Notably, multiple children utilized thought bubbles or images of their thoughts to articulate the inner cognitive experiences of their disabilities, suggesting that there are aspects of disability that are difficult to put into words.

Figure 3

Bob's Drawing



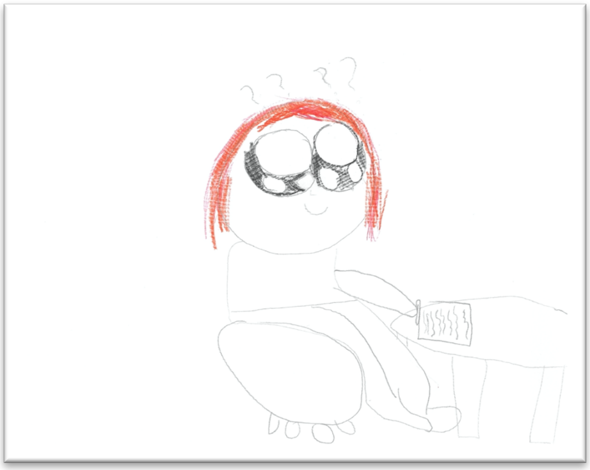
Bob depicted dysgraphia by drawing an image of a nuclear explosion in his mind, explaining the following:

> When it comes to writing, my mind literally feels like it dropped a nuke and wiped out my entire memory. But I can't think of anything… This is

> inside my head after I start writing. A blank ball. I mean, I can remember stuff. But I mostly forget the point that I'm writing, why I'm writing, what I'm writing about. At one point, I'll probably start just scribbling because I had no idea what to do.

Figure 4

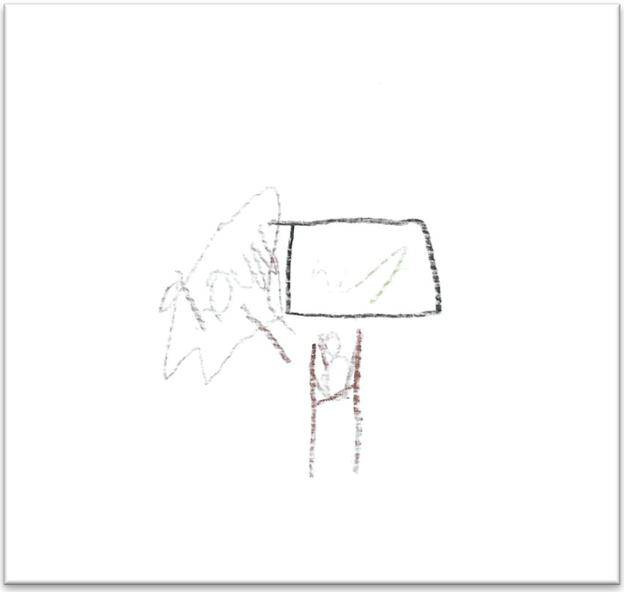
Rose's Drawing



In Rose's picture, she is looking at a learning task and feeling confused because she "doesn't know what the answer is." She indicated that she feels this way for both math and reading.

Figure 5

Tyler's Drawing



Tyler’s image is of him sitting at his desk, looking at one of his “struggle words” and thinking “huh?” In this moment, he feels, “Stuck. Like I don’t know how to read the word and I want to know what the word is. That’s how I feel… I want to know what the word is so I can get it over with… so I can go to game time.”

For three of the children with autism, they used thought bubbles to depict parts of their disability that make them unique or special.

Figure 6

Caleb’s Drawing

Caleb identified the sensory experiences related to having autism as being an important part of this disability. During the picture drawing activity, Caleb selected to draw an image of him thinking about how he has stronger sense than others. He remembers a time when he was able to identify a puzzle piece that his family had been looking at for several minutes. He also remembers a time when his mother commented that his hearing is stronger than other people.

Figure 7

Bunny's Drawing

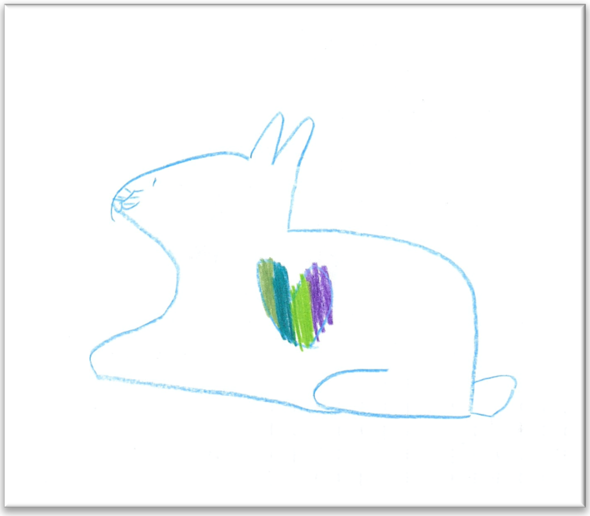
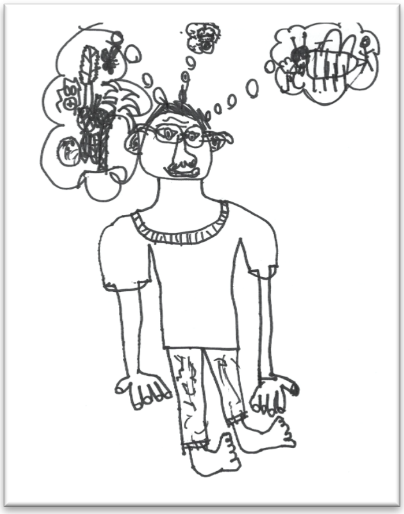


Figure 8

Stan's Drawing

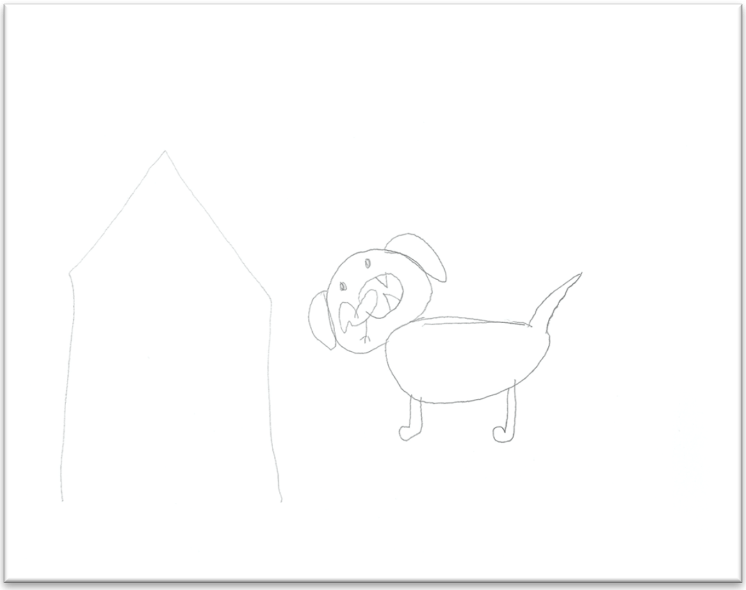


Bunny and Stan focused on their areas of special interest in their drawings. Bunny's interpretation of her picture is that having autism means she loves bunnies. Stan's interpretation is that having autism means he is constantly thinking about his special interests and has difficulty tuning this interest out when asked to think about other information.

Izzy and Tex both tried to capture moments of anxiety using their drawings. For both girls, they used the drawing activity as a way to conceptualize how their disability feels, rather than how it appears to others looking at them.

Figure 9

Izzy's Drawing



Izzy selected to draw an image depicting one of her strongest triggers. Izzy's anxiety heightens when she thinks about animals being hurt. She has a specific memory of when her dog tried to eat one of their chickens. She recalls that after that moment, she remained irritable for an entire day and had difficulty regrouping. While this event would likely be traumatic for most children, Izzy identified this moment as related to her disability because it exemplifies something that regularly brings her distress. More specifically, Izzy identified that whenever she thinks about any animal becoming hurt, or the possibility of someone hurting an animal, she has a large reaction. According to Izzy, this happens more frequently for her than it does for her friends, who have learned to warn her if the topic of animals emerges in a movie or story.

Figure 10

Tex's Second Drawing

Tex, meanwhile, drew what it feels like to be in a moment of anxiety. From her perspective, feeling anxious is like feeling completely trapped in a cage, knowing there is a key nearby that could help release the feeling. Tex decided to add a pill to her picture, as she notes that taking medication clears away the interfering feelings of anxiety so she can think more clearly. The inclusion of her pill and a key was an interesting symbol within this presentation of what it is like to feel anxious. When someone is caged, they are being kept away from something. I wonder if unconsciously, Tex depicted herself in a cage in efforts to communicate that her disability prevents her inclusion into the norm. The use of the key, however, suggests that there are interventions or other methods that, if used by the caged individual, free the person from oppression. I wonder if there are times where Tex feels like others join her in the cage rather than expecting her to be the person to free herself.

CONCLUSION

As is evidenced by the above stories, disability according to children is more complex than a list of symptoms and behavioral characteristics. Rather, it is a complicated concept that requires grappling with difference, normalcy, severity, and struggle. Further, children need multiple methods to communicate the complexity, as is shown by the moving, vulnerable features within the drawings and stories that children use to conceptualize the disability experience. Moving forward, this has implications for how disabilities are explained to children in a productive and helpful manner as to aid in healthy self-concept development and advocacy. In the next chapter, more evidence will be provided regarding how children make meaning of experiences related to disability and how this informs the support adults can provide to children in mid-childhood.

CHAPTER 6

HOW CHILDREN UNDERSTAND THEIR EXPERIENCES

INTRODUCTION

As highlighted by the literature review, a gap in the literature exists regarding how children make meaning from their experiences with disability, including how disability feels on a day to day basis, how it informs future aspirations, and how disability sets children apart from their peers. Research using rating scales highlights variability in the self-concept of individuals with learning disabilities, with some researchers indicating decreased overall self-concept and others indicating decreased academic self-concept, but adequate global self-concept (Bear, Minke, & Manning, 2002; Chapman, 1988; Gadeyne, Ghesquiere, & Onghena, 2004; Gans, Kenny, & Ghany, 2003; Kloomok & Cosden, 1994; Martinez, 2002; Rothman & Cosden, 1995). Outside of numerical ratings, qualitative research highlights students with learning disabilities being able to sense their disabilities prior to receiving a diagnosis and turning to both healthy and unhealthy coping mechanisms to manage feelings of distress or frustration related to the experience of disability (Cosden, Elliot Noble, & Keleman, 1999; Pestana, 2014; & Rodis, Garrod, & Boscardin, 2001).

In research conducted across multiple disabilities, self-confidence remained similar across disability groups until age eight, then declined, then elevated once students were in a new developmental stage, around approximately age 12 (Wei & Marder, 2012). Researchers also found that disability type impacted self-confidence. Children with social disabilities presented with lower self-confidence according to rating scale measures. Students with communication impairments indicated having negative experiences in childhood regarding labeling and social perception that impacted their self-concept negatively over time (Edmonds, 2012; Lyons & Roulstone, 2016).

As is highlighted within the literature review, the most significant gaps in the literature exist within the age range of participants and the use of qualitative research. While the previous chapter highlighted how children construct the concept of disability and normalcy, this chapter seeks to explore the meaning children derive from their experiences and how they incorporate these experiences into their developing senses of identity. Underneath these definitions, children told stories of what it means to have a disability and how it relates to their identity. It is hard to put that question into words: what does it actually *mean* to have a disability? What personal meaning do you derive from being told you are different? What can be learned from that experience? These are higher level, existential questions that are difficult for any individual to grasp. Each child had a different way of communicating how they make meaning of their experiences and how they relate disability to their overall identity.

HARDSHIP

Tyler was initially identified with dyslexia in first grade. At first, he remembers that the label was anti-climactic: he was told of his label and then he continued on with his daily activities. Over time, however, Tyler slowly developed an understanding of what it means to have dyslexia. As work increased in demands, Tyler became more cognizant of how his disability impacts him. From Tyler's perspective, demands have grown in intensity and he has not been able to keep up. The weight of his experiences grow more and more burdensome as learning becomes harder and the pace quickens. This has meant that his disability has shifted from impacting just reading to impacting him across other subject areas:

> First grade it was kind of… it started really picking up to me because it was getting harder and harder and I wasn't with everybody at that pace, so, I was being pulled out of important stuff, so I might be able to learn sight words, but I'm missing math, and things like that so that's also a problem because I'm not as caught up with math because I was being pulled out [at] math time… I could be learning cursive, things like that. So I feel like that was a problem because I was being took [sic] out of important things in my life.

Tyler's use of the phrase "I was being took [sic] out of important things in my life" highlights a growing awareness of what is valuable for eight year old students to experience, and how Tyler's disability acts as a barrier to reaching what all other eight year old children have access to. Seemingly no one has told him that certain features of third grade are important or essential to being an eight year old, but Tyler has given these events value, meaning that missing them has a bigger emotional impact than perhaps adults recognize or want to acknowledge. For example, learning cursive may take a back seat to reading from the adult's perspective, but for Tyler, learning cursive alongside his classmates is a rite of passage.

Prior to learning his label, Tyler remembers "I felt like, I didn't really think, I just learned that life was hard, I never knew why it was hard or anything like that." This period of time would have been during Tyler's kindergarten year. According to Harter's (2012) model of self-concept, early childhood is when children have concrete representations of their experiences and do not readily assign positive or negative judgement to experiences. Yet, Tyler at the age of five and six had an all-encompassing sense of hardship and struggle. Other children similarly spoke about recognizing difference and hardship in young years, as young as preschool. This causes me to pause and question Harter's framework for early childhood. Perhaps there are not explicit, isolated features of self-concept in early childhood that suggest an awareness for hardship, but from the words of these participants it is possible to hear that the difficulty of disability is palpable and intense.

DEFEAT, FRUSTRATION, EMBARRASSMENT, AND SADNESS

Defeat, frustration, and sadness also echoed throughout interviews, coming up in a variety of contexts. In the literature, these themes emerged in discussions of maladaptive coping strategies in older individuals with disabilities, mainly turning to drugs and alcohol as methods of coping with negative emotions and experiences (Rodis, Garrod, & Boscardin, 2001). For the younger participants in this study, these intense emotions emerged in discussions of school, relationships, and the difficulty of feeling misunderstood by others. While children have not yet turned to maladaptive coping strategies, they hint that they are wondering what to do with intense emotions.

Defeat

Tyler and Samantha spoke of feelings of defeat and fixed mindset when they shared about their experiences with teachers and with school. For Tyler, he felt defeated as the demands increased in school and he realized teachers didn't have the time to spend on him nor do they have the time to truly understand him. In his words, "if they want to understand it, they just couldn't… they couldn't really commit to it because it's too like, much work. They've got other kids to take care of." From Tyler's experiences, he feels that teachers can only spend a short time with students and once they are done, your opportunities are over. Feelings of defeat also emerged when Tyler described getting stuck on words or reading slower than other children. For Tyler, he gives the impression that on the surface, he has had to accept the conditions as they are: underneath, however, he seems to give the sense of loss and helplessness. These patterns seem to suggest that children are locating the problem of disability inside themselves, rather than identifying the outside conditions that do not match their profiles.

Samantha, similarly, sounded defeated by having a disabling condition. When asked about what life would be like without disabilities, Samantha commented that she thought life would be easier because then she wouldn't have to be in the front of the line: "It would be way easier because then I won't be like, always in the front of the line when we line up for height because I've always been at the front of the line. Even when we do it by grade. And it just makes me feel like, really negative about myself." Samantha also commented that without disabilities, she wouldn't have to have a brain scan every time she has a seizure. Samantha has not had a seizure in two years, but the possibility of having to have a brain scan is anxiety provoking for her. Instead of focusing on the fact that she has not had a seizure for two years, she instead is anticipating the worst.

Louis also alluded to feelings of defeat briefly, although in a slightly different context. When I asked him if labels are helpful, he initially responded yes, then started to say, "labels used to…" before he started to mutter to himself and hit himself in the head. I asked him if he would be willing to explain that thought. He indicated that labels have been used as part of slavery, and it concerns him that slavery still exists in our society because “it shouldn’t.” In the moment, he seemed unsettled and so I did not pursue this thought further, merely responding “I actually have a part of my dissertation on that.” What I think Louis was alluding to, however, is that labeling has been used as part of oppressive practices, as is discussed by disability historians and activists (Baglieri & Shapiro, 2012; Brune & Garland-Thomson, 2013; Davis, 2002; Hehir, 2002; Lalvani, 2015; Oliver, 2004). When Louis said that slavery still exists, I connected this to the idea that labels may be useful, but it is also defeating that oppressive practices continue and people dismiss these practices because the common narrative is that slavery and oppression no longer exist.

Frustration and Embarrassment

Frustration emerged as a common theme for several children, with some indicating it within the symptomology of their disabilities and others suggesting frustration as an outgrowth of existence with a disability. Kylie specifically indicated that part of having ADHD is becoming frustrated more quickly. This in of itself is frustrating for Kylie, as it makes her recognize how she is different from her peers. In other words, she gets frustrated for being frustrated when others are not frustrated. When she is frustrated, she bangs her hands against her thighs. So, when she starts to bang her hands, at times the banging increases as she recognizes the strong emotion of frustration. This is a vicious loop for her and a consistent reminder that she is not like other kids. In a similar vein, Bunny becomes frustrated when her teacher asks her to do sudoku, both because sudoku is frustrating but also because she notices that she is frustrated when other children are not. Rose perceives her disability as preventing her from receiving top grades on her report card, which prevents her from feeling “super happy.” She also feels frustration regarding having to take medicine in the morning to help her focus. She perceives this as annoying, but there seemed to be a narrative underneath her descriptions suggesting that she also feels frustrated about being the child who cannot receive top grades or function effectively without medication or other services. In other words, she’s frustrated that she has to be different based on how her school functions and the way expectations are structured.

Alongside the feelings of frustration were stories of embarrassment. Kylie and Bunny noted that not only do they feel frustrated in the aforementioned stories, but they also feel embarrassed that they can’t be like everyone else. Izzy and Samantha’s stories about being smaller allude to embarrassment because of the constant awareness of looking different and the insensitive practice of lining children up by height. For both these girls, it calls direct attention to their difference.

George shared of an instance where he was reminded of his disability and then felt down or disheartened. George shared that he usually feels comfortable around his family, but there was an instance where he was with his aunt and she commented, “Wow, George has really bad handwriting! This is horrible, I can’t understand this!” George was embarrassed, but also angry that she had forgotten about his disability and made such an insensitive comment. Since this event, George’s family has experienced a strained relationship with his aunt.

Together, the meaning making process for these children seems to include the step of grappling with recognizing how one is different and working through this frustration and embarrassment to reach the next step. Further, this grappling is not always supported or understood by others, perhaps being instead mislabeled as maladaptive behaviors or denial of "the truth" in the label. It is unclear what the next step is, whether it is acceptance, depression, or something else, but frustration in general seems to be an essential part of meaning making. It also seems that more space could be made for outward exploration of the cognitive dissonance inherent in understanding difference.

LONELINESS AND ISOLATION

Samantha and Louis spoke to feelings of loneliness and isolation, specifically sharing about how their disabilities are unique and make them feel more alone. Samantha's emotional responses to talking about her disabilities were often deep and intense. Much of this seemed related to the medical features of her diagnoses as well as the bullying that have come alongside her diagnoses. Samantha has found solace in knowing that there was a famous actor with epilepsy, but this knowledge has also made Samantha hypervigilant about the possibility of having a seizure. While she has not had a seizure in over two years, "when I heard that Cameron Boyce had epilepsy it just reminded me that I might have a seizure right there." Samantha finds that she has to actively find ways to keep herself busy so she doesn't think about having epilepsy. If she doesn't, she finds that "when we're talking about like, just like random stuff, I just start – I just connect a bunch of stuff in my brain. And it leads me to thinking about epilepsy."

Disability is also often a lonely place for Samantha. Her hypervigilance regarding seizures alongside the instances of social isolation and bullying, have resulted in Samantha carrying anxiety and stress alongside her hopes and dreams. She feels different from other children, particularly because she does not know many people with her disabilities. She is able to relate to her sister, who also has Leri-Weill's, and she has a connection with other children with ADHD. But with epilepsy, she doesn't know anyone with the diagnosis and “It just makes me feel really alone.” Samantha became visibly emotional as we talked. She often slowed her speech, shifted her eye gaze downwards, and shifted uncomfortably. She appreciated breaks in the conversation where she could answer lighter questions or talk about acting and reading. In this sense, Samantha actively showed how she copes with existential feelings on a day to day basis: she turns to her interests, talents, and supportive community to find strength and perseverance.

The emotional undertones of Louis’s interview were thick with feelings of isolation and loneliness. When I asked Louis about his friends, he responded that he has no friends. He expressed that he prefers to stay home and away from family events. He cannot recall instances where his family tried to set him up with other autistic children who are similar to him. When he did spend time around other children in public school, he described the experience as “terrible.” From Louis’s perspective, the way he thinks and exists is so complex, that he is alone in his understanding of self:

> M: Is there anybody in your family or any doctors [that understand you]?
>
> L: (laughing loudly) No.
>
> M: No, no one understands.
>
> M: Okay. Can you tell me why they don't understand it?
>
> L: Because they're NTs.
>
> M: They're neurotypical. Okay. So it's hard to understand something if you're neurotypical?
>
> L: Yeah. I mean, I didn't understand the things I do until I started exhibiting signs of it.

M: Ok. So is this fair to say: that you can't understand a disability unless you have it?

L: Yeah.

Louis's inclusion of himself in this description suggests that his autistic self was even isolated from his overall concept of self when he initially started presenting with autism. In addition to feeling misunderstood, Louis experiences day to day frustrations with feeling alone.

School has also presented a long-term message of isolation. Louis attended public school until the end of first grade. He was then moved to a private therapeutic placement that utilizes Applied Behavior Analysis. This setting was extremely traumatizing for Louis. Whenever school was broached during our interview, Louis would start hitting himself in the head and saying phrases like "I have to kill it out of my head." Louis couldn't initially state why this school was so traumatizing due to the level of distress he experiences when he thinks about this school, so his father clarified that Louis felt extremely misunderstood. Louis later added that he feels like the behavior of school personnel should be considered illegal. After this school placement, Louis moved to another private therapeutic school, but was asked to leave because he kept eloping from the property. He is now homeschooled.

A report conducted by a hospital-based evaluator commented that "It appears that the current plan to have Louis receive home based services until a more appropriate setting can be found is appropriate." Currently, Louis receives ten hours of services a week, all of which focus on his bands of interest: he is learning the programming language Python, computer science, European history, and Japanese. I imagine what it must be like for Louis to be told that he doesn’t belong at three different schools, and to have a medical professional suggest that a correct placement may not be easily found. Now, his education is catered to his individual interests, which in some ways could be empowering for Louis, but on the other hand could be considered another way that the message of isolation and rejection from society is perpetuated. I asked Louis, “are there places where your disability feels like they match the situation? So like, where like your disability is, like celebrated or accepted or like a really great thing?” He simply responded, “no.”

RECOGNIZING GROWTH AND CHANGE

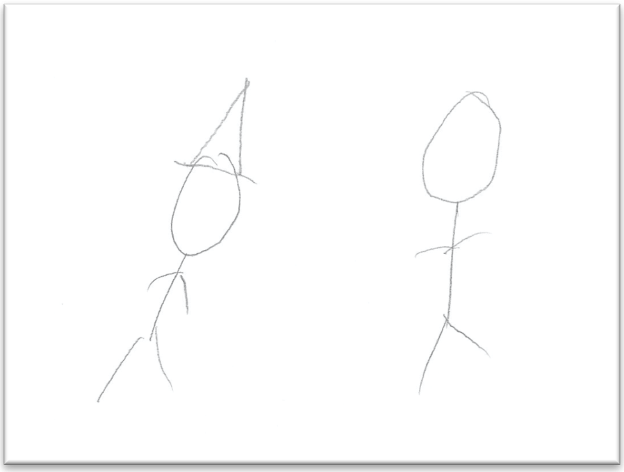
Alongside intense emotions, multiple participants identified ways in which they have grown over the course of their lives, recognizing that they have also experienced positive changes. All participants with dyslexia identified that while their disabilities make academic subjects difficult, they receive intervention so they can make improvements. George, in particular, sees dyslexia as an opportunity to overcome a challenge. George’s brother has dyslexia, and George admires how his brother has overcome a disability and now only needs limited support. To George, “I don’t think about it as a disability. I think about it as, I think differently. And it doesn’t really pull me down, I can’t like ‘aww I can’t think of this word.’ It’s um, I’m having problems with this, but I can get around them.” This narrative builds a foundation for his positive outlook. While he did speak of frustration and discouragement, he repeatedly fell back upon this mindset, suggesting that for some children, seeing others gain skills can be a motivator for further growth.

Kylie, Caleb, Izzy, Tex, and Bob highlighted specific behavioral changes that indicate they have made growth. For all five children, they could identify previous behaviors that interfered with their functioning and how they have changed over time. Bob's change in behavior, for instance, has led him to wonder if his Social Pragmatic Communication Disorder diagnosis is still relevant or as prominent within his overall identity. Bob told of SPCD with the aid of his drawing:

> When I was in kindergarten I had no idea about social stuff. So I put a cone on my head and charged, I hit someone with a cone. Kid didn't know because I thought we were playing rhinoceros… When I was younger, because of my social thing, I didn't know a lot of things.

Figure 11

Bob's Second Drawing



Now, Bob feels that he doesn't have social difficulties because he has worked with his therapist on improving his social skills and managing his anxiety in social situations. Kylie also wonders about the accuracy of her dyslexia diagnosis due to her progress over time, stating "I don't really get how I have dyslexia because I'm where I'm supposed to be in reading level. In the beginning of fifth grade you're supposed to be a level T. I am a level T. So I don't really get it, I don't really know why."

Together, these children also highlight an interesting feature of how children think about disability. The three aforementioned children all spoke of overcoming disability, as though it is something to grow out of or that it will eventually disappear. This mindset poses its own set of questions: is it helpful for children to think they can outgrow disability? Or, is it more effective to provide a more critical or realistic perception to children so they can prepare for future difficulty? These two lines of thought may be able to exist simultaneously, but require explicit discussion.

POSITIVE OUTLOOK AND MINDSET

Mindset

A subset of children used words like "I think different from other kids" or "I need a little extra help" to define their disabilities. From the perspectives of many participants, disability at times is a difference which is not necessarily negative. In other words, several children challenged the cultural message that disability can be seen as "less than" or a hardship. Tex, for example, stated:

> It's not a bad thing… Like if people think that it's a bad thing to have it, then it's like if they had it and they didn't want it, then I would say like, it's not a bad thing. You're still a human. And you like, just think differently, that's all.

Tex did contradict herself at times when describing other aspects of disability, but when speaking about how she would advocate and support others, she emphasized that it is okay to have a disability. Bunny, too, also highlighted that "it's okay to be different."

While she would like her disability to stay private, she also sees value in promoting the idea that difference is not necessarily a bad thing. Izzy, meanwhile, contributed the following idea:

> You don't always have to look down [on people with disabilities]. Because you don't always look down say like, that kid isn't right, we shouldn't let her go into ice skating or anything. But if they knew exactly what would happen, they will be like, oh, yeah, you can do this that, just be careful of that.

Izzy said she would deliver this message to both adults and children. Similar to Bunny, Izzy feels that disabilities do make individuals different, but adults and children can take the time to understand that it is okay to be different.

Caleb put it simply as “every child is unique.” From his perspective, it’s okay to have a sense of humor or light-heartedness about having a disability. For example, when describing what it is like to have ADHD, Caleb laughed and shared the following:

> No, we already knew that I had – well I, straight off the bat we knew that I had ADHD. We knew already. Like they could see it. Cuz I was just forgetting everything, and be like “oops sorry, I forgot” *laughing* They would tell me to do one thing… and then [Mom] tells me to do two things at once and I’m like, “mom you told me to do one thing and then you just told me to do the other!” And then like, I’m still petting the dog after and then I go, like, I go to put some clothes on, then like, I still am not brushing my teeth and I’m like, my mom is like “BRUSH YOUR TEETH!” and I’m like, “oh sorry!”

Caleb also shared that his family used to joke about having autism, so when his mother and sister told him of his disability, he chuckled and responded, “really? I guess I do have it then.” While other people might perceive this approach as “rude,” Caleb thinks of it as a comfortable and familial way to engage with the topic of disability.

SUPPORTS TO MEANING MAKING

Family

All but one child identified their parents as having a good understanding of their disabilities, making statements like “my mom is very helpful,” “mama is really nice,” and “they just really get it.” Several children gave examples of how their parents have advocated for them at school and in their community. The majority of children also noted that their parents were the first people to notice behaviors that may have suggested they had a disability, and thus their parents seemed to understand them best. One child, Tex, did note that her father seemed to have a decreased understanding of her disability compared to her mother, which she attributed to the fact that her father also has a disability. She suggested, however, that he tries to understand.

All but one participant with siblings identified that their brothers and sisters were people in their lives that showed support and understanding of their experiences with disability. Support looked different depending on the participant. For some, support meant having a sibling who appreciated the characteristics of their disability and who encouraged them. For others, support meant including them in activities despite having disabilities.

George, Tex, Bob, Izzy, Samantha, and Tyler additionally spoke of the comfort found in knowing that others in the family have disabilities. George aspires to be like his older brother, who also has dyslexia. Izzy and Samantha were in the room together when they both found out about their Leri-Weill's diagnoses and are comforted by having a sister with the same condition. Izzy, Samantha, and Bob are all well aware of their mother and father's disabilities. Tex feels most comfortable when she is with her older sister who is diagnosed with Asperger's, but who Tex describes as simply "cool." Tyler feels a strong connection to the paternal side of his family due to the number of men in his family with dyslexia, sharing "my dad has it, my uncle has it, both my uncles have it, so yeah. It's kind of a bunch of my family, my grandfather has it." As a parent, I have wondered about my own disabilities and their impact on my children, but from a negative point of view. Hearing these children speak of the inspiration they have found in having family members with similar conditions, I am rethinking how to speak of genetics and disability. Perhaps there is a positive way to spin disability so children see the value of being an insider of the disability community, just like their family before them. One could even argue that having family members with disability is actually a protective factor, which goes against the medical mindset that family history is a risk.

Friendships

Several children identified close friends as being essential supports to their identity development journey. For some children, pivotal friendships included having friends who have disabilities, either the same or different from the participant. Tex, for instance, identified that her closest friend understands her best because she also has anxiety and ADHD, saying "we pay attention more to each other cuz like, we know what it feels like… And we both like, we barely talk about it, but we sometimes talk about it. So that is like, 'I'm very glad you get me.'" Izzy and Samantha both spoke fondly of friends who have diabetes, identifying these friends as understanding what it is like to have a disability as well as what it is like to have a sibling with a disability. Caleb identified having two close friends with autism and George identified his best friend as having dyslexia. Bunny shared that she has disclosed her disability to only two friends, both who have disabilities and who she perceives as understanding the experience of disability. Children cited that these friends are able to distract them when they are feeling discouraged or know how to offer the right kind of support. Izzy and Samantha, for example, shared that their friends both recognize that they feel burdened by their decreased height and they talk openly to one another about this feeling. Tex appreciates that her friends recognize when she is feeling anxious and will ask her "are you ok? Do you need to go to the nurse? Which is helpful." She also points out that her ADHD symptoms match well with her friendship group, as she describes them as "crazy" and she describes her ADHD symptoms as making her "all over the place."

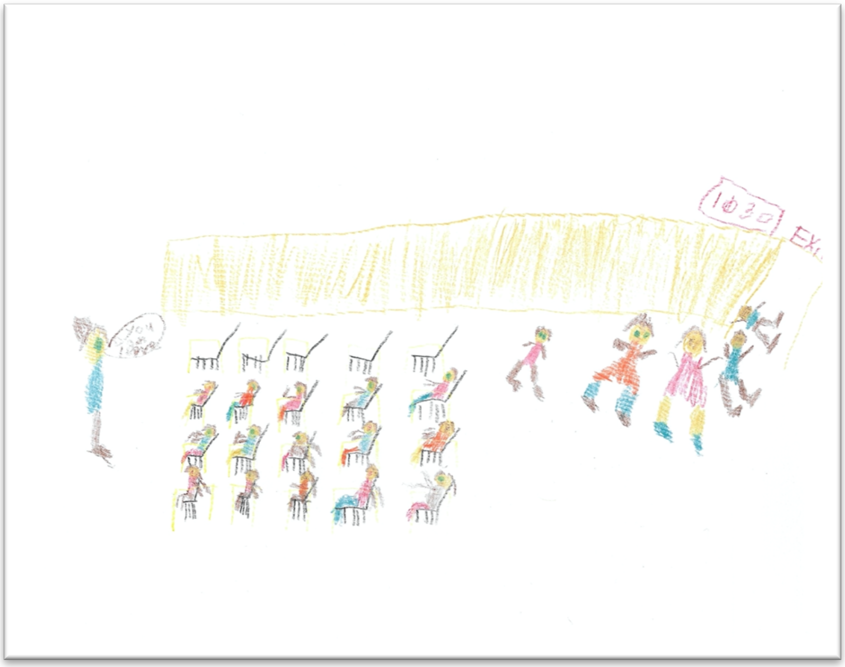
In addition to feeling supported, some participants also noted that their disabilities seem to disappear in the presence of friends or they have little significance. George, for instance, indicated that he does not notice his disability when he is playing soccer with his friends. Rose enjoys playing with her neighbors and also reported that her disability has no significance when she is running around or playing. Kylie noted that she feels just like everyone else in times when she is not frustrated. Tyler also shared that because he has a "hidden disability," most of his friends don't even know he has a disability unless he selects to disclose it. Somehow, these children have learned how to be accepting and encouraging, even if the lesson has not been taught directly. Rather, the power of friendship has been a stronger influence than the presence of disability in shaping how these children interact with one another and offer support. It has also provided opportunities for disclosure in supported arenas, which can be empowering and confidence-building for these participants.

Classmates

Supportive classmates have also had an impact on the sense of identity in participants. For both Kylie and George, they reported that it helps to have classmates going through similar intervention or to have classmates know about their disabilities. In other words, the small group of students with disabilities with whom they work offer a sense of community. George depicted this classroom group through his illustration of what it is like to have a disability.

Figure 12

George's Drawing



George described this picture as the moment when his group of classmates with disabilities leave the room to attend their English/Language Arts tutorial session. George describes himself as a leader in this group and feels like having this group allows him to model his skills and support others. Notably, George selected to depict “his group” as separate from the other children in the classroom. So, while he feels supported within his small group, his picture also reveals possible cognitive dissonance about being othered amongst an entire classroom of students.

Bob and Rose gave a slightly different interpretation on whether classmates or peers should know about their disabilities. These perspectives were not overly positive or negative; rather, they were matter of fact. According to Bob:

> You can kind of say what adults should know about [disabilities], but kids, for one you know they don’t care about it that much. So it would be hard to kind of come up with [something they need to know or something to tell them], because you kind of just ignore them.

Reflecting this mindset, Bob chose to tell his classmates he has dysgraphia because he missed school for a day to attend testing. To him, it is “no big deal” that classmates know he has a disability. Rose, meanwhile, feels classmates do not need to know about her disability. Put simply, “it’s none of their business.”

As a school psychologist, I was regularly asked to join classrooms for a conversation about strengths and weaknesses. I was almost always asked to lead this conversation when there was a child with a disability within the classroom who was struggling with managing his or her behavior. I always felt conflicted about this lesson. From one perspective, it gave children the chance to normalize strengths and weaknesses, recognizing that everyone is different. However, these lessons also inevitably lead to me stressing, “some kids are MORE different” or “some kids need MORE help.” From the data gathered through this study, I believe the question as to whether or not this lesson is helpful is still partially unanswered. For some children, this conversation is empowering as it allows children to feel recognized. For other children, however, these conversations may bring up anxiety about having to disclose or be noticed. Like many other points made by the children within this study, encouraging understanding and empathy may require more individualized consideration than is currently thought.

Therapeutic Supports

Several children mentioned working with therapeutic supports that have supported their growth and resilience. Kylie talked about a therapeutic mentor who engaged her difficulties with regulation by practicing with puzzles and teaching her distraction strategies. She also works with an emotions supporter at school, who she finds helpful. Bob spoke fondly of his current therapist as well as his previous therapist, both of whom he felt understood his needs and have helped him develop regulation strategies. Caleb is proud of the work he has done with his therapist, occupational therapist, and speech/language pathologist. Notably, all these children spoke to having therapeutic supports who addressed the topic of disability directly by naming areas for continued growth and specific strategies or skills that needed to be learned. Together, these children advocate for the importance of individualized therapeutic supports as well as the need to be direct or clear in explaining why children receive this individualized help.

THE FUTURE

All children were asked about how they perceived their futures being different given their disabilities. This question was difficult for many children to answer, and responses were variable depending on where children are in their thinking process regarding who they will be as they grow older.

Malleability

Multiple children indicated feelings of hope and openness related to being a person with a disability in an ableist world. Of the children who spoke of hope, many indicated that they see their disabilities changing over time and becoming less impactful as they grow older. George, for instance, has his brother as an example, sharing "my brother, he also had [dyslexia] but he's come over it and now he doesn't do special ed, so I know I will come over it after a while." This reflects George's overall understanding of disability, namely that disability changes over time and is perhaps a temporary condition. Other children expressed similar sentiments, that disability is malleable over time and has the potential to disappear once in adulthood or it will feel less impactful. This strikes me as similar to the differences between the medical and social models of disability. A significant difference between these two models is how impairment is then translated into disability. According to the medical model, a disability is when an impairment interferes within a specific environment (Darling, 2013; Davis, 2015; Garland-Thomson, 2019; Nielsen, 2012). Differently, an impairment according to the social model of disability is only revealed as a disability when the environment oppresses or discriminates against the person with the impairment (Baglieri & Shapiro, 2012; Brune & Garland-Thomson, 2013; Davis, 2002; Hehir, 2002; Lalvani, 2015; Oliver, 2004). George's definition falls between the two models. In other words, George feels that disability may present itself in a specific environment, but once someone is able to gain the skills to overcome the oppressive conditions of disability, someone is no longer considered disabled.

Tyler similarly predicts he will always have dyslexia, but that life will get easier because “life’s just easier when you’re older.” When asked to be more specific, he grappled with finding the right words, simply saying “[dyslexia makes it] more brighter. Thinking differently. I don’t know. I really don’t think about the future. I’m not a big future guy.” In describing how disability might impact others in the future, however, Tyler makes an interesting statement:

> I mean if I had autism, I mean it would wear off, but at one point, I feel like if I had autism I would be really behind and that would not be fun because when I get older, I don’t want to be working at a gas station. I mean… I just am saying that I feel like I would not be caught [up] enough.

Tyler’s words are a bit confused, leading me to wonder if he is talking about the experiences of people with autism, or his perception of what will happen if he doesn’t catch up. Similar to the aforementioned analysis, Tyler also seems to have the belief that disability is malleable and is simply a function of how far behind you are from the norm. Further, if the correct intervention is not provided, that is what holds one back from making enough progress and emancipating oneself from disability.

Radical Empathy

Tex expressed a different perspective regarding her future and how anxiety and ADHD may impact her. In describing what she would like other people to understand about disabilities, she would like others to understand that having a disability “kinda sucks” but it’s also “a bit more interesting.” She feels that it would be very beneficial for people without disabilities to experience what it is like to have her disabilities so they can better grasp what it is like to have a disability. She also feels like this would increase the level of respect individuals have for one another. Interestingly, something she feels individuals could understand better is that people with disabilities want to be treated how "they want to be treated." This is a twist on the golden rule, as it puts the attention on the other person's feelings and aspirations, rather than the feelings of oneself. When Tex spoke of her future, she gave the impression that having anxiety and ADHD has increased her emotional intelligence. In the future, Tex would like to be a teacher and it is because of her disabilities that she feels she has increased abilities to think about her students in terms of how they want to be treated and what best serves their individual education needs.

In this vein, I feel as though Tex is talking about how having a disability allows her better to communicate radical empathy (Jordan & Schwartz, 2018). Radical empathy is more complex than the original conceptualization of empathy:

> Empathy that produces change and growth in both people goes far beyond a warm and fuzzy feeling of closeness or being understood. It is the vehicle for deep learning and acknowledgement of the power of relationship where both people experience growth. The power to change in connection is at the heart of radical empathy (p. 27-28).

Tex's experiences have deepened her understanding of what life meaning she carries. Different from many of the other children who participated, Tex feels like it is appropriate to treat people with disabilities differently, as long as you are treating them the way they would want to be treated. As a teacher, Tex would be responsible for quality differentiation for her students. Given her level of emotional intelligence, she appears prepared to execute radical empathy in her future classroom. Tex also seems to suggest that educators and supporters could think more critically about how the children they interact with want to be supported and inspired, thus utilizing radical empathy as part of creating plans for the future.

Uncertainty

Amongst the interviews were instances where children expressed uncertainty or concern regarding their futures in relation to disability. Kylie, Tex, and Izzy expressed concern that features of their disability will impact how they interact with others in the future and their careers. For Kylie, she is concerned that her frustration will continue with her into adulthood, making it difficult for her to regulate herself in adult situations. Tex is concerned that due to her impulsivity, she will have difficulty managing money and keeping a job. Izzy worries that while her anxiety increases her empathy for animals, she also anticipates that her anxiety could impact her ability to do the work of a zookeeper well. These girls suggest a more traditional view on disability, thinking of their symptoms as fixed and continuous throughout life. They also again highlight the difference between boys and girls within this study. Whereas many of the boys were the individuals talking about inspiration and success in relation to disability, more girls were likely to speak to career uncertainty or fear. Again, I reflect on the actual difference in outcomes for girls versus boys with disabilities and how these patterns are perpetuated in the way that we discuss the future with children.

Louis also made an interesting comment that seemed, at first, as an aside to our conversation, but with further analysis suggests an underlying fear related to future with a disability:

M: If you were going to make a prediction, what do you think your future will be like?

L: According to dad when he's really angry, me in jail.

On the surface, this seems to suggest that Louis's father has merely made a comment in frustration when Louis is having a hard time. However, I connect this comment with the knowledge that incarcerated individuals are likely to have disabilities or mental illness (Schlanger, 2017). There are likely hundreds of messages about his future that Louis has internalized, yet the one that comes to mind when I ask about his future is this one. I wonder if Louis has made an unconscious connection between the behaviors relevant to his disability that interfere with his interactions and daily living, and the likelihood of difficulties with law enforcement. Louis also experiences extreme isolation and has experienced rejection from institutions meant to support him, so he already grapples with needing to find a place where he fits. Perhaps in telling me that his father thinks he is going to end up in jail, he is trying to understand how characteristics of his disability could be perceived as illegal or dangerous, particularly as he grows older, and fits in a setting such as jail.

CONCLUSION

It is clear that children make significant meaning of their experiences related to having disabilities. When given the opportunity to tell their stories, children share deep and meaningful moments that are likely to inform their futures in significant ways. In the next chapter, children will further explore how they experience their disabilities, this time through the discussion of stigma. Specifically, experiences in schools, homes, and community settings will demonstrate how children cope with stigma as well as develop resilience and resistance in the face of misunderstanding or othering.

CHAPTER 7

HOW CHILDREN UNDERSTAND EDUCATION

INTRODUCTION

The purpose of this study is not to directly expose school-based systems from the perspectives of children; however, the discussion of schools and therapeutic supports naturally emerged as children talked about their worlds. School plays a significant role in how children develop an understanding of self. It is their primary social world, as well as the place where children encounter messages from adults about disability and its acceptance or rejection. Based on my experiences as a school psychologist, educators have strong and determined opinions about how disability should and should not show up in the classroom. At times, these values appear to trump the wishes and individual needs of children. This theme emerged from the children interviewed for this study, indicating that there is still significant areas for growth in school systems and educational institutional practice.

From the literature, Lalvani (2015) noted that parents and teachers often have differing perspectives regarding disability. Teachers most frequently believe that labeling is helpful for academic planning and leads to better service delivery. Further, teachers find that removal from the classroom helps to boost instruction, leading to what they perceive as more rapid progress. Notably, Lalvani further indicated that teachers most frequently prescribe to the medical model of disability, locating the presence of a disability within the child. This has implications for how teachers design their classrooms for inclusion and treat their students as individuals.

Missing from the literature is the perspective of children regarding the interplay between labeling and school institutions. This study reveals that not only do children have perspectives on labeling, but they are perceptive and aware of how school based practices and institutions have an impact on who they will be as individuals and future members of society.

TEACHERS

Notably absent from the stories told by children are stories about supportive teachers. Of the 12 children interviewed, eight children briefly mentioned teachers as part of their social network. Four participants (Tex, Bob, Louis, and Caleb) were decidedly negative about teachers, noting that they can be strict, scary, insensitive, or lacking empathy. Tex and Bob both had stories about teachers saying seemingly supportive phrases, but with tones of voice that suggested they didn't care or were making judgements on their behavior. For example, Tex has heard and seen her teachers say, "are you okay" with a side-eye glance. While these words are the same as those used by her peers, Tex feels like her teachers are seeing her as different and strange compared to peers. Bob also gave the sense that teachers are quick to dismiss when a child says they are struggling. Bob's interpretation is that teachers are more likely to associate struggle with a lack of motivation and thus be unsupportive and judgmental. Both children alluded to the use of nonverbal cues as ways that teachers communicate their discontent.

When children are learning about communication skills, they are often told that nonverbal communication is the primary method by which people understand each other. From the stories told by Tex and Bob, it seems as though this lesson needs to be better taught to all individuals in schools, not just children who have difficulty with social communication. Had I asked more directly of all children about how teachers communicate their understanding or misunderstanding, I predict that nonverbal signals would have come up with a high level of frequency. I also think about the commonly promoted “5 to 1” rule, where teachers keep track of their comments and try to have five reinforcing statements for every one correction. I wonder if there has been consideration to how that applies to nonverbal behaviors as well as the strength of the different types of comments. From the perspectives of these children, it sounds as though the ratio doesn’t matter as much as the nonverbal intent.

George’s perceptions of teachers are conflicted and also speak to the different styles of communication teachers use on a day to day basis. In some instances, he used the word “trust” to describe how he feels about teachers. He sees his teachers as authority figures who make decisions about his education that are for his benefit. He also feels like teachers have “heard of [dyslexia] and know what it is.” However, he also observes that sometimes, the instruction provided by teachers does not match the needs of students. He has witnessed his peers in his special education class cry because of how teachers have interacted with them. From George’s perspective:

> If you just keep on asking them [for the answer], it’s peer pressure basically, but it’s from a teacher, that’s why for the harder kids [with] dyslexia, for like my friend, he has it super bad, and he sometimes cries, because I can tell that the teacher are going way too far in saying, “Why don’t you know this? You have to know this!” And like, leave him alone. He has it, you know it, teach it to him, don’t say “why don’t you know this.”

Similar to earlier stories, George alludes to the many types of communication teachers use in their classrooms to communicate attitudes and perceptions of students.

Still, when asked to tell a story about a child with a disability, George focused on how teachers play a role in “fixing” disabilities:

> Once upon a time there was a kid, named George. George had a problem. His problem was that he needed, that he did not understand what he was learning. So, he asked his friend Bob what he should do about his problem. Bob said “go to the teacher… and ask, um, her what you should do.” Bob said that the teacher knew everything. So George went to the teacher and said “I have a problem. Can you fix it?” And the teacher said, “I will fix your problem. What is your problem?” … The teacher said, “it’s, lets go to the principal. He, uh, he will know, what, to, do.” So they went, and the principal… sat down and thought for a moment, um and then said “we need a special ed class here for this boy. He needs some help.” And in the end, they all found out that all the kids at the school need special help. So they all lived happily ever after.

George sees teachers as valuable supporters who have positive intentions. Yet, there are barriers to their ability to provide the support that students are looking for or need to be successful. Also, George brings to light the importance of reflecting on what it means to be in the position of authority over children. From a teacher’s perspective, at first glance authority may mean having power over the behavior and compliance level in the classroom, but from the student’s perspective, authority means much more, including being the person with the answer for everything. How anxiety-provoking it must be, then, to be a student who feels their teacher does not have an answer to struggle. Conversely, how frustrating it must be for teachers when they do not have the immediate answer or solution for a child in need.

PLACEMENT

Co-taught Versus Pull-Out

An ongoing debate in schools is whether or not to use co-taught models for classroom instruction or to utilize pull-out instruction to specifically target areas of disability. This debate runs rampant between educators, administrators, parents, special education advocates, and special education lawyers. In Massachusetts, for example, all teachers are encouraged to complete the Foundations for Inclusive Practice professional development training (Educator Effectiveness Guidebook for Inclusive Practice, n.d.). From the perspective of school districts, co-taught classrooms achieve better results and are also more cost effective. It is the most rapidly endorsed inclusion model and is thought to strongly support the principles of Least Restrictive Environment for students (Keeley, Brown, & Knapp, 2017). Yet, if one peruses the findings from the Massachusetts Bureau of Special Education Appeals, a preponderance of cases favor the use of substantially separate settings to address the needs of children with disabilities. Within the literature, there is still a significant need to explore child perceptions of co-teaching, as preliminary research has suggested that children's perceptions of inclusion models differ from teacher perceptions (Keeley, Brown, & Knapp, 2017).

The children interviewed in this study presented varying opinions on teaching models and indicated that children are aware of different classroom designs, despite adult efforts to make all classrooms inclusive. On the surface, Rose seemed neutral about teachers. She noted that they understand disabilities, but otherwise only spoke of how teachers follow their daily responsibilities. I asked Rose if she could differentiate the different types of teachers in her classroom, as I wasn't sure of her classroom model, specifically it was a co-taught classroom, inclusion classroom with an assistant, or another design. Rose noted that her classroom was one of the few that has two adults in the classroom, but could not identify their individual roles. This fact did not seem to bother Rose, rather she seemed comfortable with her classroom design and how it supports her needs. If I were an administrator, I might use this classroom as an example of "inclusion done right."

Kylie, meanwhile, identified her instruction design as involving a general education home room and a special education teacher who provides instruction out of the classroom. Kylie described her teachers as "special teachers" who "help" her specifically with her emotions and reading skills. Kylie described these individuals as people who understand her disability and who support her. She notably turns to these teachers most often for support when she is frustrated. Again, if I were an administrator, I may associate this perception as evidence that a pull-out model is most effective.

Tyler feels frustration with how the school system is mismatched with the way he feels his needs should be met, indicating that neither pull out nor co-teaching has been effective in his educational history. From Tyler's perspective, he felt the demands increase exponentially as he moved through grades and felt like he wasn't getting the support he needed. He also felt like his instruction was taking away from opportunities that all children should have in school. He most critically, however, felt like teachers just don't have the time to dedicate to students with disabilities:

> School has like 365 kids to take care of… They only care about, let's say one person at a time. And it's rare you even get your chance. Like, you get it, like for 10 minutes a chance, that's like the only time you'll ever get it… I just feel like [my old teachers] didn't give enough, like they would only give one student for 10 minutes attention, and that'd be like, in this like 365 kids, they would do that for. So I feel like, a small… place is better, [where] most people are gonna learn… If they want to understand it, they just couldn't, they couldn't really commit to it because it's too like, much work. They've got other kids to take care of.

George similarly values the idea of a smaller, substantially separate classroom and school: his best friend "sued the school" so he could change placements to the same school where Tyler attends. From George's perspective, the use of a one on one model of instruction is most effective for achieving academic success so one can overcome disability. George currently receives pull out services and feels that even with this design, he is not able to receive the differentiation he needs. He predicts that if he were in a general education classroom for English/language arts instruction, he would struggle even more because he would not be able to receive individualized attention.

Together, these children indicate that the argument over teaching models perhaps has overshadowed the individual desires of children. Test scores provide one data set regarding childhood success. However, test scores do not reflect the emotional journeys and meaning making that come out of how a child perceives a classroom placement. Instead of relying on outcome data, these children suggest educators could be more process oriented as they consider the social/emotional growth of these children alongside their academic performance.

Out of District Placements

Caleb, Louis, Stan, and Tyler all currently attend some form of out of district placement. Stan and Tyler see these placements as opportunities to receive more specialized instruction. Caleb and Louis, meanwhile, take a more critical stance on out of district placements and their role in determining student success.

Caleb has clearly developed ideas about his out placement's ABA approach and how it impacts students:

> we don't really do anything fun, I mean besides like earn breaks. I earn breaks every three worksheets I do. But like, it's nonstop worksheets so we don't get to go to like specials or anything, we don't have music class or anything, so like, so all I do is worksheets. All the kids in my classes are lower functioning, so I have to do all that little kid stuff like them. It's frustrating because I'm already used to that stuff, I've already done that stuff.

Caleb recognizes that his initial placement at this school matched his behavior profile at the time of entry. When Caleb started at this school, he regularly "threw fits" and would bang on tables, flip chairs, hide from staff, or destroy property. Caleb has since learned strategies for managing his frustration and is proud of the work he has done. In his words, "I just needed the skills." Now, he finds the use of ABA strategies to be cumbersome and almost demeaning to the skills he has obtained. From Caleb's point of view, his teachers don't seem to recognize that he has made this progress, and it impacts Caleb's future outlook because he is concerned that people will overlook him and not provide him with the opportunities he deserves. Namely, “this is my second year and it’s pretty tough. I’ve had some troubles, like my mom keeps saying I have a long way, I’ve come a long way from how I used to act and stuff. And I believe her, but this school is trying to keep me back.”

Moving forward, Caleb is hopeful that he will move to a transition classroom program that is designed to help students move from being in a highly restrictive setting to being back in a “normal school.” His mother has advocated for this change and Caleb feels he is ready.

Caleb is proud of what he has accomplished, yet also anxious that it is not enough. Caleb aspires to be a veterinarian and is aware that his current educational placement may not aid in meeting this goal:

> That’s why I’m at [this school] now, because of the autism and it’s on my IEP that I can’t go to a regular school. Me and my mom were talking, because my sister – nothing wrong with her. She’s just, she goes to a regular school… we went there for a thing to eat food… And I was just like, “I really want this, mom.” Cuz like the school and stuff, you know, seventh and eighth graders, I’m in sixth grade, so one more year and I could go there if I’m allowed to. And my mom was like, “I know, but you still need…” we’re still talking it over and I know I still need a little more help but I’m like, mom if you can just – she knows that I’m ready, but I’m just saying, I need to show those other people that I’m ready. Because my mom’s afraid… my mom can do it, but she’s just afraid to say, “that’s it, I

> don't want the IEP." If she says that, I can just go to a regular school. But my mom is afraid to do that because I still need a little help, and then I would lose all my services and stuff… I want to become a veterinarian, I'm high functioning, so I wanna… my dream school for high school is to go to a place called [the] Tech, which is technically Voc, because they have a veterinary program there, so my mom keeps telling me, like my whole family is saying "that's the perfect school for you." I know, I want to go there, but like if this keeps happening I might not be able to.

Caleb doesn't perceive his disability as a barrier to achieving his goals. Instead, it is the constraints of his school that are interfering with his dreams. Still, Caleb remains hopeful and is optimistic that with the support of his mother and his own advocacy for his hard work, he will be able to transition away from the ABA school and back toward "regular school."

TEACHING METHODOLOGY

Caleb also shared thoughts about ABA as an educational approach. At its core, Caleb is frustrated that the principles of ABA do not provide space for educators to understand children in the way they want to be understood:

> [My mom] used to work at a place where like, where I just said the kid wanted to go outside but it was raining, so he couldn't, but he threw kind of a meltdown because he like, he didn't know he couldn't go out because of the rain because they're not kind of showing him that, that it's raining outside and stuff. But like, he throws a fit and then they, all they do because it's kind of like ABA, they put him in a hold and bring him into

> the room, safe zone, safe room, whatever you want to call it, panic room, whatever… So, yeah, people really don't know how to treat kids. Like, what I would do is I would probably be like, well you can't go outside because it's raining. Not like, if he's being like, like throwing stuff around like I used to do, then yeah you might wanna put him in a hold, but don't like hold him so tight and stuff…Like don't just automatically assume that if someone's like really loud and they're yelling and screaming and like, they're mad and frustrated that you just need to put them in a hold and bring them into the room. That's not like, identifying why they're mad and stuff, you have to talk to them in what way they would understand.

Caleb calls attention and frustration toward the idea of best practice. Specifically, ABA is currently advocated for as the "best practice" for children on the autism spectrum (Turns, Ramisch, & Whiting, 2019). Yet, Caleb feels he has not responded to this teaching style and his frustration increases when it is used. Louis has also outwardly rejected ABA methodologies, resulting in him being asked to leave two school settings because he refused to comply to the school's methods. From the perspective of these boys, best practice does not mean best for every individual. Rather, the use of ABA suggests that educators have not taken the time to understand these children as individuals, nor have they listened to hear how the children want to be educated. Still, recommendations to use ABA continue to be made once an autism diagnosis is provided. This is a frustrating procedure that continues the oppression and discrimination of children with autism and leads to perpetual stigma.

CONCLUSION

In this section, details were provided regarding how children understand the education system and structures. Their perspectives reveal that children are aware of the decisions that adults make in efforts to educate children as well as how they transform the lives of children in both positive and negative ways. Based on their responses, children suggest that there is still a critical divide between what children view as helpful for their education and what educators believe is helpful. Further, there is a wide range of how services are provided and implemented, which can impact teachers' abilities to meet the needs of children. Children are grappling with how their disabilities change their educational instruction as well as how to reconcile the difference between best practice for large groups and best practice for the individual child. In the next chapter, I will provide further results exemplifying how children are working to situate themselves amongst other predetermined structures, namely those that create feelings of difference or otherness.

CHAPTER 8

HOW CHILDREN SITUATE THEMSELVES AMONGST PRE-EXISTING STRUCTURES

INTRODUCTION

Many stories shared by children were not easily captured by one singular code, but rather demonstrated the difficult-to-describe experience of children trying to understand the structures in society. Children shared about understanding that there are pre-existing expectations for what does and does not belong in their world as well as what measures are needed to integrate into structures. Just like meaning-making is not easily summarized in a few words, this concept is also difficulty to grasp. In other words, how do children learn of pre-existing societal rules and expectations? How do children respond to the discovery of invisible rules? Finally, how do children internalize these experiences and integrate them into their overall sense of identity?

In some interviews, stories related to stigma emerged. Stigma, as initially conceptualized by Goffman (1963), is the construction of socially designed concepts that help foster categorization. Goffman notes that visibility and the concept of "passing" are both features that impact the stigma developed around minority conditions. Further, feelings of being within a group or outside a group can interfere with how one develops his or her identity in relation to the stigmatizing condition. A significant critique of Goffman is that his discussion of stigma relies on the concepts of ability and normalcy, both of which cannot be easily defined (Love, 2013).

Hunt (1966) meanwhile identified stigma through the lens of lacking service delivery for people with disabilities and impacted relationships due to disability. Hunt argues that stigma is not as challenging for a person as much as it is a challenge to society and its ability to function inclusively (Love, 2013). Corrigan and Watson (2002) alongside Watson and River (2005) also highlight that when individuals observe instances where society is not inclusive, they start to develop stereotype awareness that can eventually morph into stereotype agreement and then self-stigma. The previously conducted research highlights processes within adults, but what the children in this study demonstrate is that the early inklings of awareness develop at a young age and start to set a cognitive foundation for how children eventually understand society's invisible rules.

INVISIBILITY

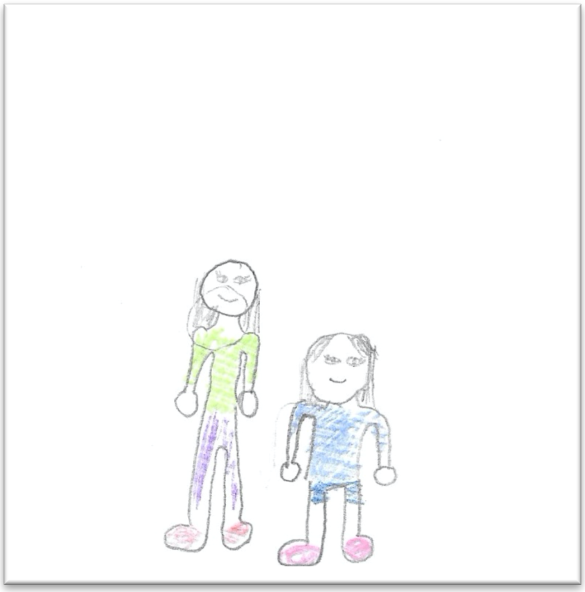
All 12 children were asked about the concept of invisibility and if their disabilities ever disappear or have no meaning. Each child had a different interpretation or opinion about what it means to have a disability be "invisible." Louis and Bob feel like their disabilities were invisible prior to their diagnoses. Before receiving the diagnosis, they felt like they didn't notice the disability at all, nor did others. Now that they have their diagnoses, they notice their disabilities all the time. In Louis's words, "[it never disappears.] Not in my thoughts!" Similarly, while Tyler refers to his dyslexia as a "hidden disability" because no one can see it, from his perspective, "I never feel it disappear. I always know it's there, it's always gonna be there, it's not ever gonna go away. It's in your brain forever."

More than half of the children indicated that they don't notice their disabilities or they disappear to themselves and others when they are engaged in distractions. Several children mentioned activities like gymnastics, recess, playing outside, and karate. In their minds, they are so focused on their preferred activities that they do not dedicate cognitive space in those moments to thinking about having a disability. Rose, George, Bunny, and Stan indicated that they notice their disabilities in school settings more than other settings. Stan and Bunny both also stated that it is hard to explain the idea of invisibility, just that sometimes their disability feels like it isn't there and sometimes it is very obvious to them.

Samantha and Izzy both grappled with how to describe the invisible nature of Leri-Weill's Syndrome, given that their height is not invisible. Samantha selected to try to depict this in her picture.

Figure 13

Samantha's Drawing



She stated, "[My disability is] happening inside my body, you can't really see inside of it. You can only tell because what it effects on the outside of my body. With this one, you just think that I am just short. Both Izzy and Samantha shared that this complexity is difficult at times, because they have peers comment on their heights or stature and feel conflicted about whether they should describe it as a disability.

Kylie and Caleb indicated their disabilities seem to disappear when they notice an absence of their disability symptoms or are not surrounded by reminders of their disabilities. Kylie, for example, feels like she does not display cerebral palsy or ADHD when she is sitting because she isn't dropping items, tripping, or becoming angry. She notices her disability more when she is with other children with disabilities or when she is in a situation where her symptoms are likely to appear, like frustrating situations or times where she might trip.

Similarly, Caleb notes that his awareness for his disability varies depending on the setting and people surrounding him. From his perspective:

> [I notice it] probably when I'm around others that are lower functioning, but when they're like, high functioning, I feel just like that I'm, like with my friends… I'm talking to normal people. Because they know how to communicate… But when I'm with the lower functioning people who don't really know how to talk and stuff, then I notice that I'm like, "oh, I'm one of them. I have autism." But again, when I'm with normal kids and stuff, I don't really notice that I have it, because I can talk and stuff, and I like the things they like, and all of that.

Together, the variability in responses regarding invisibility suggests that the idea of disabilities being hidden may need to be re-evaluated. While disabilities may not always be apparent to others, they have a different meaning to the children who are diagnosed with them.

DISCLOSURE

Secrecy

Two children suggested that it is important to keep disabilities a secret. Namely, both children indicated that they have only selected to disclose their disabilities to friends who they know will keep it a secret. To Bunny, she feels like her best friend understands her really well because her friend knows that Bunny is scared of being teased for her disability. So, she trusts her friend to keep her disability a secret. Tex, meanwhile, also indicated that she has only disclosed to her friends for the same reason: “I told them to keep it a secret, which isn't like a bad thing to have as a secret.” Interestingly, Tex found out from her friends that they were already aware of the traits of her disability, thus they were not surprised when she disclosed.

Disclosure by Choice

Many of the children indicated that they have disclosed their disabilities by choice. Tex, Izzy, and George all shared that they have told their friends about having their respective disabilities because they trust their friends. They also feel like their friends have seen them experiencing aspects of their disability, so they feel like their friends understand what they are talking about when the subject of disability arises.

To make her disability visible, Kylie has made a point to disclose her disabilities in a meaningful manner. In her homeroom at school, a different student is featured as the “Spotlight Student” each week. During their featured time, students complete a visual activity to describe traits that are unique to them and make them important to the classroom community. Kylie has not yet been the Spotlight Student, but when it is her turn, she plans to disclose her disabilities to her peers. More specifically, Kylie plans to answer the question “something you might not know about me is…” by responding “I have 33 people to help me.” After identifying the importance of these relationships, Kylie plans to describe her disabilities using the same words she used throughout the interview. After explaining her plan, Kylie also said “well, I guess you make 34.” To Kylie, it is special to have the chance to be heard, understood, and appreciated, especially when she is not feeling confident or comfortable with her own profile.

Disclosure as a Form of Advocacy

Disclosure as advocacy was a strong theme running through Caleb’s interview. Caleb’s initial reasoning behind coming to be interviewed was to tell his story and advocate for the world he envisions. His role model and strongest advocate is his mother. He sees his mother constantly advocating for him in school as well as advocating for the autism community in her work. From Caleb’s perspective, his mother strikes a healthy balance between advocating for the services that Caleb needs while honoring the independence that he deserves. She often does this by explaining autism to others.

The key to advocacy, according to Caleb, is speaking up, using your communication skills, and sharing a story, no matter how uncomfortable or difficult it is. This came through most strongly in Caleb’s storytelling. When asked to tell a story about a child with a disability, Caleb produced this powerful narrative:

> Um, let’s see, his name is Brian, he has autism… His parents are very understanding and know about this, but like the people he meets and stuff don’t really treat him well… people weren’t really liking him, and they were like, they were going online and posting stuff about him and saying he’s a freak and stuff, and then he just got really sad, and then his parents stepped in and were like, enough is enough!... They wanted to talk to someone about what is autism, and why do so many people not know, like

> how to treat people and why do they call them freaks and stuff. And then Brian, Brian told the person that he… wanted to know why, why people think he's a freak. And the person said that people think they're freaks because they don't know the person really well, and they think when they hear autism, they think of like, hand flappers and all that, like they're not really unique, but really autistic kids are really unique kids, or just autistic kids in general are very unique. And that, that he is, and then the person told Brian that he is very special and that her and him should do something about it. The End.

Caleb's story includes several negative experiences that Caleb did not describe as part of his own experiences, but his inclusion of them suggests that he is aware of how people in the autism community can be treated if they are not advocated for or supported. Caleb's story also alludes to some of the challenges that may lie ahead for him as he transitions to a "regular school." There is the possibility that his social life becomes more difficulty or complicated if he returns to the public schools; however, this does not seem to be a deterrent for Caleb and he is determined to advocate and remain resilient in the face of adversity or challenge.

Forced Disclosure

Four children spoke of instances where they have felt forced to disclose their disabilities. Samantha shared, "Like, in third grade someone said, well, I don't think you should be that part because you're so short. And then I said that I have a disability, and then the person, they realized." Samantha has also felt like she needed to disclose in situations where peers have made mean comments about her height. Similarly, George and Bob shared stories of disclosing their disabilities when peers have asked questions. For George, he feels like many children don't understand what dyslexia is, resulting in him needing to explain it. Students have regularly asked him why he leaves the classroom, to which George has responded, "I have dyslexia, I, it hurts me in writing and in reading and math, but other than that, I'm totally fine and I just learn a different way." Bob has similarly felt forced to disclose when peers have asked him direct questions. When peers have asked him questions, he has responded as follows:

> They were wondering why I had such a hard time writing and I said I have dysgraphia. I actually told a lot of people about it. When I was in fifth grade because I took a day off and they were all wondering why I was out. And so I just said, I was taking a test and I have dysgraphia.

Bob and George have been put in a place where they have needed to disclose in efforts to advocate, but both boys feel this hasn't been a negative experience. Rather, these situations have been chances to educate others on disability and learning differences.

Differently, Tyler has chosen to disclose his disability to a small group of friends that he feels like he can trust, but in one instance, Tyler was forced to disclose his disability in efforts to help his friend understand him and play with him on a play date. In his words:

> My friend John is a big reader… they like having barbeques at their house, he would want to read books the whole time, like waiting for dinner, then after dinner he'd want to read some more. I didn't want to, so I would hang out with the younger kids that did, they don't like reading as much as

> John does… so at one point I told him [I have dyslexia] because I could not deal with sitting there reading, looking at a book, all day, for like 2, 5 hours, like, it felt long, very long… I said, why don’t we do something else? You have plenty of fun stuff. He said no, I want to keep on reading.

Tyler presented this story in a calm, even tone, but with hints of frustration, sadness, and loneliness. In this instance, disclosure did not serve to advocate for Tyler’s needs. Rather, it placed him in a position of feeling left out and isolated.

INSPIRATION PORN

“Inspiration porn” is a term coined by Stella Young as part of a TED talk where she discusses her experiences as a woman in a wheelchair. Young speaks to the idea of having people with disabilities in the role of inspirer rather than in everyday, visible roles such as a teacher or doctor (Young, 2014). In practice, inspiration porn is found in the form of widely distributed images on social media, the holding up of people with disabilities as motivators, and the overall attitude that disability is a negative condition that people must overcome. This perpetuates stigma toward individuals with disabilities, as it reinforces the idea of being an ”other” and sets an expectation that people with disabilities are here to inspire non-disabled individuals. According to Young, the use of the term “porn” is deliberate in efforts to explicitly show that people with disabilities are objectified for the benefit of others.

Inspiration porn was rampant in discussions with children about their futures and disability. In some places, inspiration porn was helpful. Bob and Samantha have found inspiration by stories of people with disabilities reaching high achievements. For Bob, he is inspired by a book that describes people with disabilities becoming famous inventors. For Samantha, she is motivated by knowing of a famous actor with epilepsy:

> I want to be an actor. So I know since Cameron Boyce was a really good actor that I could be one. Since my ADHD, my epilepsy, when I'm acting I'm always doing something so my ADHD doesn't really matter. And I don't really care about height because I know there's gonna be some person the same size as me.

For Samantha, she can look to the example of someone else who was extremely successful and who was an advocate for the epileptic community. This gives her hope for her own future and inspires her to pour her energy into the passion of acting.

George, Caleb, Louis, Bob, and Tyler shared similar sentiments that people with disabilities think differently, leading to higher performance in careers and school. Louis and Bob both identified having stronger brains for logic due to their disabilities. Bob described his thinking as highly logical, resulting in complex problem solving skills. Bob further indicated that due to his disability, he is more likely to achieve financial wealth and a high position job because disabilities make individuals unique. George and Tyler, both boys with dyslexia, used similar language to describe famous and powerful people who have succeeded due to the thinking patterns of people with dyslexia. Tyler stated, "You can think differently, with dyslexia. That's what all the people do who are famous. It's a long conversation, but somehow all the famous people who have dyslexia and they run companies… because they think different than other people." George specifically described Einstein's way of thinking, sharing "Albert Einstein, he had dyslexia. And he overcame it, they found out once he was dead, but, like I think it will help me with very good engineering in my head because that’s what my mom says, I… have an engineering brain.”

I feel conflicted about analyzing the presentation of inspiration porn in the stories told by these children. From one perspective, many of the children who shared about disability as inspiration seemed genuinely moved and excited by the idea of reaching celebrity or success due to disability. For these children, having idols with disabilities serves to motivate and increase positive outlook. I can understand why the adults in these children’s lives have provided examples of successful people with disabilities. Yet, from an alternative perspective, I wonder if these children have been sold stories that don’t match with their abilities or that have actually served to disempower these children. The people that were described as idols were not necessarily successful because of their disabilities. Rather, they were successful AND they happened to be disabled. I puzzle with how to reconcile the need to inspire children to achieve while also remaining realistic and finding characteristics outside of disability as sources of inspiration. Further, I wonder how we can help children find themselves inspiring, without the pressure of society trying to raise them up as sources of inspiration.

STEREOTYPE AWARENESS

In the self-stigma model, one must develop a negative belief about oneself and then agree with the belief or have a negative reaction to it (Corrigan & Watson, 2002; Watson & River, 2005). For these participating children, stereotype awareness permeated stories and responses. It felt like practically everything stated could have been re-stated as an “I statement” to describe the internal turmoil of many of these children. In other words, it is easier to say “words are dumb” than to say “I’m dumb.” It is also easier to say, “ADHD means it’s hard for me to control my emotions” than it is to say “I don’t know how to control my emotions.”

While never said directly, many of the children spoke of characteristics of disability that could be described as stereotypical or an overgeneralization. It often felt like children were trying to minimize the behaviors or cognitive characteristics associated with their disabilities as though they were something to be ashamed of. Several children with specific learning disabilities suggested an underlying feeling of stupidity or injury. This undercurrent glimmers across perceptions of school, learning, and approach to academic tasks. According to Tyler, school is “boring,” “no fun,” and “dumb.” Sight words are “struggle words.” Words are “dumb, stupid, so I just want to get [them] done with.” According to George, having a disability “hurts him in reading and math.” According to Bob, when he struggles to write, he notices that teachers think he’s just “bailing out” and not trying hard enough. The stories these children told cry out to exemplify the contrast of what it means to not care on the surface while also caring deeply. The multiple examples from a wide swath of stories feels like an important message: these children are looking for someone who can fully comprehend their learning styles as well as the energy it takes to manage in environments not built for their brains. Further, they are looking for adults to hold these things with respect and dignity, rather than focusing on changing them.

Girls and Stereotype Awareness

Limited research is available about the experiences of disability in relation to gender. There is a gender difference between girls and boys and their level of self-concept, with girls presenting with higher temperamental and moral self-concept and lower physical self-concept (Kulshrehtha, 2016). Many of the girls talked about their disabilities in very matter-of-fact ways when defining them, but then gave inklings of defeat or embarrassment or shame when telling more specific stories. It was peculiar that it was all the girls who spoke in this manner, causing me to pause and ponder the implicit exchange of assumptions regarding disability and gender. Whereas the boys seemed to use disability as a surface level source of inspiration at times, the girls tended to identify more with the negative stereotypes associated with disability.

Samantha, for instance, had two strong stories about instances where peers have bullied her. In her first story, she spoke of a boy who makes fun of her for being short. In her second story, Samantha shared that a peer had found out about her growth hormone shots and had told another peer, who then yelled out this information on the bus for everyone to hear. Instead of being angry, Samantha shrugged her shoulders and looked down. I couldn’t quite make meaning of this behavior. On the one hand, her behavior was a reflection of the emotional rawness that this event carried. On the other hand, I wanted to ask what Samantha made of this event. I wanted to know if Samantha saw this as an opportunity to build resilience and strength in the face of bullying, or if she found it to be confirming of her disability as a form of “other.” Returning to the idea of self-stigma (Corrigan & Watson, 2002; Watson & River, 2005), I could see this event as leading to self-prejudice if she sees the event as a confirmation of negative stereotype associated with disability. From this interpretation, it suggests that the way that adults respond to situations of bullying can have an impact on how children understand stigma and internalize it or apply it to other scenarios.

Rose and Bunny shared sentiments that disability is something that should remain secret or that should not be discussed because it is “no one’s business.” Bunny, in particular, was insistent that the people who understand her disability best are the people who keep it secret. When I asked her why it needs to remain a secret, she didn’t expand on this notion, rather stated “I don’t know. I just want it to be a secret.” Again, the idea of self-stigma emerges here. Both Rose and Bunny embrace the stigmatizing idea that disabilities mean that someone is “less than” or “different,” but in a negative way. I’m curious as to what events or conversations inspired this sense that disability should remain a secret. In the case of invisible disabilities, self-stigma can result in difficulties associating with others within their disability group, which makes it more difficult to access the protective factor of group identity (Corrigan & Watson, 2002; Darling, 2013). For Rose, Bunny, and the other children who spoke about secrecy, I wonder if making the invisible visible would result in differing feelings of self-confidence and identity.

CONCLUSION

This chapter sought to exemplify instances in which children experienced stigma either directly or indirectly, as well as how they conceptualize the existence of societal expectations and rules. In some instances, stories suggested an underlying awareness that being an “other” is less accepted or misunderstood. Other stories directly cited situations in which children were discriminated against or treated differently. Children have responded to this knowledge in a variety of ways in efforts to make sense of their experiences. Together, this chapter highlights that young children are aware of stigma, even despite best efforts to protect children or inspire them to see difference as solely positive. These concepts will be further integrated into a discussion of how childhood perceptions of disability can be wholly conceptualized and the implications of developing this understanding.

CHAPTER 9

DISCUSSION

INTRODUCTION

I entered this research process with several pre-existing assumptions. First, I predicted this research would demonstrate that children are able to speak to higher level concepts regarding disability. This prediction was formulated through several experiences speaking to children in the counseling setting, where they explored abstract emotions and complex thinking patterns related to having a disability. Second, I predicted that children would focus on the medical symptoms of disability. This assumption is a result of hearing children describe disabilities to others as well as seeing how educators and families teach about disabilities in classrooms or other settings. Finally, a third assumption was that children would have concrete examples of how children with disabilities are treated differently, revealing an emerging understanding of stigma.

Findings from this research confirm aspects of these assumptions as well as reveal that the disability identity process is rich and complex. The following discussion will explore the key findings of this study in relation to pre-existing assumptions and the literature regarding the subject. The first key finding is that children can speak to different models of disability, which compliments the current discussions within the disability studies community. The second key finding is that children are able to verbalize an abstract understanding of disability and the factors that contribute to developing self-concept regarding disability. This counters self-concept theory that suggests that children in mid-childhood tend to use black and white understandings to conceptualize their world. The final key finding is that children display an early awareness of ableism and stereotype. This means that the foundation for stigma awareness and self-stigma development emerges during childhood, a finding that is not yet discussed in literature regarding these areas.

MODEL OF DISABILITY

The gathered data reveals that children are able to talk about disability in a sophisticated and nuanced manner, similar to the dialogues in the disability community. Some children, like Kylie, Tex, Samantha, and Louis, spoke to the checklist like features of the medical model of disability, highlighting key behaviors that suggest difference and difficulty. This style of response aligned with medical definitions of disability, which state that impairments negatively impact a person's ability to access features of their world, such as a school or business (Darling, 2013; Davis, 2015; Garland-Thomson, 2019; Nielsen, 2012). Meanwhile, children like Caleb, Tyler, and Bunny, contributed ideas about how their disabilities are exacerbated by social expectations and difficulties, highlighting the social model of disability which posits that society oppresses people with impairments and treats them as a minority (Baglieri & Shapiro, 2012; Brune & Garland-Thomson, 2013; Davis, 2002; Hehir, 2002; Lalvani, 2015; Oliver, 2004).

Just like the dialogue happening between medical professionals and critical disability theorists, children experience the tension between prescribing to solely a medical model versus social model of disability. When speaking solely to the definition of disability, the majority of children named symptoms or other behaviors that suggested the use of the medical model when concretely describing disability. However, further questions reveal that children prescribe to much of what the social model of disability suggests. Children in mid-childhood have a growing awareness of what systems are in place in their worlds that encourage a sense of normalcy as well as how they fall outside this expectation. Notably, Lalvani (2015) discusses that disability studies is driven by Vygotsky's socio-cultural theory, indicating that the understanding of experiences with disability cannot be separated from the context in which they occur. This was a consistent theme for children as they discussed how they experience their disabilities in settings like school, social activities, and home. In particular, children see school as a location in which they are constantly compared themselves to others and where teacher behavior is providing a constant feedback loop about the negative features of being different.

Together, the way children conceptualize disability is best conceptualized by Glover's theory of binocularity (Parens, 2017). As discussed within the literature review, Glover's theory posits that multiple lenses can be used to consider the different facets of an individual, resulting in both the consideration of objective symptoms and the consideration of how these subjectively inform behavior, social interactions, and feelings of acceptance. Parens specifically argues that using a binocular approach allows for the flourishment of individuals with disabilities by simultaneously embracing limitations alongside how disabilities enhance the human experience. Children approach the subject of disability by recognizing areas of difficulty while simultaneously considering the multiple life options ahead as well as the strengths they have obtained through their experiences. This theme most often emerged when children were asked what they want other people to know about disability. More often than not, children wanted others to know that having a disability can be hard, but it does not stop them from pursuing their dreams or behaving like "any other kid." In other words, children see how they can flourish despite a predominantly ableist message about how disabilities function in society.

SELF-CONCEPT

Harter (2012) conceptualizes self-concept as how an individual measures competence across social, physical, and academic domains. In Harter's work, she notes that mid-childhood is marked by several developmental changes, including abilities to think abstractly about one's experiences as well as identify attributes that are similar or different to peers. They become more focused on competence and are able to hold both positive and negative attributes simultaneously. In the literature, measures self-concept in mid-childhood for children with disabilities are inconsistent in their findings, with some results indicating decreased self-concept compared to same aged peers and other research finding no difference. This was often dependent on the type of disability. For instance, children with learning disabilities and social skill deficits often indicated decreased self-concept in the areas related to their disabilities (Bear, Minke, & Manning, 2002; Chapman, 1988; Gadeyne, Ghesquiere, & Onghena, 2004; Gans, Kenny, & Ghany, 2003; Kloomok & Cosden, 1994; Martinez, 2002; Rothman & Cosden, 1995; Wei & Marder, 2012).

The data compiled in this study further adds to the inconsistency in findings, as the qualitative information gathered highlighted that children's self-concept is broad and variable depending on a wide breadth of factors. On the surface, children seemed to appraise themselves similarly to how Harter (2012) describes, with some areas being stronger than others and some areas being more impacted by disability than others. Where the children in this study differ from the numerical measurements of self-concept cited in the literature is their exploration of the many conditions that result in the fluctuation of self-concept, such as peer interactions, school intervention, and how disability is defined. These children display an awareness of the idea that strengths and weaknesses present themselves differently depending on a variety of factors, and thus a global statement regarding self-concept in children with disabilities is not likely obtainable. Rather, supporters of children with disabilities can be aware of the quantitative data indicating inconsistent self-concept while also placing greater emphasis on individuality of the children in front of them.

Another aspect and critique of self-concept was revealed through the research process. Namely, self-concept structures as they exist now suggest that self-concept is a measurable, fixed feature of identity that requires intervention directly within the child with decreased self-concept. This mindset mirrors that of the medical model of disability in that the problem or deficit is located within the child. If the paradigm is shifted to instead consider the social model of disability, self-concept measures are incomplete in how they reflect children's development. From the lens of the social model, self-concept is perhaps less important than an overall consideration of identity and how it changes or develops depending on how one views disability, particularly from the viewpoint of the person with the disability. In other words, "[it] is crucially important that people are not excluded from the processes of theorising [sic] their own lives and experiences" (Boxall, 2019, p. 205). This better allows for an inclusive social model of disability that considers the constructs that are valuable to the individual. One approach to shifting to a more inclusive identity model is posited by Cameron (2014), who suggests that "the affirmation model [can be used] as a tool for identifying ways in which people with impairments are required to become disabled people in everyday interactions and as a tool for resilience in the face of day-to-day disabling encounters" (p. 24). In short, self-concept is merely one consideration, and thus the conceptualization of how children understand disability should be expanded to be more inclusive and considerate of the fluidity of development and identity.

STIGMA

Children additionally provide insight on stigma at an earlier age than has been discussed in the literature. Goffmann's (1963) original work namely focused on visibility and passing within the "normal" community. In his discussion, Goffmann highlighted the concept of in-group and out-group attitudes, citing that people with stigmatized conditions are aware of how they are clustered into a specific group given their symptoms or traits. Children confirmed the presence of these attitudes, providing examples of instances in which they sense their disabilities or sense how their disabilities make them fall outside the definition of normal. In-group association was important to children, with many identifying the importance of connections with family members, classmates, and other friends with disabilities.

Different from Goffmann's definition, however, children seemed to express a more fluid emotional understanding of being an "other." Children's emotional responses ranged from being defeated and frustrated regarding disability all the way to feeling inspired, encouraged, or determined. Children did not express an outright desire to "pass" as normal, instead suggesting that they are able to move fluidly between conditions. Further, several children felt like they could disclose their disabilities to peers without the likelihood of stigma. The children who seemed to be most impacted by stigma were those who had experienced drastic differences between the symptoms of their disability and the environmental conditions within school and other community settings. Further, most children indicated that feelings of stigma emerge in interactions with adult-controlled environments, suggesting that there is some part of development from childhood to adulthood that unfortunately fosters deeper divides between those who are considered “normal” and those who are considered “other.”

Children also appeared acutely aware of the inadequacies or mismatch of services to children’s needs or desires, similar to Paul Hunt’s (1966) discussion of disability services in early discussions of disability stigma. Children who critiqued their schools shared insight that classrooms are not always conducive to individual desires and needs. Rather, classrooms continue to cater to global understandings of disability and intervention instead of evaluating individual needs. While the IEP process is meant to be individualized, children expressed an awareness that their services and placement seem governed by bigger systems and expectations. Further, students suggested that adults in the decision making chair seem to focus on their own perspectives, rather than thinking about how children want to be treated. There is still a great area for continued growth in the area of radical empathy.

In Hunt’s (1966) work, additional contributors also suggest that what is most impacted by disability is the quality of relationships. Children spoke to the quality of relationships; however, they suggested that the preponderance of relationships were supportive and encouraging of differences. Further, children found opportunities for deeper relationships with family or other community members with disability, indicating an important finding that children seek to belong to a community where individuals understand the experience of disability. The relationships that seemed the most strained were those that existed within the context of normalcy or the expectation of passing, namely school and more distant relationships with peer and family.

Corrigan and Watson (2002) highlight that self-stigma develops through a process of becoming aware of stigma, then agreeing with it and eventually applying the stigma toward oneself. Eaton, Ohan, Stritzke, and Corrigan (2016) describe that self-stigma develops in parents of children with mental health disorders as they engage in their understanding of their child's condition and start to blame themselves for their child's condition and difficult experiences. Children did not speak of explicit feelings of self-stigma; however, their definitions of normal and difference highlighted emerging senses that not only are they different, but that being an "other" has some kind of meaning in our society. Further, when asked to apply this understanding to their futures, children cited inspirational stories that suggest that within the window of mid-childhood, children counter the possibility of self-stigma with stories that have been shared about others overcoming disability. Countering this narrative, however, were fears regarding future difficulty and an awareness that disability may have lifelong impact. Together, the collected data highlights that the model of self-stigma development can be generalized to younger populations, with the understanding that children are influenced by the stories they are told alongside their awareness of their own difficulties.

STUDENT-TEACHER RELATIONSHIPS

Findings of this research reveal the specific concerns children have about their school environments, including the relationships that children develop with their teachers and how these relationships are informed by broader constraints including class size, methodology, and teacher knowledge. This contributes to literature discussing the importance of teacher-student relationships and the pivotal role they play in the development of children. Claessens et al. (2017) indicate that the context of a relationship between a student and a teacher is important, and often interactions between a student and teacher are impacted by the need to engage in behavior management or other educational strategies. This has implications on teacher wellbeing and rates of burn out. According to Claessens et al., many positive relationships occur outside the classroom due to the decreased level of stress teachers experience outside of their classrooms. Related to the current study, children spoke of interactions they have with teachers inside the classroom, suggesting that these interactions are not always positive or are impacted by a variety of contextual factors. The current study adds to Claessens et al.'s findings by indicating that children are aware of the impact of classroom factors to relationships, and thus both students and teachers experience classroom stress that informs how relationships are fostered. Moving forward, educators can consider the presence of classroom stress and consider how relationships can be fostered across a variety of settings, particularly those where students feel more successful or competent.

The current research revealed that students rarely spoke of positive relationships between themselves and teachers, a critical finding when compared to previous research conducted regarding teacher-student relationships. Prino, Pasta, Gastaldi, & Longobardi (2016) have indicated that children with special needs experience more difficulty forming positive relationships with teachers. Meanwhile, this finding in the mid-childhood age range is particularly of interest given the previous research conducted regarding student-teacher relationships and academic trajectory. According to Hamre and Pianta (2001), students with positive teacher relationships in kindergarten were measured to consistently have more positive outcomes up through eighth grade when compared to same-aged peers who had difficulty forming relationships. The research participants from this study indicated difficulties in their relationships with teachers currently, but several children also highlighted difficulties with teachers in previous school years. In combination, this current research affirms the difficulties with forming relationships, and also highlights that these students may be at increased risk of school difficulties given the challenges of teacher-student relationships early on in school.

Previous research also indicates the importance of teacher-student relationships to performance in school as well as overall health and wellbeing (Conners, Miles, & Pope, 2014). Further, students in high-performing schools increasingly require support, with previous researching indicating that students in these settings are better protected as they increase the number of relationships with teachers, versus having a single positive relationship with an adult. This stresses the necessity for all educators to consider the importance of fostering positive relationships, in efforts to have not just one positive relationship, but many.

Similarly, research participants also highlighted variability in how they understand their school's methodology and organization, with some children highlighting success in inclusion and other children highlighting success in smaller, more specialized settings. This is consistent with Buli-Holmberg and Jeyaprathaban's (2016) findings that creative planning according to student's individualized special needs leads to the most positive outcomes. Moving forward, this has implications on how educators plan their classroom design and organize students into learning groups.

CONCLUSION

In whole, this research unmasks the idea that the phenomenon of disability is complex and often unexplored in children. When children are consulted and given the opportunity to voice their stories, a deep understanding of disability and its role in society is revealed. More specifically, children are able to speak to the variability in self-concept alongside the need for multiple definitions of disability and a better discussion of stigma at earlier ages. In the next section, concluding thoughts about this study will be provided, including a review of the limitations of this study and implications for future practice.

CHAPTER 10

CONCLUSION AND REFLECTIONS

The goal of this research study is to develop a phenomenological understanding of childhood experiences with disability in efforts to add to the literature that already exists regarding self-concept in children with disabilities. Through phenomenology, this research seeks to illuminate how children conceptualize the disability construct, make meaning of their experiences, and grapple with stigma. While other sections have reviewed the literature, defined methodology, and explored findings, this chapter is meant to offer concluding thoughts and reflections to the research process, including suggestions for future research and implications for applied practice in both education and psychology.

SCHOOL PSYCHOLOGIST CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

This research has direct application to the field of school psychology and its practice across the domains of assessment, counseling, and consultation. According to the National Association of School Psychologists, “School psychologists are uniquely qualified members of school teams that support students' ability to learn and teachers' ability to teach. They apply expertise in mental health, learning, and behavior, to help children and youth succeed academically, socially, behaviorally, and emotionally” (Who are school psychologists, n.d.). This research reveals that school psychologists need to be aware of how children perceive their disabilities, both for the purpose of supporting a student’s ability to learn as well supporting teachers as they seek to successfully educate and advocate for all students.

Overall, the data gathered in this study highlight that school psychologists and educational professionals need to build upon their ability to consider children as unique individuals. Many of children's responses highlighted that they do not feel understood or people do not take the time to consider their perspectives. This results in children questioning practices that impact their education and future. Specific to the IEP process, educational professionals should consider ways of individualizing portions of the IEP by asking children what accommodations they need, what strengths they want stressed, and what subjects in school matter most to them. While children are not invited to their IEP meetings until age 14, there are ways that children can be included in the decision making process. This can include having children create their own concerns statements or vision statements, or having them write a paragraph to be included in the student evaluation summary so their experiences and personality are better captured. Further, results suggest that children are not as focused on academic progress as they are on having experiences that build their identities as individuals. It is important to children that IEPs balance the need for academic progress alongside the maintenance and encouragement of confidence, pride, and strengths. Further, it is important to children that their IEPs are read and understood, suggesting that teachers need better support to read, understand, and implement IEPs from a developmental and empathic perspective.

In the area of assessment, this research suggests that school psychologists need to be aware of how children perceive testing practices and what messages are communicated via the testing process. While testing manuals provide basic guidance to the testing process, including the suggestion to refrain from using words like "test," children are attuned to the purpose of assessment. Further, children are aware of how they struggle, thus the purpose of testing is not a secret to children. For school psychologists, consideration should be given to how testing is explained. Further, children are curious individuals who would likely benefit from explanations of their learning profiles, testing findings, and recommendations. This could include the creation of child-friendly reports or providing children the opportunity to ask questions about their results. While these practices are more common for older students, the data compiled in this study suggests that these conversations can occur at ages younger than previously thought.

Regarding counseling, ongoing conversations should be held between parents and school psychologists or other counseling professionals in efforts to generate a mutual understanding of how the parents want the child to understand disability. Further, school psychologists should support parents in understanding how to explain disability to children. School psychologists should be aware that parents are going through their own process regarding the identification of their child with a disability; these parents need guidance and support just as much as children. Specific to the discussion between parents and children, these conversations should include a balanced representation of medical symptomology so students are aware of their weaknesses, as well as a discussion of how disabilities are and are not supported at school, at home, or in the community. The purpose of this latter discussion is to help students build meaningful advocacy skills. This also uniquely sets up children to become future advocates for the disability community. These conversations can include more than just the parent and the child. In some instances, it may be more beneficial for the school psychologist or other trusted adult to explain the disability. These conversations should also be ongoing, particularly as services change, children make progress, and children encounter stigma or support that informs how they feel about their disability. It is also recommended that school psychologists consider how to offer counseling support on a short term basis for children recently identified with disabilities who need help understanding changes in schedule, changes in curriculum, and addition of teachers or interventionists to their routine. Again, the purpose of this short term support would be to develop advocacy skills as well as foster an additional relationship for the child that can be seen as a protective agent in the possible case of bullying or discrimination. This should be considered on a child by child basis, knowing that what children highlight most within this study is the importance of being considered an individual.

In the area of consultation, school psychologists are adequately prepared to offer professional development and consultation to teachers that aids in the development of supportive practices. The participants in this study suggest that teachers need to be better aware of stigmatizing behaviors and practices, including how they set up their classrooms, talk about differences, and use non-verbal behavior. Children take in more than educators realize, including the recognition that teachers are often burdened with increasing instruction demands, larger class sizes, and the need to follow specific methodology or complex IEPs. Just like children need time to individually reflect, there needs to be opportunities for teachers to reflect specifically on how their teaching practices perpetuate stigma and generate negative meaning making. This is likely to increase teachers' consideration of individual needs and profiles, as well as instilling higher levels of confidence as teachers interact with children with disabilities.

Finally, the data and analysis gained through this research highlights the importance of school psychologists engaging in ongoing reflection regarding ethical practice and adherence to field guidelines. Much of what the children described in their interviews as negative experiences in school are in direct opposition of what is ethically outlined by the National Association of School Psychologists. Namely, NASP supports the involvement of children in the decision making process and the importance of allowing children “to choose for themselves whether to disclose their private thoughts, feelings, beliefs, and behaviors” (National Association of School Psychologists, 2010, p. 5). School psychologists also promote healthy environments for students, including working to prevent social injustices that affect children and schools. In their work with children, school psychologists should consider how to support children as they prepare to understand their individual profiles, advocate for themselves, and disclose when necessary. These ethical guidelines should also be clearly reflected in how school psychologists speak for children in the context of consultation, assessment reports, and IEP meetings.

BROADER EDUCATIONAL PROFESSIONALS

There are also implications for educators in the role of teacher or administrator. Special education teachers, in particular, can learn from this research and apply the implications to professional practice. In general, it is of critical importance that teachers reflect on the structures that allow them to have meaningful conversations with children. The traditional education model suggests that teachers should be spending the majority of their time delivering specially designed instruction; however, their impact is broader than just the curriculum. Teachers have the opportunity to deliver positive messages about disability and to foster safe spaces to explore disability identity. They do this through both verbal and non-verbal behavior, as well as the way they structure their groupings both inside and outside the classroom.

Children provided critique regarding social grouping of students with disabilities, suggesting that the placement process of students with disabilities should be monitored and regularly evaluated. While some placements are recommended as best practice given disability profiles, this research indicates that individual child needs should be given first priority when grouping children. These discussions also suggested that children are aware of their needs and could perhaps even be included in decisions about how they would be grouped with other students.

Further, several children advocated for the need to have a community built of children with like experiences with disability. Educators can more critically consider how disability is discussed in classrooms so the topic is safe for discussion, disclosure is welcome but not required, and so students feel like part of a community. This may include opportunities for children to connect across grade levels or classrooms in efforts to build a community of children with the same disabilities.

Specific to disability discussions and disclosure, special education teachers also need to be aware that they can provide valuable support for children as they come to understand their disabilities and learn how to disclose. Special education teachers can describe the difference between impairment and disability to their students, as well as how disabilities emerge differently depending on the environment. Further, teachers can explain the reasoning behind methodologies, which can help students understand why their instruction appears in a certain way or why certain techniques are being used. Through these conversations, special education teachers allow for children to advocate for what they need and take ownership of their education. These discussions are not only empowering for children, they can also reflect that teachers' want to support the child's identity development journey. In other words, special education teachers have countless opportunities to ally and advocate with children, and perhaps need support in developing the vocabulary and comfort in having these conversations with students.

RESEARCH SIGNIFICANCE

This research is a significant contributor to the literature in that it reveals a novel perspective that is not readily accessed. This research can be thought of as an opportunity to create a foundation for future phenomenological exploration as well as a foundation for possible future quantitative research. Namely, this research confirms the hypothesis that children have significant information to contribute to the disability studies field. While children have been historically understood as naïve or underinformed, this research counters that narrative by revealing that children will speak to higher order concepts when given the opportunity. Furthermore, children are able to engage in the ongoing dialogues regarding disability construct and stigma, including critiquing currently used definitions and practices. For the field of disability studies, this suggests that work needs to continue to address the lack of childhood voices within the literature.

Related, the methodology utilized for this research is significant in that it is a unique approach to gathering data regarding children. The use of interviews as well as drawing and storytelling is different from the research that instead utilizes quantitative measures like third person rating scales or test scores to make determinations and recommendations for children. Drawings and stories both added to the interview process in that it better accessed childhood ways of thinking, and allowed for creativity alongside reflection. This research sets a methodological foundation that can be utilized in justifying future qualitative research regarding children with disabilities.

SOCIAL JUSTICE SIGNIFICANCE

A strong reason behind the conduction of this research was to illuminate childhood experiences in efforts to push against childism and the societal assumptions that children have little to say about significant experiences. This study completely turns these assumptions upside down, showing that children are able to explore complicated topics when given the opportunity, time, respect, and sensitivity. Moving forward, researchers should take the time to consider what value is added to research when including the child’s voice as part of the process. Additionally, this research challenges the breadth of literature that totes ableist perspectives regarding disability. As is discussed by the children, an approach that considers both the medical and social models of disability helps challenge dominant values that disability is fixed and negative. Children highlight that for individuals to practice in a socially just manner, they need to think of how their job descriptions and job structures promote ableism, as well as how this mindset can be challenged.

Finally, this research also highlights the importance of considering age not just as a construct, but instead a valuable variable. The unique aspect of this research is that it is done with children, otherwise thought of as a vulnerable and highly influenced population when it comes to ethical research practice. When done effectively, research with children promotes ethical standards by honoring this group of participants and showing them the respect and dignity they deserve.

LIMITATIONS

Alongside the significance of this research are limitations within research design and execution. The sample recruited for this study is homogenous in nature, meaning that the findings may not generalize to significantly differing settings or groups of children. Namely, this sample was compromised of all White, middle class children. These children were not able to speak to the constellation of strengths and challenges that emerge at the intersection of race, class, and educational access. It is a possibility that if this study were to be replicated in non-White populations or in impoverished populations, different results would have emerged, particularly regarding access to services and stigma as well as resiliency factors, mindset, and strengths. Further, this study was conducted in Massachusetts: given the difference in educational law across states, it is likely that discussion of school-based services would look different if this study was to be conducted in different areas of the country or in other countries.

Next, all the children who participated have access to individualized education services through IEPs, and many students have additional access to private supports. This is a group of children who carry educational privilege compared to children who are not yet identified with disabilities or who do not receive quality services given their district, financial standing, or other risk factors. It is also noted that several children who participated in this study are supported through the IEP process both by their parents as well through the support of educational advocates. In this sense, these children are well protected and may not have had as much exposure to heightened stigma or challenges within school systems.

Related, this group of children is unique regarding their familial supports and disability awareness. In order to participate, all 12 children had to have parental consent prior to providing assent. This means that parents had to be willing to expose their children to vulnerable conversations of difference, disability, and difficulty. This theme was confirmed in many of the email exchanges between myself and parents, with many of them using phrases like "I want him to tell his story," "this makes me think of 'nothing about us without us,'" and "he's perfect for this, he's such a helper." Further, the parents involved in this study had to have been willing to tell their children of their disabilities, something that not all parents are comfortable with or ready for when their children are in middle childhood.

This sample is also uniquely heterogenous in its collection of disability types. This was intentional, as the goal of this study is to demonstrate childhood understandings of the disability construct, rather than their understanding of specific disabilities. Due to the heterogenous mix of children, however, this research may not always fully represent specific subsets of disabilities or the experience of dual diagnosis. This limitation emerged, for instance, in how children with autism speak about disability definition versus children with other disabilities. Further research with a smaller subset of disability types is likely to reveal further information regarding disability communities.

Finally, phenomenological exploration, alongside the use of hermeneutics, relies on the interpretation and meaning-making of the words used by the participant. A possible critique of this research is that the data used in this study did not allow me to go as in-depth regarding intersectionality in efforts to generate a full, robust understanding of disability and surrounding factors. To challenge this consideration, I believe the way we educate children regarding intersectionality is perhaps the area to be more deeply explored and researched. From my experience, I have observed that the implicit nature of intersecting identities and marginalization are not taught in a critical, meaningful manner, and thus children lack the words to express the complexity of these experiences. This is especially true for younger children, given the mindset that younger children are not socially prepared to have uncomfortable discussions of race, class, and gender, even if they are living those experiences. For children to be able to flush out the phenomenological experience of disability, they need to have been taught the language and meaning behind intersectional features of identity and how a variety of societal structures can inform feelings of power or disempowerment.

RECOMMENDATIONS FOR FUTURE RESEARCH

This research is considered an entry point into several research possibilities. Of greatest importance is replicating this study with a broader sample of participants. As discussed in limitations, the purpose of replicating this research would be to gather additional data across a more diverse population in efforts to increase its generalizability. Furthermore, replicating this study would provide the opportunity for additional children to have their stories heard and celebrated. As the methodology of this study is meant to promote listening to children’s voices and incorporating childhood voices into modern disability studies debates, replicating this study will continue to add to this conversation.

To build on this study, data should be collected across a wider age range, including children in pre-adolescence to later adolescence and early adulthood. This research would allow for the possible development of a stage model or more deeply developed theory of self-concept and disability awareness. This would also provide further guidance for educational professionals when they are working to support students entering into key stages of development and transition. Similarly, longitudinal study would also provide essential data to understanding how the definition of disability changes over time based on personal experiences and school-based practice.

Moving forward, this research could also be advanced by developing a disability perception scale using the data collected from this study and its replication. The purpose of a disability perception scale would be to aid in intervention planning for children recently diagnosed with disability, as well as those children who are experiencing emerging signs of maladjustment related to the experience of being identified with a disability. The development of a scale would also support future research regarding self-concept in that it would provide additional tools to be used in quantitative-based or mixed methods research.

REFLECTIONS AS RESEARCHER

The research process has further confirmed my desire to be a vocal advocate for the needs and desires of younger children facing heavy topics, including disability and social injustice. As I engaged with the data, increasingly I felt passionate about representing these children accurately and with unconditional positive regard. It was genuinely a challenge to narrow down their stories into essential concepts because I found value in every individual word and statement. I put myself in the shoes of these children: these 12 children were brave enough to sit with a stranger and share about something that is incredibly raw and vulnerable for many of them. There were aspects of this research process that were difficult for me due to this level of empathy: I regularly had to check my bias and verify that I was representing the children in a balanced manner, without chasing my own agenda. I have the utmost respect for these children and am indebted to their contributions to the field of disability studies. I truly hope I have represented them in the way they see themselves. I also hope they found the experience inspiring and as an opportunity to practice or build advocacy skills.

This research process has also confirmed, to me, the presence of social injustice in how we address children and their individuality in our society. As I worked through selecting my dissertation topic, I found it ironic how many professionals asked me why I wanted to interview children so young, especially children with disabilities. From the perspective of these individuals, children weren't going to be able to provide thick descriptions, meaningful information, and reflective thoughts. The lack of childhood voices is not only drastically apparent in the literature, it is present in everyday conversation and practice. It further confirms the need to keep this research process alive, in efforts to bring more childhood voices into the field as well as encourage adults to value and respect what children have to say.

OVERALL CONCLUSIONS

The research goal guiding this dissertation was to illuminate how children experience and perceive their disability labels. The literature review process revealed several gaps in the literature. Within the area of disability construction, additional research is required to generate understandings of disability from the child's perspective as well as include more robust perspectives on invisible disabilities. Regarding self-concept, a review of the literature identified a predominantly quantitative methodology in defining self-concept levels in children, with qualitative research being used sparingly or for retrospective accounts. Results were also mixed regarding if children with disabilities experience decreased self-concept compared to same-aged peers. While the literature is extensive on self-concept, the individual voices of children are notably absent from the field and thus little is available to conceptualize how children view disability in relation to their overall self. A review of research on stigma also demonstrates the absence of childhood voices in discussions of both the stigma experienced in an ableist society as well as the development of self-stigma in individuals with disabilities. Together, the literature indicates that the research conducted as part of this dissertation is of importance and significance.

Given the research question, qualitative methods, specifically phenomenology, was selected for gathering data. Phenomenology is a qualitative method that requires the researcher to consider both the minute details as well as the overarching characteristics that merge to create a phenomenological understanding of the subject. Interview was used as a primary source of data. A drawing prompt and storytelling prompt also added to the data collection process in efforts to include more implicit or nuanced ways of revealing experiences with disability. 12 children engaged in the data collection process and shared their experiences with a wide range of disabilities.

Findings and analysis revealed several significant findings. First, children are able to speak to the subject of medical versus social model of disability. Children have a pre-conceived understanding of what it means to be “normal” and can communicate what normal looks like in society using words, stories, and pictures. Children see disability from both the medical and social lenses and are able at a young age to identify social structures that inform how disability is constructed.

Children develop meaning from their experiences with disability, with many children identifying negative or challenging experiences as meaningful. Children can recognize the hardship and frustration that comes along with having a disability. They are also acutely aware of how they are different from peers and how disability has the possibility of changing life trajectories and future aspirations. Furthermore, children are also aware of what stigma looks and feels like, with many children identifying the stigmatizing practices they witness at school and in their communities. Children spoke to the subjects of disclosure and secrecy in efforts to communicate what it feels like to be disabled amongst peers who are not disabled. They also spoke to the importance of meaningful connections with close friends and family as well as with individuals with like disabilities. It is in this manner that children find resilience and strength. Children also spoke about the stories they internalize about disability that inform how they feel regarding disability and their futures, with some children highlighting inspiration and others citing fear or concern. Together, results strongly confirm that children have well developed awareness of what it means to be disabled in an ableist society and are able to communicate this understanding in abstract, complex ways.

Moving forward, this research has implications both for future research and future practice within the field of school psychology. Researchers should consider the replication of this study with broader age ranges and with a more diverse sample in efforts to gather increasing amounts of data to add to the established phenomenological understanding. Further, research could be deepened as to eventually develop a disability perception scale or other quantitative instrument, thus complimenting the already in-depth literature regarding self-concept. For school psychologists, this study can inform current practices in assessment, counseling, and consultation. These practices can impact not only the lives of children, but also the educators that work with these children every day and the parents that cherish these children unconditionally. Updating practice to reflect the findings within this study also meets the ethical criteria set forth by the National Association of School Psychologists.

In closing, I encourage readers to take the time to reflect on how adults can better advocate for children and include children in the decision making process. Don’t just be inspired by the bravery, intelligence, wisdom, and inquisitiveness of the children who participated in this study. Listen to what they have to say and use it to make a difference. Furthermore, find opportunities to listen to other children, particularly those who are oppressed or stigmatized, and to ask them what they want for the world they will inherit. Listening to children does not just have to occur within the vacuum of doctoral research: every child deserves to be heard, celebrated, and acknowledged for their individuality and potential, and every adult has the ability to take on this challenge.

REFERENCES

About IDEA. (n.d.) Retrieved from https://sites.ed.gov/idea/about-idea/#IDEA-History.

Agee, J. (2009). Developing qualitative research questions: A reflective process. *International Journal of Qualitative Studies in Education, 22*(4), 431-447.

A guide to disability rights laws (2009). Retrieved from https://www.ada.gov/cguide.htm.

Annamma, S., Ferri, B., & Connor, D. (2019). Cultivating and expanding disability critical race theory (DisCrit). In K. Ellis, R. Garland-Thomson, M. Kent, & R. Robertson (Eds.), *Manifestos for the future of critical disability studies: Volume 1* (pp. 230-238). New York, NY: Routledge.

Baglieri, S. & Shapiro, A. (2012). *Disability studies and the inclusive classroom: Critical practices for creating least restrictive attitudes.* New York, NY: Routledge.

Bear, G., Minke, K., & Manning, M. (2002). Self-concept of students with learning disabilities: A meta-analysis. *School Psychology Review, 31*(3), 405-427.

Bogart, K., Rottenstein, A., Lund, E., & Bouchard, L. (2017). Who self-identifies as disabled? An examination of impairment and contextual predictors. *Rehabilitation Psychology, 62*(4), 553-562. doi: 10.1037/rep0000132.

Boxall, K. (2019). Revisiting the foundations of (critical) disability studies: Manifestos for an inclusive social model. In K. Ellis, R. Garland-Thomson, M. Kent, & R. Robertson (Eds.), *Manifestos for the future of critical disability studies: Volume 1* (pp. 199-208). New York, NY: Routledge.

Brune, J. & Garland-Thomson, R., eds. (2013). Forum introduction: Reflections on the fiftieth anniversary of Erving Goffman's *Stigma*. *Disability Studies Quarterly, 34*(1). doi: http://dx.doi.org/10.18061/dsq.v34i1.

Buli-Holmberg, J. & Jeyaprathaban, S. (2016). Effective practice in inclusive and special needs education. *International Journal of Special Education, 31*(1), 119-134.

Bussing, R. & Mehta, A. (2013). Stigmatization and self-perception of youth with attention deficit/hyperactivity disorder. *Patient Intelligence, 2013*(5), 15-27. doi: https://doi.org/10.2147/PI.S18811.

Cameron, C. (2014). Developing an affirmative model of disability and impairment. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers – enabling environments: Third edition (*pp. 24-30). Thousand Oaks, CA: Sage.

Cardemil, E. & Battle, C. (2003). Guess who's coming to therapy? Getting comfortable with conversations about race and ethnicity in psychotherapy. *Professional Psychology: Research and Practice, 34*(3), 278-286.

Chan, K. & Lam, C. (2018). Self-stigma among parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 48,* 44-52. doi: http://dx.doi.org/10.1016/j.rasd.2018.01.001.

Chan, Y., Chan, Y.Y., Cheng, S., Chow, M., Tsang, Y., Lee, C., & Lin, C-Y. (2017). Investigating quality of life and self-stigma in Hong Kong children with specific learning disabilities. *Research in Developmental Disabilities, 68,* 131-139. doi: 10.1016/j.ridd.2017.07.014.

Chapman, J. (1988). Learning disabled children's self-concepts. *Review of Educational Research, 58*(3), 347-371. doi: https://doiorg.ezproxyles.flo.org/10.3102/00346543058003347.

Claessens, L., van Tartwijk, J., van der Want, A., Pennings, H., Verloop, N., den Brok, P., & Wubbels, T. (2017). Positive teacher-student relationships go beyond the classroom, problematic ones stay inside. *The Journal of Educational Research, 110*(5), 478-493.

Conners, J., Miles, S., & Pope, D. (2014). How many teachers does it take to support a student? Examining the relationship between teacher support and adverse health outcomes in high-performing, pressure-cooker high schools. *The University of North Carolina Press,* 22-42.

Cooley, C.H. (1902). *Human nature and the social order.* New York, NY: Schribners.

Corrigan, P., Buchholz, B., Michaels, P., & McKenzie, S. (2016). Adult perceptions about whether children should disclose their mental illness. *Journal of Public Mental Health, 15*(4), 200-208. doi: https://doi.org/10.1108/JPMH-03-2016-0012.

Corrigan, P., Watson, A., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology, 25*(9), 875-884. doi: https://doi.org/10.1521/jscp.2006.25.8.875.

Corrigan, P. & Watson, A. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice, 9*(1), 35-53. doi: https://doi-org.ezproxyles.flo.org/10.1093/clipsy.9.1.35.

Cosden, M., Elliot, K., Noble, S., & Kelemen, E. (1999). Self-understanding and self-esteem in children with learning disabilities. *Learning Disability Quarterly, 22*(4), 279-290. doi: 10.2307/1511262.

Danaher, T. & Briod, M. (2005). Phenomenological approaches to research with children. In Greene, S. & Hogan, D. *Researching children's experiences.* London, UK: Sage Publications. (Kindle locations 5211-5646).

Darling, R.B. (2013). *Disability and identity: Negotiating self in a changing society.*

Boulder, CO: Lynn Rienner Publishers.

Data display: Massachusetts identification of children with disabilities. (2013). Retrieved from https://www2.ed.gov/fund/data/report/idea/partbspap/2013/ma-acc-stateprofile-11-12.pdf

Davis, L. (2002). *Bending over backwards: Disability, dismodernism & other difficult positions.* New York, NY: New York University Press.

Davis, L. (2015). *Enabling acts: The hidden story of how the Americans with Disabilities Act gave the largest US minority its rights.* Boston, MA: Beacon Press.

DePape, A. & Lindsay, S. (2016). Lived experiences from the perspective of individuals with Autism Spectrum Disorder: Qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities, 31*(1), 60-71. doi: https://doi-org.ezproxyles.flo.org/10.1177/1088357615587504.

Digest of educational statistics. Chapter 2: Elementary and Secondary Education. (2016). Retrieved from https://nces.ed.gov/programs/digest/d16/ch_2.asp.

DSM-5: Frequently asked questions. (2018). Retrieved from https://www.psychiatry.org/psychiatrists/practice/dsm/feedback-and-questions/frequently-asked-questions.htm.

Eaton, K., Ohan, J., Strizke, W., & Corrigan, P. (2016). Failing to meet the good parent ideal: Self-stigma in parents of children with mental health disorders. *Journal of Children and Family Studies, 25,* 3109-3123. doi: 10.1007/s10826-016-0459-9.

Edmonds, C. (2012). Diff-ability, not disability: Right-brained thinkers in a left-brained education system. *Support for Learning, 27*(3), 129-135. doi: https://doi-org.ezproxyles.flo.org/10.1111/j.1467-9604.2012.01524.x.

Educator Effectiveness Guidebook for Inclusive Practice. (n.d.). Retrieved from http://www.doe.mass.edu/edeval/guidebook/.

Enrollment of students with disabilities served under IDEA. (2014). Retrieved from https://ocrdata.ed.gov/StateNationalEstimations/Estimations_2013_14.

Evans, H. (2017). Un/covering: Making disability identity legible. *Disability Studies Quarterly, 37*(1). Retrieved from http://dsq-sds.org/article/view/5556. doi: http://dx.doi.org/10.18061/dsq.v37i1.5556.

Foley, K-R., Blackmore, A.M., Girdler, S., O'Donnell, M., Glauert, R., Llewellyn, G., & Leonard, H. (2012). *To feel belonged:* The voices of children and youth with disabilities on the meaning of wellbeing. *Child Indicators Research*, *5,* 375-391. doi: 10.1007/s12187-011-9134-2.

Fossey, E., Harvey, C., McDermott, F., Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journey of Psychiatry, 36,* 717-732.

Freeman, M. & Mathison, S. (2009). *Researching children's experiences.* New York, NY: The Guilford Press.

Freire, P. (1970). *Pedagogy of the oppressed.* New York, NY: Continuum.

Gadamer, H. (1975). *Truth and method*. New York, NY: Bloomsbury Publishing.

Gadeyne, E., Ghesquiere, P., & Onghena, P. (2004). Psychosocial functioning of young children with learning problems. *Journal of Child Psychology and Psychiatry, 45*(3), 510-521. doi: https://doi-org.ezproxyles.flo.org/10.1111/j.1469-7610.2004.00241.x.

Gans, A., Kenny, M., & Ghany, D. (2003). Comparing the self-concept of students with and without learning disabilities. *Journal of Learning Disabilities, 36*(3), 287-295.

doi: 10.1177/002221940303600307.

Garbarino, J., Stott, F., & Faculty of the Erikson Institute. (1992). *What children can tell us: Eliciting, interpreting, and evaluating critical information from children*. New York, NY: Jossey-Bass.

Garland-Thomson, R. (2019). Critical disability studies: A knowledge manifesto. In K. Ellis, R. Garland-Thomson, M. Kent, & R. Robertson (Eds.), *Manifestos for the future of critical disability studies: Volume 1* (pp. 11-19). New York, NY: Routledge.

Gergen, K., Josselson, R., & Freeman, M. (2015). The promises of qualitative inquiry. *American Psychologist, 70*(1), 1-9.

Green, C. (2017). Four methods for engaging young children as environmental education researchers. *The International Journal of Early Childhood Environmental Education, 5*(1), 6-19.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Englewood Cliffs, NY: Prentice Hall Inc.

Hamachek, D. (1988). Evaluating self-concept and ego development within Erikson's psychosocial framework: A formulation. *Journal of Counseling and Development, 66,* 354-360.

Hamre, B. & Pianta, R. (2001). Early teacher-child relationships and the trajectory of children's school outcomes through eighth grade. *Child Development, 72*(2), 625-638.

Harter, S. (2012). *The construction of the self* (2nd ed.). New York, NY: Guilford Press.

Heher, T. (2002). Eliminating ableism in education. *Harvard Educational Review,* 72(1), 1-32.

hooks, bell. (1994). *Teaching to transgress: Education as the practice of freedom.* New

York, NY: Routledge.

James, W. (1890). *Principles of psychology.* Chicago, IL: Encyclopedia Britannica.

Jackson, P., Skirrow, P., & Hare, D.J. (2011). Asperger through the looking glass: An exploratory study of self-understanding in people with Asperger's Syndrome. *Journal of Autism and Developmental Disorders, 42,* 697-706. doi: 10.1007/s10803-011-1296-8.

Jones, J. (2012). Factors associated with self-concept: Adolescents with intellectual and developmental disabilities share their perspectives. *Intellectual and Developmental Disabilities, 50*(1), 31-40. doi: https://doi.org/10.1352/1934-9556-50.1.31.

Jordan, A. & Lovett, B. (2007). Stereotype threat and test performance: A primer for school psychologists. *Journal of School Psychology*, *45*, 45-59.

Jordan, J. & Schwartz, H. (2018). Radical empathy in teaching. *New Directions for Teaching and Learning,* 153, 25-35.

Josselson, R. (2004). The hermeneutics of faith and the hermeneutics of suspicion. *Narrative Inquiry, 14*(1), 1-28.

Josselson, R. (2013). Interviewing for qualitative inquiry: A relational approach. New York, NY: The Guilford Press.

Keeley, R., Brown, M., & Knapp, D. (2017). Evaluation of the student experience in the co-taught classroom. *International Journal of Special Education, 32*(3), 520-537.

Kelly, B. (2005). 'Chocolate… makes you autism': Impairment, disability, and childhood identities. *Disability and Society, 20*(3), 261-275. doi: 10.1080/09687590500060687.

Kloomok, S. & Cosden, M. (1994). Self-concept in children with learning disabilities: The relationship between global self-concept, academic "discounting," nonacademic self-concept, and perceived social support. *Learning Disability Quarterly, 17*(2), 140-153. doi: https://doi-org.ezproxyles.flo.org/10.2307/1511183.

Kozol, J. (1991). *Savage inequalities.* New York, NY: Crown Publishing Group.

Kulshreshtha, P. (2016). A comparative study on self-concept of the boys and girls among school-going adolescent. *Indian Journal of Health and Wellbeing, 7*(2), 204-207.

Lalvani, P. (2015). Disability, stigma, and otherness: Perspectives of parents and teachers. *International Journal of Disability, Development, and Education, 62*(4), 379-393. doi:10.1080/1034912X.2015.1029877.

Link, B., Struening, E., Neese-Todd, S., Asmussen, S., & Phelan, J. (2001). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services, 52*(12), 1621-1626. doi: 10.1176/appi.ps.52.12.1621.

Lyons, R. & Roulstone, S. (2016). Labels, identity and narratives in children with primary speech and language impairments. *International Journal of Speech-Language Pathology,* 1-16. doi: 10.1080/17549507.2016.1221455.

Mackay, S. & Parry, O. (2015). Two world views: Perspectives on autistic behaviors. *Journal of Health Psychology, 20*(11), 1416-1426. doi: https://doi-org.ezproxyles.flo.org/10.1177/1359105313512515.

Manago, B., Davis, J., & Goar, C. (2017). Discourse in action: Parents' use of medical and social models to resist disability stigma. *Social Science and Medicine, 184*(2017), 169-177. doi: 10.1016/j.socscimed.2017.05.015.

Mano, Q., Jastrowski Mano, K., Denton, C., Epstein, J., & Tamm, L. (2017). Gender moderates association between emotional-behavioral problems and text comprehension in children with both reading difficulties and ADHD. *Psychology in the Schools, 54*(5), 504-518. doi: 10.1002/pits.22011.

Marshall, C. & Rossman, G. (2016). *Designing qualitative research, Sixth Edition.* Thousand Oaks, CA: Sage.

Martinez, R.S. (2002). A comparison of learning disability subtypes in middle school: Self-concept, perceived social support, and emotional functioning (Unpublished doctoral dissertation). University of Texas at Austin, Austin, TX.

Massey, S. & Barreras, R. (2013). Introducing "impact validity". *Journal of Social Issues, 69*(4), 615-632.

Mikami, A., Chong, G., Saporito, J., & Na, J. (2015). Implications of parental affiliate stigma in families of children with ADHD. *Journal of Clinical Child and Adolescent Psychology, 44*(4), 595-603. doi: 10.1080/15374416.2014.888665.

McKeague, L., Hennessy, E., O'Driscoll, C., & Heary, C. (2015). Retrospective accounts of self-stigma experienced by young people with attention-deficit/hyperactivity disorder (ADHD) or depression. *Psychiatric Rehabilitation Journal, 38*(2), 158-163. doi: 10.1037/prj0000121.

Morgan, P., Farkas, G., Cook, M., Strassfeld, N., Hillemeier, M., Pun, W., & Schussler, D. (2017). Are black children disproportionately overrepresented in special education? A best-evidence synthesis. *Exceptional Children, 83*(2), 181-198. doi: https://doi-org.ezproxyles.flo.org/10.1177/0014402916664042.

Morrow, S. (2007). Qualitative research in counseling psychology: Conceptual foundations. *The Counseling Psychologist, 35*(2), 209-235.

Nario-Redmond, M., Noel, J., & Fern, E. (2013). Redefining disability, re-imagining the self: Disability identification predicts self-esteem and strategic responses to stigma. *Self and Identity, 12*(5), 468-488. doi: https://doi-org.ezproxyles.flo.org/10.1080/ 15298868.2012.681118.

National Association of School Psychologists. (2010). Principles for professional ethics. Retrieved from https://www.nasponline.org/standards-and-certification/professional-ethics.

Nielsen, K. (2012). *A disability history of the United States*. Boston, MA: Beacon Press.

Oliver, M. (2004). If I had a hammer: The social model in action. In J. Swain, S. French, C. Barnes, & C. Thomas (Eds.), *Disabling barriers – Enabling environments* (2nd ed.). (pp. 7-12). London: Sage Publications.

Patton, M. (2002). *Qualitative research and evaluation methods* (3rd edition). Thousand Oaks, CA: Sage.

Pestana, C. (2014). Exploring the self-concept of adults with mild learning disabilities. *British Journal of Learning Disabilities, 43*, 16-23. doi: https://doi-org.ezproxyles.flo.org/10.1111/bld.12081.

Piers, E., Shemmassian, S., & Herzberg, D. (2018). *Piers-Harris 3: Piers-Harris Self-Concept Scale, third edition manual.* Torrence, CA: Western Psychological Services.

Ponterotto, J. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology, 52*(2), 126-136.

Prino, L., Pasta, T., Giovanna, F., Gastaldi, M., & Longobardi, C. (2016). The effect of autism-spectrum disorders, down syndrome, specific learning disorders and hyperactivity and attention deficits on the student-teacher relationship. *Electric Journal of Research in Educational Psychology, 14*(1), 89-106.

Rodis, P., Garrod, A., & Boscardin, M.L. (2001). *Learning disabilities and life stories.* Needham Heights, MA: Allyn & Bacon.

Rothman, H. & Cosden, M. (1995). The relationship between self-perception of a learning disability and achievement, self-concept, and social support. *Learning Disabilities Quarterly, 18*(3), 203-212. doi: 10.2307/1511043.

Ricoeur, P. (1981). *Hermeneutics and the human sciences.* Cambridge, UK: Cambridge University Press.

Schlanger, M. Prisoners with disabilities. In Luna, E., ed. (2017). *Reforming Criminal Justice: Punishment, Incarceration, and Release.* (p. 295-323). Phoenix, AZ: Academy for Justice.

Section 300.8 Child with a disability. (2017). Retrieved from https://sites.ed.gov/idea/regs/b/a/300.8.

Section 504 of the Rehabilitation Act of 1973. (2018). Retrieved from https://dredf.org/legal-advocacy/laws/section-504-of-the-rehabilitation-act-of-1973/.

Siebers, T. (2004). Disability as masquerade. *Literature and Medicine, 23*(1), 1-22. doi: 10.1353/lm.2004.0010.

Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity.* New York, NY: Penguin Random House.

Special education disability definitions and related links. (2018). Retrieved from http://www.doe.mass.edu/sped/definitions.html.

Suzuki, L., Ahluwalia, M., Arora, A., Mattis, J. (2007). The pond you fish in determines the fish you catch: Exploring strategies for qualitative data collection. *The Counseling Psychologist, 35*(2), 295-327.

Tatum, B.D. (1997). "*Why are all the black kids sitting together in the cafeteria?": and other conversations about race.* New York, NY: Basic Books.

Torres, W. (2019). Not now but right now: Creating advocates and scholars. In K. Ellis, R. Garland-Thomson, M. Kent, & R. Robertson (Eds.), *Manifestos for the future of critical disability studies: Volume 1* (pp. 30-37). New York, NY: Routledge.

Townsend, P. (1966). Foreword. In Hunt, P., *Stigma: The experience of disability* (Foreword). London: Geoffrey Chapman.

Turns, B., Ramisch, J., & Whiting, J. (2019). *Systematically treating autism: A clinician's guide for empowering families.* New York, NY: Routledge.

Parent and Educator Resource Guide to Section 504 in Public Elementary and Secondary Schools. (2016). Retrieved from http://www.wrightslaw.com/law/ocr/sec504.guide.ocr.2016.pdf.

Veale, A. (2005). Creative methodologies in participatory research with children. In Greene, S. & Hogan, D (Eds.). *Researching children's experiences.* Kindle Edition. London, UK: Sage Publications. (Locations 6043-6524).

Vogel, D., Bitman, R., Hammer, J., & Wade, N. (2013). Is stigma internalized? The longitudinal impact of public stigma on self-stigma. *Journal of Counseling Psychology, 60*(2), 311-316. doi: 10.1037/a0031889.

Watson, A. & River, L.P. (2005). A social-cognitive model of personal responses to stigma. In Corrigan, P., (Ed.), *On the stigma of mental illness: Practical strategies for research and social change* (Chapter 6). Washington, D.C.: American Psychological

Association.

Wei, X. & Marder, C. (2012). Self-concept development of students with disabilities: Disability category, gender, and racial differences from early elementary to high school. *Remedial and Special Education, 33*(4), 247-257. doi: https://doi-org.ezproxyles.flo.org/10.1177/.0741932510394872

Who are school psychologists (n.d.). Retrieved from https://www.nasponline.org/about-school-psychology/who-are-school-psychologists.

Zola, I. (1989). Toward the necessary universalizing of a disability policy. *The Milbank Quarterly, 67*(2), 401-428.

APPENDIX A

VERBAL ASSENT SCRIPT

Hi. My name is Meredith. I'm a student at Lesley University and my job is being a feelings supporter, sometimes called a therapist, for kids. Right now, I'm trying to learn about what it's like to be a kid and have someone tell you that you have a disability. I would like to ask you to help me by being in a study, but before I do, I want to explain what will happen if you decide to help me.

I will ask you to answer some questions about who you are, what your disability is, and what school is like for you. There are no right or wrong answers and you can say as much or as little as you want. Some of these questions might be uncomfortable because you might not have thought about them before. I will be recording our interview so I can listen to it later. The only person who will listen to the recording is me. I'm also going to ask you to draw a picture and tell me a story. By being in the study, you will help me understand what it's like to be a kid with a disability.

Your parents and teachers will not know what you have said or written. If you say something in our interview that you want a parent or teacher to know, you can tell me and I will share this information with your permission. When I tell other people about my study, I will not use your name, and no one will be able to tell who I'm talking about.

Your parent says it's okay for you to be in my study. But if you don't want to be in the study, you don't have to be. What you decide won't make any difference on your grades, friends, or relationships. I won't be upset, and no one else will be upset, if you don't want to be in the study. If you want to be in the study now but change your mind later, that's okay. You can stop at any time. If there is anything you don't understand you should tell me so I can explain it to you

You can ask me questions about the study. If you have a question later that you don't think of now, you can call me or ask an adult to call me or send me an email.

Do you have any questions for me now?

Would you like to be in my study and talk to me?

Name of Child: ___________________**Parental Permission on File:** ☐ Yes ☐ No
(If "No," do not proceed with assent or research procedures.)

Child's Voluntary Response to Participation: ☐ Yes ☐ No

Signature of Researcher: ______________________________ **Date:** - ___________________

(Optional) Signature of Child: _______________________________ **Date:** ______________

Appendix B

PARENTAL CONSENT

LESLEY UNIVERSITY
PARENTAL PERMISSION FORM FOR CHILD'S RESEARCH PARTICIPATION

Study Title: The Intersection of Disability, Self-Concept, and Childhood

Principal Investigator: Donna San Antonio (Faculty Advisor); dsananto@lesley.edu
Co-Investigator: Meredith Edelstein (Lesley Doctoral Student); mschmidt@lesley.edu

IRB Study Number: TBD

Your child is being asked to take part in a research study. This form has important information about the reason for doing this study, what we will ask your child to do, and the way we would like to use information about your child if you choose to allow your child to be in the study.

Why are you doing this study?

Your child is being asked to participate in a research study about disability identification and age. The purpose of the study is to explore and better understand the experience of being labeled with a disability as a young child.

What will my child be asked to do if my child is in this study?

Your child will be asked to answer questions regarding their disability, how their disability was identified and shared with them, their overall identity, and school experiences. Your child will also complete a drawing. Participation should take about 1 to 1.5 hours; however, interviews may be split into multiple sessions if preferable for your child.

I would like to audio record your child as he/she participates in the interview, to make sure that I remember accurately all the information. I will keep these recordings digitally encrypted on a password protected computer and they will only be used by myself. Audio recording is required for participation in this study. If you or your child do not wish to be recorded, it is not possible for your child to be in this study.

What are the possible risks or discomforts to my child?

Your child's participation in this study may involve the following risks:
- Your child may get tired during the tasks. Your child can rest/take a break at any time.
- Your child may feel emotional or upset when answering some of the questions. Your child can tell the interviewer at any time if he/she wants to take a break or stop the interview.

•Your child may be uncomfortable with some of the questions and topics we will ask about. If your child is uncomfortable, they are free to not answer or skip to the next question.

As with all research, there is a chance that confidentiality of the information we collect about your child could be breached – we will take steps to minimize this risk, as discussed in more detail below in this form.

What are the possible benefits for my child or others?
Your child is not likely to have any direct benefit from being in this research study. This study is designed to learn more about self-concept and disability identification. The study results may be used to help other people in the future.

How will you protect the information you collect about my child, and how will that information be shared?
Results of this study, including drawings and quotes, may be used in publications and presentations. Pseudonyms will be used for all participants and named parties or locations shared during interview. If necessary, information may be meshed to provide salient data, but protect the identification of subjects. All paper copies of transcripts will be kept in a secure location (locked cabinet) and separate from pseudonym codes. All digital information will be encrypted and stored on a password-protected device. Upon completion of this study, data will be kept for 5 years in protected form and then destroyed.

All information disclosed in this interview will remain confidential. If your child shares something that he/she identifies he/she wants you to know, the child will be asked to give verbal permission to share that information with you. If I think that your child intends to harm himself/herself or others, I will notify you at the appropriate time within the interview as well as the appropriate people/agencies with this information.

Financial Information
Participation in this study will involve no cost to you or your child. Your child will receive a gift card for participating in this study.

What are my child's rights as a research participant?
Participation in this study is voluntary. Your child may withdraw from this study at any time -- you and your child will not be penalized in any way or lose any sort of benefits for deciding to stop participation.

If your child decides to withdraw from this study, the researcher will ask if the information already collected from your child can be used.

Who can I contact if I have questions or concerns about this research study?
If you or your child have any questions, you may contact the researcher at:
Meredith Edelstein
978-387-5187

mschmidt@lesley.edu.

There is a Standing Committee for Human Subjects in Research at Lesley University to which complaints or problems concerning any research project may, and should, be reported if they arise. Contact the Committee Chairpersons at irb@lesley.edu.

How do I explain this study to my child?

The following script is provided to help you explain your child's participation to the child: "this person is curious about what it's like to have a disability. She wants to meet you so she can get to know you and what school and home are like for you. She is going to ask you questions about your interests, relationships, and life at school. You can say as much or as little as you want and you can ask her questions, too." For the purpose of reducing bias in responses, please do your best to refrain from using valued statements such as "she wants to know about how hard it is to have a disability" or "she wants to know about what teachers have made school difficult."

Parental Permission for Child's Participation in Research

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 give permission for my child to participate in the research study described above and will receive a copy of this Parental Permission form after I sign it.

____
____

Parent/Legal Guardian's Name (printed) and Signature
Date

____
____

Name of Person Obtaining Parental Permission
Date

Parents, please be aware that under the Protection of Pupils Rights Act (20 U.S.C. Section 1232(c)(1)(A)), you have the right to review a copy of the questions asked of or materials that will be used with students. If you would like to do so, you should contact Meredith Edelstein to obtain a copy of the questions or materials.

APPENDIX C

INTERVIEW PROTOCOL

Rapport Building:

What are your interests?

What do you enjoy doing?

Tell me about your school and class.
- Favorite/least favorite subjects
- Favorite/least favorite teachers

What are you really good at?

Tell me about your family.

Tell me about your friends.

The Past and Present

What is your disability?
- Could you explain what that means?

Can you tell me about how you found out you have a disability?
- How old were you
- Where were you
- What was memorable in that moment
- How did you feel in that moment

Drawing Prompt

I'm curious to see a picture of a time when you noticed your disability. Could you draw me a picture of what it's like to have X.

Interview Continuation

How do you think adults figured out you have a disability?

When do you notice your disability?

Where do you feel most comfortable?

Are there situations in your life where your disability has no meaning at all or feels like it isn't there?

- When is your disability invisible?
- When does your disability disappear?

Are there people who understand your disability really well?

Are there people who don't understand your disability at all?

Who else knows you have a disability?

Do you know anyone else with a disability? Could you tell me about them and how you know they have a disability?

Storytelling Prompt

Now we are going to do a different activity. I want you to imagine and make up a story about a kid with a disability. When you're ready, I'd like to hear your story.

- Main character
- Beginning/middle/end
- Setting
- Character thoughts and feelings
- Alliances, enemies, heroes
- Conflict
- Resolution

The Future

What would your life be like if you didn't have X?

If you got to rename your disability, what would you change it to?

What do you wish adults knew about having a disability?

What do you wish other kids knew about having a disability?

How do you see your disability impacting your future?

APPENDIX D

SOCIAL MEDIA AND EMAIL POST

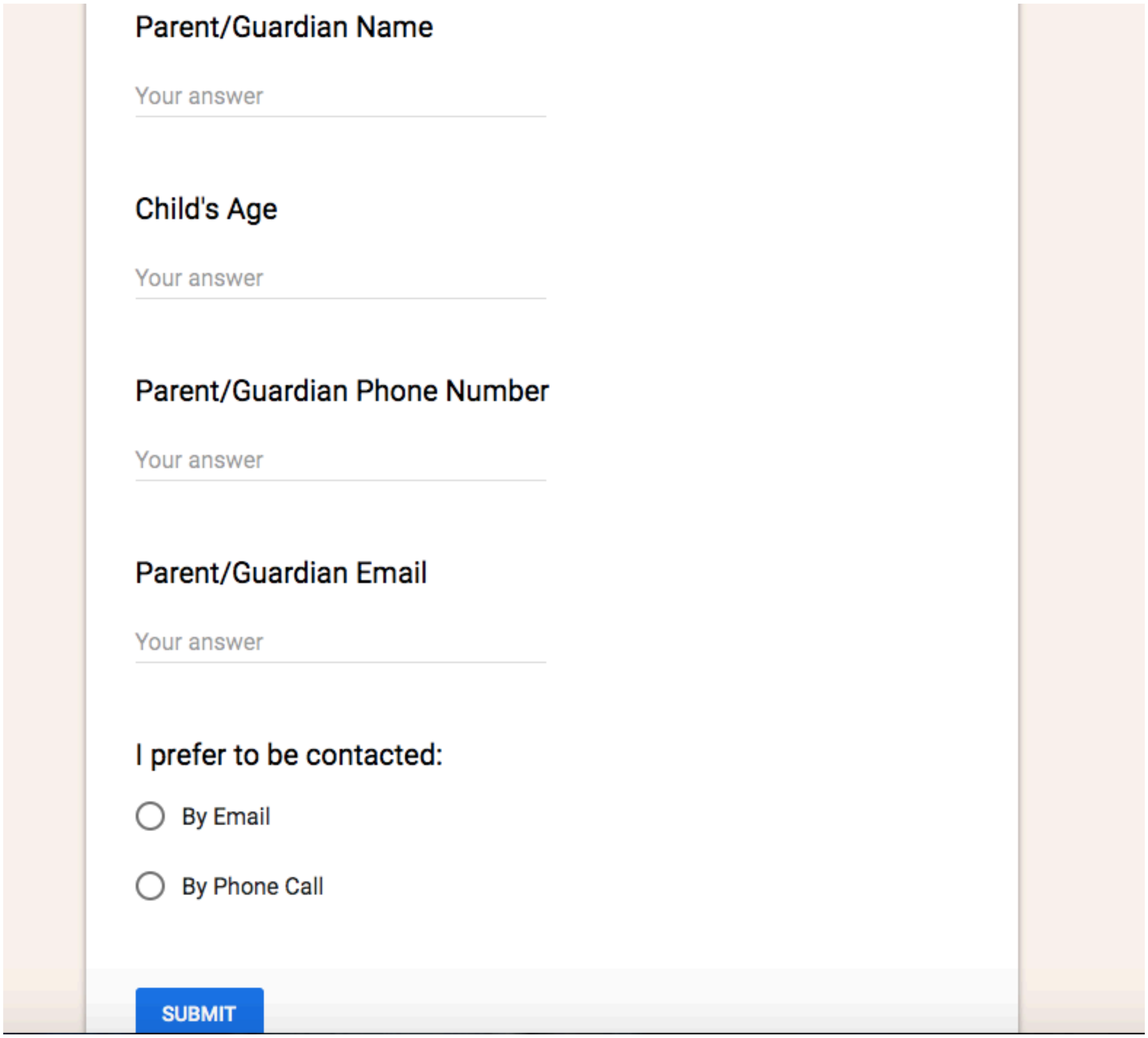
I am currently looking for children to participate in a research project looking at the childhood experiences of being identified with an invisible disability. Participating children should have an invisible disability (defined as a disability that one cannot see on the surface, allowing the child to pass as typically developing) and be between grades 3 and 6. Participating children should know they have a disability, including knowing the name of their disability. All participants will be interviewed as well as asked to complete a drawing and a story. Children will be compensated for their time with a gift card. For further information, please private message me on Facebook, email me at mschmidt@lesley.edu, or visit https://forms.gle/Qv59Rg4g6QH7j86z7 to fill out an interest form. Please also consider sharing this information with individuals you believe would be interested. Thank you!

Meredith Edelstein

APPENDIX E

GOOGLE FORM

Google Form Access: https://forms.gle/Qv59Rg4g6QH7j86z7



Parent/Guardian Name

Your answer

Child's Age

Your answer

Parent/Guardian Phone Number

Your answer

Parent/Guardian Email

Your answer

I prefer to be contacted:

○ By Email

○ By Phone Call