

PARENT PREFERENCES ON DISABILITY LANGUAGE REGARDING THEIR
PRESCHOOL-AGED CHILD WITH SPECIAL NEEDS

by

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ABSTRACT

LINDSAY BROOKE ALPAUGH. Examining parent preferences on disability language regarding their preschool-aged child with special needs. (Under the direction of DR. JANEDIANE SMITH)

The purpose of the study was to examine the disability language preference of parents with a child with special needs who is between the ages of three and five. Specific research questions included: What form of disability language do parents choose to adopt for their preschool-aged child immediately following a diagnosis and prior to their child's ability to assist in the decision-making process? What factors influence the decision regarding what form of disability language to use when referring to their preschool-aged child with special needs? How is the disability language preference of parents related to the intensity or frequency of services their child receives during preschool (Section 619) programs? To what degree does the disability language preference of parents relate to the short-term goals they have created for their child? Data were collected through an electronic survey given to parents whose child is enrolled either through the Exceptional Child (EC) program at a local preschool or organization. The survey was used to determine parent's preference of disability language in addition to examining possible associations between the preferred disability language and demographics, as well as between the disability language and the services the child was receiving and the goals the parents have created for their child. Person-first language was chosen by 12 out of the 14 participants. No statistically significant correlations were found between disability language and the other variables. Limitations included a small sample size and a researcher-created survey.

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PARENT PREFERENCES ON DISABILITY LANGUAGE

INTRODUCTION

Throughout the history of Psychology and Special Education, time periods have been separated into conceptual models. These models now provide the “framework for guiding psychological research as well as practice” (Dunn & Andrews, 2015, p. 258). An additional benefit of following the evolution of the conceptual models are their contribution to the documented history of disability culture. Prior to the 19th century, the conceptual models noted the preferred disability language of the time as well as how individuals with disabilities were viewed by society during that period. These models extend into present day, where the World Health Organization/International Classification of Functioning, Disability, and Health (WHO/ICF) model is currently recognized as the national standard (Dunn & Andrews, 2015). Until recently, person-first was the only disability language accepted by the American Psychological Association (APA) and the majority of academia. Now, under the WHO/ICF model, person-first and identity-first language are used interchangeably to “address concerns of disability groups while promoting human dignity and maintaining scientific and professional rigor” (Dunn & Andrews, 2015, p. 256). For the purpose of this study, person-first language was defined as the act of mentioning a person before any of their attributes. Some examples include: person with an amputated limb, person who is visually impaired, or person diagnosed with schizophrenia. Identity-first language was defined as the opposite—mentioning an internal or external characteristic before the person. Examples include, but are not limited to: autistic person, deaf person, or even addict. These differences in disability-language are also reflected in legislation.

When laws were first created to improve the lives of those with disabilities, the words and labels used were not considered to be offensive but rather objective in nature. One of the most widely known examples of these words is “mental retardation.” This phrase and others were commonplace in American policies and legislation (Fernald, 1995). Over the past 22 years, this term has been removed not only from legislation such as the Americans with Disabilities Act (ADA) and Education for all Handicapped Children Act— which later evolved into Individuals with Disabilities Education Act (IDEA)— but also from use in popular culture as society has become more aware and culturally sensitive. Currently, person-first language is prevalent in all major disability laws including IDEA and ADA (Fernald, 1995; Jensen et al., 2013; Peers, Spencer-Cavaliere, & Eales, 2014). While the fluid use of person-first language suggests cohesiveness and validity, a series of court cases known as the Sutton Trilogy revealed the flaws in ADA as well as how society views people with disabilities. When ADA came into effect in 1990, its original purpose was to end years of suppression for individuals with disabilities by setting objective and enforceable national standards that would lessen discrimination (Rozalski, Katsiyannis, Ryan, Collins, & Stewart, 2010). After the Sutton Trilogy, the Supreme Court redefined what it means to have a disability, consequently narrowing the protection these individuals held when facing discrimination in the workplace (Colker, 2007; Harpur, 2012). During each section of the Sutton Trilogy, three separate cases concerning employee discrimination were discussed. From all three, the Supreme Court decided “mitigating measures must be considered in determining whether an individual has a disability” (Rozalski et al., 2010, p. 23). For example, an individual with poor vision who uses corrective lenses to improve their

vision is no longer protected under ADA. This decision has caused an estimated two-thirds of the disability culture population to lose protection from ADA regardless of their impairment (Colker, 2007; Harpur, 2012). For the purpose of this study, disability will be defined as a single or comorbid physical or psychological condition or characteristic (Dunn, 2016) that consistently restricts a person from an activity. Impairment will be differentiated from disability by labeling it as a long-term anomaly of a person's physical or psychological function—an impairment leads to a disability. Consequently, the impact of ADA is still questioned despite amendments that broadened ADA's scope in 2008 (Rozalski et al., 2010). Although the United States still struggles to find the correct verbiage to address those with disabilities, other countries have found unity through the exclusive use of identity-first language.

Researchers in Canada found that disability terminology differs by both the speaker's region and discipline (Peers, Spencer-Cavaliere, & Eales, 2014). Similarly, a study by Fernald (1995) concluded "words are culture bound...even when cultures share the same language" (p. 99). Cultural differences are magnified when comparing the positions of the United States, Australia, and the United Kingdom on their use of language to refer to individuals with disabilities. On the surface, differences between these countries appear to be their use of either person-first language or identity-first language. The context between these two choices reveal the relationship between society and a person's impairment (Harpur, 2012). In the United Kingdom, the social model is highlighted as opposed to America and Australia's WHO/IFC model (Harpur, 2012). Under the social model, people have impairments; society turns an impairment into a disability (Dunn & Andrews, 2015; Fernald, 1995; Harpur, 2012; Peers et al., 2014).

Therefore, the United Kingdom uses identity-first language which reflects the person's impairment rather than the disability society has assigned them (Fernald, 1995; Harpur, 2012). The United States and Australia almost exclusively use person-first language. These two countries define impairment and disability differently than the United Kingdom. Dunn (2016) describes disability as a physical or psychological characteristic that restricts a person from completing a naturally occurring activity. An impairment is similar to a disability, but, according to Dunn (2016), is "due to injury, disease, or some other chronic health condition" (p. 256). In either definition, there is no mention of society's role. While each country has their own definition of impairment and disability, it is clear that semantics play a major role in the treatment of those with disabilities (Jensen et al., 2013).

When looking at legislation and academics in the United States, person-first language is used exclusively. Although legislation has not changed, the newest addition of the American Psychological Association's (APA, 2010) publication manual notes that subjects should be individually asked about their preference of disability language before the use of person-first language is assumed. Furthermore, many organizations have spoken out against person-first language by calling it oppressive and discriminatory (Harpur, 2012). The National Federation of the Blind and the individuals who identify as a part of Deaf culture have all spoken out against the use of person-first language (Bickford, 2004; Dunn & Andrews, 2015; Peers et al., 2014). At the same time, organizations such as the American Speech-Language-Hearing Association (ASHA) have requested person-first language to be used exclusively (St. Louis, 1999). Although the number of organizations on either side of the person-first/identity-first debate is small, it

demonstrates that the choice should be individualized. Historically, individuals have had to follow the majority when it comes to word choice; now the individual is being emphasized. It is hypothesized that, because of this discourse, more organizations (e.g., Autism Society, National Alliance of Mental Health [NAMI]) have not made an official stance on which disability language they prefer. These opinions are manifested by the varying results found by researchers in the field and the anecdotal responses by participants and colleagues (Dunn & Andrews, 2015). From previous research, it was suggested that the language choice of individuals merely reflected their opinion on how they viewed their disability or impairment (Dunn & Andrews, 2015; Peers et al., 2014). There is now research to suggest that the decision made by these individuals directly impacts not only their identity but their identity within the context of disability culture (Dunn, 2016).

Disability culture was recently identified as a minority group in the United States (Dupré, 2012). Like many minority groups, disability culture has its own set of values, beliefs, and jargon (Barnartt, 1996). Although it might be assumed that as an individual receives a diagnosis or is identified with an impairment, their entrance into disability culture is inevitable. However, every experience is specific to each person and is dependent upon their self-identification and their physical and social environment (Dunn, 2016; Gilson, Tussler, & Gill, 1997). Entrance into disability culture is also delineated by two separate but equally important processes: adaptation and adjustment. According to Dunn (2016), “adaptation is an active process, one where the individual, family and friends, and rehabilitation professionals continually reflect on the disability’s impact” (p.258). Adaptation focuses on how one’s impairment affects them mentally and

physically every day. Adjustment begins when the individual is content with their relationship with the environment around them (Dunn, 2016). Although adjustment is a personal process that every individual with a disability must go through, adaptation can be affected by multiple people in the individual's microsystem. Therefore, younger people with disabilities may have a different process of adaptation or may remain in the cycle of adaptation until they reach an age where they can continue on their own.

1.1 Statement of the Problem

Despite the extensive research on person-first language, identity-first language, disability legislation, and disability culture, several gaps still remain. Much of the research surrounding these topics are literature reviews. Although a few studies exist in which participants are asked their preference on disability language, the majority of this research reflects a professional's interpretation of data; the views of the stakeholders have not been considered (Bickford, 2004). The studies that do exist on the subject of disability language often have small participant pools with a homogeneous population. This does not allow for a full picture of the opinions of disability culture and the importance of language within it.

Furthermore, the relationship between one's entrance into disability culture and the influence of the individual's friends and family has been identified, yet the strength of this relationship remains unknown. Past research also seems to assume that adaptation occurs when an individual with disabilities is both older and more emotionally mature in their identity. However, with advances in the field of psychology and special education, both the identification process and subsequent early intervention in Section 619 Preschool programs are becoming more successful with regards to individual goals and

kindergarten readiness. With many diagnoses occurring earlier than ever before—some even prenatally—it could be hypothesized that one's entrance into disability culture happens before the previously assumed timeline. Based on current research, entrance occurs when the individual is an adult and, therefore, self-aware. If this statement proves to be true, action research is needed to examine the experience of the child during this time as well as the inevitable role of the family.

Research conducted by Webster, Majnemer, Platt, & Shevell (2008) found that the parents of children who received a diagnosis of developmental delay while in preschool still had clinically significant levels of stress three to four years later. A similar study reported the same results almost seven years post-diagnosis (Webster et al., 2008). Although parents were not asked specifically what their main stressor was, one of the significant findings from the study is parents need support during this time. One area of support parents might need assistance in is the initial diagnostic process. Navigating the diagnostic process at any age would appear to be overwhelming for parents, but entering this process during preschool has more hurdles (e.g., elevated preschool expulsion rates, typical behavior mimics that of a disorder) than any other life stage (Finello, 2011). As a child enters testing in preschool, there is usually no formal medical, educational, or behavioral history because the child is typically only three years of age (Finello, 2011). To complicate this process even more, lapses in development often mimic the symptoms of several diagnoses, presenting the assessment team the task of deciding if a child simply needs more time or early intervention (Finello, 2011).

Receiving the label of a disability or impairment between the ages of three and five is occurring more than ever before (United States Census Bureau, 2012). Not only

does this event cause a child's family to experience high levels of stress, but it also causes families to make decisions for the child that can cause significant impacts on their life later on (e.g., type of goals, services received). Whereas a child who receives a diagnosis or experiences an impairment later in life can assist their parents in some aspects of the decision-making process (e.g., preferred disability language, level of involvement in disability culture), a child with special needs during the ages of three to five is not able to; mainly because of their young age. Therefore, it is the parents who are left to decide what services—if any—their child should receive, what goals they want their child to obtain, and what form of disability language they will use to refer to their child. The answers to these questions have the potential to impact a child's future in life because everything from the services they receive to the language their parents choose will lay the foundation for his or her identity in disability culture.

The purpose of this study was to investigate the decision process between identity-first and person-first language that parents undergo after their child is diagnosed between the ages of birth through five. Through speaking with peers, family, or service-providers about their child, a parent—for example—will automatically refer to their child as “diagnosed with autism” or “autistic.” While it is expected that some parents make this decision subconsciously, a choice is made nonetheless. In addition to the decision-making process, parents were asked via survey to report their goals for their child, the current services their child received, and what decision (i.e., person-first language or identity-first language, or both) they had arrived at and why. Parents were given the choices: person-first language, identity-first language, or using both interchangeably. From this information, the researcher determined which factors (e.g., culture, child's

diagnosis/impairment, parent education)—if any—can predict the disability language preference of the parent and any associated consequences affecting the child (positive and negative) that are attached to their decision.

1.2 Research Questions

Through descriptive research, this study attempted to answer the following questions:

1. What form of disability language do parents choose to adopt for their preschool-aged child immediately following a diagnosis and prior to their child's ability to assist in the decision-making process?
2. What factors influence the decision-making process of parents while deciding what form of disability language to use when referring to their preschool-aged child with special needs?
3. How does the disability language preference of parents relate to the intensity or frequency of services their child receives during preschool programs (Section 619)?
4. How does the disability language preference of parents relate to the short-term goals they have created for their child?

REVIEW OF THE LITERATURE

While conducting a search of the literature on parents of preschool students with special needs and their decision to either use person-first or identity-first language, the resources of the University of North Carolina at Charlotte (UNCC) library were used as well as Google scholar. The UNCC library provided access to the following databases: ERIC, PsycInfo, ScienceDirect, Academic Search Complete, and Sage Journals Online. The terms *person-first language*, *identity-first language*, *Americans with Disabilities Act*, *preschool diagnosis*, *disability culture*, *disability studies*, *Sutton Trilogy*, *parents* and *preschool diagnosis*, and *disability identity* were employed. When a secondary source was being searched for through an original article, the author or the full title of the source was searched for via the entire UNCC library or Google Scholar. All articles were peer-reviewed.

As of 2010, the United States reported close to 56.7 million people with disabilities through the national census (United States Census Bureau, 2012). This number has increased by more than 12 million people since 1990 when the United States Congress enacted the Americans with Disabilities Act (ADA) legislation (Rozalski et al., 2010). With these changes, disability awareness has increased exponentially. A search of *disability studies* through PsycInfo was conducted within the parameters of peer reviewed and a publishing date between 1990 and 2000. The search yielded 526 results. The same search term was applied to peer-reviewed articles published between the years 2001 and 2011. This search revealed 2,280 articles. Based on these results, it appears that since ADA was created in 1990, research on people with disabilities has increased. However, this research is no longer singular in its focus. There are articles concerning disability

language (Dunn & Andrews, 2015; Fernald, 1995; Harpur, 2012; Jensen et al., 2013; Peers et al., 2014), disability culture (Barnartt, 1996; Conyers, 2003; Dunn, 2016; Dupré, 2012; Gilson et al., 1997; Peers et al., 2014; Swain & French, 2000), disability studies (DeMieri, 2012; Dunn, 2016; Harpur, 2012), as well as the history of disabilities – which examine how conceptual models, legislation, and even popular culture have impacted those with disabilities (Colker, 2007; Conyers, 2003; Dunn & Andrews, 2015; Dupré, 2012; Jensen et al., 2013; Fernald, 1995; Harpur, 2012; Moller & McLoughlin, 2013). Through the years, individuals with disabilities have created their own sub-culture (Conyers, 2003). Although a review of the literature reveals that only a small portion of this culture has been studied. Dunn (2016) has argued that adaptation and adjustment into disability culture can only occur after an individual receives their diagnosis or impairment. If this holds true, then there is a large population of disability culture that has not yet been researched, beginning at birth and extending into the preschool years. While these children may not be aware, their entrance into disability culture has already occurred and is being facilitated by those in their immediate environment.

2.1 Theoretical Background

Ecological Systems Theory

Bronfenbrenner's (1977) initial theories on human development explained the relationships between the microsystem, mesosystem, exosystem, and macrosystem in regards to their effects on an individual's social and cognitive development. One aspect of Bronfenbrenner's theory that sets his apart from other developmental ideas are the system's dynamic nature. While other theories may focus on a specific period of development (i.e., birth to five), Ecological Systems theory can be applied to a person's

entire lifespan due to the continual changes the four systems constantly undergo (Bronfenbrenner, 1977). These changes also cause each system to be specific to the individual—one child’s microsystem will look drastically different than another’s. Consequently, the changes vary between infancy (e.g., new caretaker, divorce), childhood (e.g., new sibling, move, death in the family) and adulthood (e.g., birth of a child, marriage, new job). With each growing system, they diminish in proximity to the individual. Dunn’s (2016) explanation of adaptation and adjustment—both crucial to the entry of disability culture—mirror Bronfenbrenner’s systems. Through adaptation, the impaired individual and their immediate microsystem (i.e., family, friends, therapists) constantly reflect on the impairment and the effect it has on the individual (Dunn, 2016). Although the level of intellectual insight required for this process suggests the individual is of an older age at the time, the heavy influence of others may allow for the individual to be younger than originally thought. In other words, adjustment requires a great deal of self-awareness and reflection. But if this process is not as solitary as researchers once thought, the assistance of others may help the individual reach adjustment earlier in life.

While adaptation is constant, adjustment only occurs when a person is content with their own relationships with the environment (Bricout, Porterfield, Tracey & Howard, 2004; Dunn, 2016). This includes friends, family, co-workers, and their relationship with society. Society and its rules are included within Bronfenbrenner’s (1977) macrosystem; this system is the furthest removed from the individual and therefore its relationship is one-directional. Although the individual resides within society, the macrosystem is too large to be impacted by a single person. Because society plays a major role in delegating ‘normal’ and ‘handicapping’ abilities (Dunn, 2016;

Harpur, 2009; Harpur, 2012; Peers et al., 2014; Swain & French, 2010) one must accept how the majority of society views them before entering disability culture. After successful relationships with each level of Bronfenbrenner's systems have been maintained, a person with a disability can become an active member of disability culture through a positive disability identity (Dunn, 2016). Dunn (2016) theorizes a person's level of disability identity is a crucial factor when analyzing their status in disability culture. Those with a high level of identity are often in the inner circle of the culture while those with a diminished level of identity are kept on the fringes.

In the early 1990's, Bronfenbrenner expanded on the Ecological Systems Theory with the Bioecological model. Through the Bioecological model, Bronfenbrenner's original systems remained the same but the individual's genetic differences and subsequent potential are accounted for when examining the bi-directional relationship between a system and the individual (Bronfenbrenner & Ceci, 1994). Many impairments are now identified through genetic markers (e.g., Down Syndrome, Fragile X, Cystic Fibrosis). Although this is a luxury that was not readily available in the 1990's, these recent advances have provided evidence to further support the Bioecological model. Bronfenbrenner and Ceci (1994) argued that a child's proximal process (e.g., genetic potential) plays a part in how the child experiences their environments and how their environments—specifically the macrosystem—view the child. Because every child—with or without disabilities—fall onto a spectrum of varying abilities, analyzing each child's individual potential in each of Bronfenbrenner's systems will provide the best chance of predicting their relationships with their family and peers (Bricout et al., 2004).

Theory of Stigma

In Erving Goffman's (1963) theory of stigma, the rules created by society that determine what is 'normal' are explained along with the experiences of those who deviate from these rules. For years, society has categorized attributes as either normal or abnormal (Goffman, 1963). Goffman (1963) posits that although most of these decisions regarding someone's normalcy are subconscious, they have been passed on through multiple generations. When society discovers an attribute that is abnormal (i.e., blindness, deaf), the person is thought to be dangerous or weak because of their differences and is consequently stigmatized (Goffman, 1963; Swain & French, 2000). These opinions regarding what is 'normal' were personified in the 19th century during institutionalization (Sullivan, 1991) and are continued during present day through the tragedy model of disability (Bricout et al., 2004; Swain & French, 2004). In the tragedy model, individuals with disabilities are viewed as victims and are pitied. Victimization is rampant in our society, more now so than in Goffman's day as our image of 'normal' becomes more publicized and more attainable through drastic measures (i.e., speech therapy, corrective eye surgery, plastic surgery). While many of these processes were created to help the 'stigmatized' or people with disabilities (Goffman, 1963), they also send the message: what you are going through is not normal, let us fix the characteristics that make you different. Again, most of society wants to help the person with a disability and any subsequent victimization that occurs is subconscious. This is exemplified when a person's support system cheers them on as they reach a new milestone or achieve a personal goal, all the while sympathizing with the individual because of the extra hurdles they are experiencing. Swain and French (2000) argue this tragedy model way of thinking

is responsible for a doctor's standard recommendation to abort a fetus after an abnormality is detected, despite advances in fetal medicine and early intervention. Because the fetus is now marked as 'abnormal', society (i.e., the doctor) believes the fetus should be removed rather than begin a conversation about how the fetus can be helped instead.

Despite centuries of stigmatization against those who deviate from society's norms, Goffman (1963) writes that it is possible for the stigmatized to stop caring about the rules and to feel normal in his or her own right, and instead to believe that society is the one that is abnormal. Many members of disability culture appear to be headed in this direction. By creating a positive disability identity (Dunn, 2016) and accepting that society is unfair by creating disabilities out of impairments, disability communities are beginning to speak out against the constructs society has in place. Those who speak out against inequality at their places of employment via the Sutton Trilogy (Colker, 2007; Rozalski et al., 2010), and communities who have rejected the public's norm of only using person-first language when speaking of or to individuals with disabilities (i.e. National Federation of the Blind, Deaf culture) are examples of a growing positive identity within disability culture. The people who surround those with disabilities also have the potential of making a difference in the way society sees the stigmatized (Goffman, 1963). Goffman (1963) describes these as 'wise people'; those who either work with the stigmatized or are related to a person with a stigma. Similar to Ecological Systems Theory (Bronfenbrenner, 1977) and the theory of adaptation and adjustment (Bricout et al., 2004; Dunn, 2016), Goffman (1963) theorized that the people in the immediate environment of the stigmatized person play a major role in the individual's

creation of their self-identity. Furthermore, Gilson et al. (1997) argues individuals will be unable to create a positive identity unless they can interact with other peers who have been stigmatized. Because the support system of a person with a disability (or lack thereof) is so influential in regards to their disability identity and therefore their initial entry into disability culture, it can be argued that the guardians of preschool-aged children with disabilities are the sole source of creating the foundation of their child's disability identity.

Of the same importance as a person with a disability's family are what Goffman (1963) refers to as group alignments. Although Goffman was unclear as to what these group alignments looked like in 1963, these groups used a unified language when referring to themselves. Therefore, some examples of group alignments in present day include the National Federation of the Blind, Autism Society, Deaf Culture, and the National Down Syndrome Society. Within these groups, "...unless there is some alien culture on which to fall back, the more he separates himself structurally from the normal, the more like them he may become culturally" (Goffman, 1963, p. 114). These group alignments have aided in the 'alien culture' that is now known as disability culture. Goffman (1963) refers to this culture as alien because it differs from the rest of society. Although there are some researchers that—for a variety of reasons—argue that a group of people with disabilities does not amount to a strong sense of culture (Barnartt, 1996; Conyers, 2003; Harpur, 2009), disability culture has increased in research popularity over the past five decades. Another significant characteristic of the group alignments is the use of shared disability language. Even though the debate between person-first and identity-first language is ongoing, the Theory of Stigma states that the 'normals' use the language

that a stigmatized person's community uses as a sign of respect (Goffman, 1963). For example, because the National Federation of the Blind supports the sole use of identity-first language, an outsider to the National Federation of the Blind would assume the use of identity-first language. Because few national organizations have made definitive statements regarding the sole use of person-first or identity-first language, the APA manual (2010) now, rather than continuing the use of person-first language, requests each individual is asked for their preference whenever possible.

Social Construction of Reality

Berger and Luckmann (1966) used *The Social Construction of Reality: A Treatise in the Sociology of Knowledge* as a platform to discuss their theory concerning how society creates rules about the world and its reality. This theory mirrors aspects of Ecological Systems theory and the theory of Stigma in that individuals with disabilities are again at the mercy of society's rules and must use their immediate environments and other people with disabilities as a support system. There are multiple factors that can disrupt a person's full integration into society, however most factors involve biological or physical characteristics that are easily detected as abnormal and then labeled as a misfortune (Berger & Luckmann, 1966). In recent years, Swain and French (2000) have documented a movement in disability culture where individuals are moving away from the tragedy model and towards a more positive, affirmative model. This movement is fueled by the creation of individual positive disability identities within disability culture (Swain & French, 2000). Similar to ableism (Harpur, 2009), the affirmative model focuses the 'problem' of disabilities on society rather than the individual (Swain & French, 2000). By valuing the strengths and positive experiences of those in disability

culture, Swain and French (2000) argue the affirmative model will empower individuals to embrace their impairments. The goal of this model is to change the way society views an impairment by changing the way ‘the disabled’ view themselves. Increases in positive self-identity within the disability community may be responsible for the recent outspokenness against the use of person-first language. According to Harpur (2012), identity-first language allows for individuals to celebrate their differences; it allows an individual to take ownership of their disability rather than detach from it (Dunn & Andrews, 2015). Jensen et al. (2013), however, posits that by not detaching from the disability (via the use of person-first language), the individual believes there is no chance of recovery or success.

Apart from creating an affirmative model, Berger and Luckmann (1966) theorize that by the stigmatized creating their own community, they create a counter-identity and counter-reality. Similarly, they do not have to mask their disability and can be their true self. For example, a deaf person who typically uses deaf speak can return to only using American Sign Language. Without either, the majority society’s rules will remain in effect. Once society is aware of the new reality, society will be forced to change because the stigmatized have refuted their stigmas (Berger & Luckmann, 1966). Just as individuals can create a counter-reality and identity, some individuals have the ability to choose between which reality they want to exist in. This can occur when a typically-developing child has a parent with a disability or a non-typically developing child has ‘normal’ parents. In either case, the child has been raised between two realities: the majority culture and disability culture. Consequently, the child must choose which reality it wishes to attend to. The choice for the typically-developing child becomes more

challenging with additional stigmatized family members as this changes the identity of their microsystem. The choice for the ‘normal’ parents with a stigmatized child, however, is consistently more difficult due to the lack of input their child can give about their wants and needs in regards to their impairment. Because of the child’s age and depending on their impairment, the parent will be the sole decision maker for a prolonged amount of time.

2.2 Conceptual Framework

Historically, individuals with disabilities have experienced a form of social apartheid, having been discriminated against through a multitude of venues: mainstream education, employment, and full societal participation (Dunn & Andrews, 2015; Harpur, 2009; Harpur, 2012, Jensen et al., 2013). Harpur (2009) argues their plight against social discrimination can be compared with that of racism and sexism; however, some differences do exist. Movements such as the fight against sexism, racism, and disability discrimination may not ever be fully finished in regards to their ultimate goal, but racism and sexism have made considerably larger gains in reaching their goals than the disability culture movement has. One of the largest differences between the three campaigns is disability discrimination’s lack of a socially charged term that not only puts the focus on the discriminator, but empowers the entire victimized group (Harpur, 2009). When a person commits a discriminatory act against a woman, they are labeled in society as a sexist. This term now has negative connotations with the majority of the population which guides people away from any act that would end with them being labeled as such, therefore enabling the equality of women. A similar pattern is repeated when an individual or group discriminates against someone of a different race. The term ‘racist’ is

applied which often leads to public shaming and a review of how society treats people with racial differences. Disability culture has yet to find their word.

In the United Kingdom, ‘disablism’ is the most widely used term to fight bias towards disability culture, but Harpur (2009) posits this term turns the person with the disability into the contributing factor of discrimination rather than focusing on the discriminator. Because it is society who turns impairments into disabilities (Harpur 2009; 2012; Dunn, 2016), a term must be created that focuses on the societal error of deciding who is disabled and who is not. It is with this same goal in mind that the word ‘abelism’ was formed. Although it has yet to gain social traction in western cultures, it has found its way into Australia’s academic literature and several Australian advocacy groups (i.e., Blind Citizens Australia, Women with Disabilities Australia) (Harpur, 2009). Abelism intends to do for disability culture what ‘sexist’ and ‘racist’ have done for the sexism and racism movements by focusing on the discriminator and helping those who do not meet society’s standard of the physical norm (Harpur, 2009). It focuses on “those acts and behaviors which assume a person must meet the physical standards set by a particular group in society” (Harpur, 2009, p. 164). An abelist can take many forms and the discrimination is not always intentional. For example, a person who builds a library at street level but refrains from putting in identifying signs in braille or an electronic door opener is discriminating against individuals with a range of impairments. Their error took place when they assumed everyone had the same ability to read the visual ‘Library’ sign and had the physical ability to pull open a door.

Identifying those with abelist ways of thinking is key for the continued equality of disability culture but has so far proved to be difficult due to the individual’s typical lack

of intention when committing the discrimination. While the discriminator still needs to be corrected, the non-intentional aspect magnifies a deeper complication with society and the way the majority of the population has been trained to think. Despite there being an excess of sympathy towards disability culture there appears to be a limited understanding of how this sub-culture functions within itself (Conyers, 2003). Conyers (2003) argues the divide is partially caused through the absence of society's ability to self-reflect on the constraints it puts on impairments and partially on the lack of protective legislation. Harpur (2009; 2012) theorizes a social justice model should be put into place which would ensure society's recognition of their own role in the creation of barriers towards individuals with disabilities. Increased awareness could in turn lead to less ableism and consequently more equality with regards to education, legislation, and societal participation.

Many authors trace the origins of societal repression of disability culture back to the medical model (Sullivan, 1991). In the medical model, disabilities were seen solely as a medical problem; the individual was taken out of the diagnostic equation as much as possible (Dunn & Andrews, 2015). Beginning in the 19th century, germ theory was the first step in de-humanizing disabilities. The discovery of germs took any fault of an impairment from the individual and placed it on germs over which individuals had no control (Sullivan, 1991). Next, a series of technological advances in the medical field changed how impairments were studied. The creation of the x-ray machine, stethoscope, and microscope changed how doctors looked at patients (Sullivan, 1991). Doctors no longer had to rely on self-reporting to diagnose or treat their patients. The new tools that had been invented and those that were to come allowed doctors to view patients as

exploratory objects. Finally, institutionalization permitted doctors to place a barrier between individuals with disabilities and the rest of society (Sullivan, 1991). Families seeking additional help were advised to send their loved ones away to institutions where they were assured their family member would receive the best care possible. Before one could be accepted into an institution, a doctor had to first validate their impairment through a series of medical tests (Sullivan, 1991). By a doctor medically identifying an impairment and then using that diagnosis to send a person to the outer edges of society, “a particular perception of disability and disabled people became entrenched in the bureaucratic and public mind. The medicalizing of disability was complete” (Sullivan, 1991, p. 257).

Despite their assistance in the repression of disability culture, Sullivan (1991) theorizes that these advances in medicine were beneficial and allowed for better medical treatment of all individuals such as the elimination of polio and increased awareness on how dangerous germs are spread. However, the psychological damage inflicted between disability culture and the rest of society was irreversible. Essentially doctors in support of institutionalization portrayed the following: if a person looks different and acts different, they must be treated differently. After de-institutionalization and years of advocacy, very few aspects of the medical model remain. Society’s views have changed, some for better, some for worse. Inclusive education is now commonplace at most schools, disability studies and special education are two in-demand fields of study, and the diagnostic process is typically a multi-disciplinary effort. Some researchers (Conyers, 2003; Dupre, 2003; Dunn & Andrews, 2015 Harpur, 2009; 2012; Swain & French, 2000) still argue that disability culture is years away from the equality it deserves. Disabilities may be

seen with more acceptance, but they are still seen as a personal tragedy (Swain & French, 2000). Society continues to think disabilities should be avoided and if they must be encountered, the loss of normalcy should be mourned (Swain & French, 2000).

Although most opinions within disability culture have never strayed to the tragedy way of thinking, there is research to support the growing positive identity movement within disability culture (i.e., language disputes). The debate between person-first language and identity-first language signifies the internal struggle in each individual with a disability to choose what is best for them. Many years ago when person-first language was the only choice, very few individuals voiced any opinion that spoke out against the oppression they felt when they were called “a person with ...” or “a person diagnosed with ...”. Today, many individuals are advocating strongly for either side. This controversy is less about a cultural-wide agreement and more about a positive self-identity.

2.3 Person-first and Identity-first Research

The majority of the research included are literature reviews rather than qualitative or quantitative studies. It is clear the topic of disability language and analogous subjects is relevant and controversial; however, the opinions of members within disability culture are seldom studied (Bickford, 2004). While each study provides new insight to the field, there are often limitations. First, the participant pool of each study is homogenous in either their age or disability. In a study by Bickford (2004), participants were required to have some form of a visual impairment although they varied in age and gender. However, Bickford (2004) associated his identity-first language related results to only using participants with a visual impairment. Because the National Federation of the Blind has

been so outspoken on their preference of identity-first language, the results of the study could be attributed to the participant's impairment and their loyalty to their disability community (Bickford, 2004).

Fernald (1995) had a variety of participants from 13 English-speaking countries; nonetheless, only professionals in the field of disability legislation were consulted for the survey. Similarly, DeMieri (2012) limited his study to examining the perceptions of graduate students in the field of social work. There were no significant results with regards to person-first language; however, DeMieri (2012) credited the lack of statistical significance to small sample size rather than the lack of participant variation. In another study investigating the relationship between person-first language and stuttering, St. Louis (1999) used a participant pool made up of speech-language-hearing impaired clients, the parents of clients, and speech-language pathologist students. Despite including a participant group that consisted of the general public, the majority of the participants had ties to speech-language pathology (St. Louis, 1999). Not unlike the National Federation of the Blind, ASHA has also been outspoken towards their preferred use of person-first language. Therefore, it is not surprising the results indicated the participants were overwhelmingly in favor of person-first language.

A second limitation of the four research studies employed in this thesis is the age of the participants. The youngest participant across all four studies was 21 years old (Bickford, 2004; DeMieri, 2012; Fernald, 1995; St. Louis, 1999). Although it can be argued that participants in disability language research should be of an older age so researchers can ensure their opinions are both mature and valid, there is an entire generation of disability culture that has not yet been studied. Munn stated that children

with disabilities are a “minority within a minority” (as cited in Bricout et al., 2004, p. 46). This population comes with their own specific set of hurdles that may explain their absence in research. Both “their status as dependents and the special needs of both child and family” (Bricout et al., 2004, p. 46) make this population desirable yet elusive for researchers. An older child with a disability, perhaps in their teenage years, could potentially create a new branch of research. Still, the teenage years can be characterized by rebellious attitudes and unstable opinions making them unreliable participants. When studying preschool-aged children, researchers are essentially dealing with the parents as the participants. However, the unique factor of this situation is many parents have no prior knowledge of disability culture (Bricout et al., 2004). Therefore, these parents are faced with a myriad of difficult decisions to make on behalf of their child in an area that they are unfamiliar with. Not only would the experiences of this population and their parents give new insight to the field, the practical implications would have the potential to change how professionals interact with families during early intervention and preschool programs.

2.4 Summary

After reviewing the literature, researchers have identified multiple facets of disability culture. People with disabilities are faced with inequality on a daily basis due to the subconscious stigmatization placed upon them by the majority of society. Because of their plight, many individuals find comfort within disability culture or their own impairment-specific community. Researchers, however, have discovered the entry process into the culture is more complex than simply having an impairment. It takes the individual years of self-reflection (adaptation) and acceptance (adjustment) all while

creating a positive self-identity. These processes can be supported by those in the individual's immediate environment, including peers in the disability community. One of the major factors in creating one's disability identity is choosing a preferred disability language. While person-first language is common in academia, part of the growing positive self-identity movement in disability culture is the shift towards identity-first language. Identity-first language represents claiming one's disability; having pride in every aspect of self. By having pride in an impairment, the concept that society stigmatizes and oppresses individuals through deciding what is 'normal' is lessened.

Although research on disability culture has increased as of late, there are still multiple gaps. After reviewing the literature, it could be theorized that the plight of disability culture only occurs in adulthood since that is the only population that has been studied. However, children with disabilities and their families are one of the most in-need sub-populations within disability culture. One limitation to current research is the similarity between participants in a single study either through age or impairment. Within the population of preschool-aged children with special needs, the participant pool is varied simply because of the nature of impairments. Some impairments (i.e., Fragile X, Down Syndrome) are present at birth giving parents and the child at least three years to begin the adaptation process. Families with a child who has been diagnosed with Autism or a Developmental Delay are still new to the idea of entering disability culture. Comparing the differences between these families and how they process the hurdles that arise naturally with having a child with a disability would benefit future families as well as several fields in academia.

In education and psychology, the opinions of parents with young children are studied on a multitude of topics (i.e., kindergarten transition, child progress, amount of support/communication). Therefore, it is surprising to find a lack of literature discussing how parents choose a disability language for their child. Bronfenbrenner's (1977) theory on the relationship between a child and their environment is one of the most widely referenced family theories. Because Bronfenbrenner did not specify as to whether or not the child must be typically or non-typically developing for his theory to be applied successfully, it can be assumed that non-typically developing children are impacted by their environments in the same manner as typically developing children. Dunn (2016) expands on this theory by explaining how much a person with a disability's environment plays a part in both their entrance into disability culture as well as their choice of disability language. Although Dunn was referring to adults with disabilities, a return to Bronfenbrenner's theory indicates that children, like adults, are impacted by their environment. Therefore, it can be assumed that for a child with a disability, the actions of their family, peers, teachers, and therapists all have a role in how they experience disability culture. Additionally, a parent's environment is likely to impact their disability language preference for their child. Because environment plays a major part in how a child experiences disability culture and how a parent assists their young child through disability culture, as professionals it is imperative to understand our role for these families. By gaining knowledge through research as to what the parent and child are experiencing, more appropriate support can be given to families in the future.

METHODOLOGY

In order to analyze the disability language preferences of parents with preschool-aged children with special needs, this study used descriptive research. The results of this study have the potential to provide multiple fields with new information regarding disability studies and an individual's entrance into disability culture. Many past studies have evaluated the disability language preferences of individuals over the age of 18 and participant pools are homogenous when looking at diagnoses. This study was one of the first in its genre to collect data on children between the ages of three and five, as well as include multiple disabilities within the target population.

3.1 Rationale

In the researcher's past academic career, the researcher was unaware of any option for disability language beyond person-first language. During a graduate course, the debate between person-first language supporters and identity-first language supporters was discovered. The controversy between the two is so influential that in the newest publication of the APA manual, disability language was addressed. In 2010, APA wrote "Respect people's preferences; call people what they preferred to be called. ...you may need to ask your participants which designations they prefer..." (p. 72). However during the initial research phase, it became clear that not all individuals can make this choice for themselves – particularly those who are beginning their entrance into disability culture within the first few years of their life. In the situation of preschool-aged individuals, their guardians are often making the decision for them. While many parents remain unaware that they have made a decision regarding the child's disability language,

many are also unaware of the importance of the decision. The novelty of this specific research field coupled with the potential magnitude of the results leads to a topic that requires further study.

3.2 Participants

Participants for the study were limited to parents of children with disabilities. In order to analyze the younger population of disability culture, the children were between the ages of three and five at the time the survey was taken, with either an Individualized Education Plan (IEP) or an Individualized Family Service Plan (IFSP). Parents meeting the eligibility criteria were selected through current enrollment records at a preschool located in the southeastern region of the United States and through an organization that assists the parents of children with disabilities. All participants were fluent in the English language. Despite culture being investigated as a factor with a possible correlation to a parent's disability language preference, there is currently no literature to support the inclusion of non-English speaking families in the study. The major countries involved in the debate between person-first and identity-first language (i.e., England, United States, Australia) predominantly speak English (Dunn & Andrews, 2015; Fernald, 1990; Harpur, 2012;). Without supportive research, the positive or negative ramifications of including non-English speaking parents in the sample population is unclear.

Potential participants were recruited from either a preschool or a local parent organization. Parents from the preschool were identified as meeting the study's criteria by their child's teacher while parents from the parent organization were not identified but rather given access to the survey through a social media post. Only one parent from each family was asked to complete the survey. The survey was electronic and was completed

on a volunteer basis. Because of state laws, the preschool and organization must accept children displaying a wide variety of disabilities. This ensured a varied sample for the demographic ‘child’s diagnosis’ and therefore, attempted to mimic the differences found throughout disability culture.

Thirty-two participants attempted the survey. After incomplete surveys ($n = 5$) and participants who did not meet the eligibility criteria ($n = 13$) were removed from data analysis, 14 participants comprised the sample. Responses were removed if they reported their child was less than three years old or more than five years old. Of the sample, 13 were female and one was male. The majority of participants identified their ethnicity as Caucasian ($n = 10, 71.4\%$), with African American ($n = 1, 7.1\%$) and Hispanic ($n = 2, 14.3\%$) being represented as well. One participant preferred not to report their ethnicity. Ages of participants ranged from 24-44, with the mean age being 33.2 ($SD = 5.5$). Participants were also asked to report their highest level of education. Answers varied from high school graduate ($n = 2, 14.3\%$) through doctorate ($n = 1, 7.1\%$). The majority of participants had either some college experience ($n = 4, 28.6\%$) or a college degree ($n = 4, 28.6\%$). Most of the participants’ children were three years old ($n = 8, 57.1\%$) and represented 10 different diagnoses (See Table 1). Sixty-four percent ($n = 9$) of the children received their diagnosis between birth and their second birthday.

Diagnosis	Frequency	Percent
Developmental delay	1	7.1
Autism, Speech delay	1	7.1
Speech delay	1	7.1
ADHD, Developmental delay	1	7.1
Speech delay, Behavior problem	1	7.1
Deaf/hearing loss	2	14.3
Autism	3	21.4
Speech delay, Developmental delay	1	7.1
Down Syndrome	1	7.1
22q deletion syndrome	1	7.1
Apert Syndrome	1	7.1
Total	14	100.0

3.3 Setting

Convenience sampling methods were employed by using the population at one preschool in a southeastern state where English is the primary language of instruction, and through a parent resource organization.

Preschool.

The preschool is made up of typically and non-typically developing children. A non-typically developing child is labeled as an Exceptional Child (EC) and subsequently placed into a blended or self-contained classroom. Because all children under the EC program—regardless of setting—have an IEP or an IFSP, the EC program served as the foundation of the sample. All children enrolled at the school attended on either a full-day or part-day basis but attended the school five days a week from August to June. The exact demographics for the EC population in the target school year are unknown.

Parent Organization.

Members of the organization are parents who have at least one child with special needs. Parents receive resources –both formal and informal—in addition to trainings through the organization. Parents are not restricted from being members due to their child’s age and can participate as much or as little as they want. Much of the organization’s contact with its members is online, either through email or social media posts.

3.4 Piloting the Instrument

Prior to sampling the target population for the study, the researcher piloted the survey to test for reliability. The instrument was given to families whose child had recently graduated from the EC program at the end of the 2016-2017 school year. Due to the novelty of the subject matter, the survey used was created for this study by the researcher. Because there was no past literature to support the validity and reliability of the survey, piloting the instrument was intended to screen the instrument for potential errors as well as giving the survey social and content validity. Representatives from five families agreed to complete the survey prior to the beginning of the study and were asked to contact the researcher afterwards with any questions, comments, or concerns in an attempt to increase the survey’s social validity. Although each parent completed the survey, no feedback was given. Therefore, the social validity of the survey remains unknown and no changes were made to the instrument.

3.5 Instrument

Survey (Appendix B)- the survey was used to gain background information anonymously on the study's sample. The first page of the online instrument was a waiver of consent. The next section consisted of multiple choice questions in which the participant self-reported their race, age, education level, child's diagnosis, the age their child received the diagnosis, the child's gender, and their gender. After the preliminary questions, participants were asked a series of multiple choice, open-ended and Likert scale questions regarding their child. These questions were geared toward gaining a better understanding of how the parent views their child within the context of his/her disability by analyzing their goals for the child, the services their child was receiving at the time of the survey, and ultimately, the disability language they have chosen to use with their child. The survey took each participant less than 10 minutes to complete.

3.6 Procedure

After the researcher-created survey was approved by UNC Charlotte's Institutional Review Board (IRB), data collection was split into two phases, based on setting and time. The first phase (preschool) took place during the Fall of 2017 while the second phase (parent organization) took place during the Winter/Spring of 2018. The survey was electronic and remained open for six weeks during both phases, giving all participants ample time to finish. Participants were not asked to give their name or their child's name, nor did the researcher have access to the participant's emails therefore all information was kept anonymous.

Phase One: Preschool.

At the preschool, open house occurred before the children's first day of school. During open house teachers sent home a multitude of forms and informational packets about the school, its procedures, and their individual classroom. During this time, the researcher gave each teacher the flyer (Appendix A) with general information about the study and a timeline for the survey and asked that they give it to each EC family in their classroom that met the study's criteria. If a family meeting the criteria could not attend open house, the flyer was given to the family by their child's teacher the following week at a home visit. The researcher then crafted an email containing the link to the online survey and brief instructions. One week after families received the flyer, the researcher asked all teachers to send the email with the survey link to each family who had received the flyer. Families who entered the school year after open house but prior to the survey closing were not included in the study.

A reminder email was sent to participants by their child's classroom teacher one week after data collection had begun, three weeks into data collection, and again with one week left. Ninety-three informational flyers were handed out to potential participants. From this pool, 11 surveys were returned. Once the survey closed, answers were downloaded into Statistical Package for the Social Sciences (SPSS) (IBM Corp., 2016) and coded accordingly—partial answers were discarded. Once surveys that were incomplete ($n = 2$) and not meeting the study's eligibility criteria were removed ($n = 0$), 9 surveys remained.

Phase Two: Parent Organization

Because the majority of the organization's interactions with its members were online, the informational flyer was shared via the organization's social media pages. The flyer was made available to anyone who 'followed' the organization, either through Facebook or Twitter, and therefore was not exclusive to the organization's members. The exact number of potential participants is unknown. Because the flyer was shared online, the survey was immediately open to participants. Similar to the first phase, reminders were created by the researcher but took the form of social media posts, rather than an email. Reminder posts were shared through the organization's social media accounts three weeks into data collection and with one week remaining. Twenty-one surveys were returned. After the survey closed, partial answers ($n = 3$) and surveys not meeting the study's eligibility criteria ($n = 13$) were discarded and completed surveys were downloaded into SPSS (IBM Corp., 2016) and analyzed. The final sample from phase two included five participants.

3.7 Data Analysis

Once the data from the survey was collected and downloaded from Qualtrics (Qualtrics, Provo, UT) into SPSS, each response was given a predetermined code by the researcher. The answers were organized both by question and by answer. For example, answers to the question concerning the participants gender were coded with a 1 for a 'male' response and with a 2 for a 'female' response. Codes were then input into the data analysis program SPSS. Various analytic tests (i.e., Pearson r , descriptive statistics) were subsequently performed to analyze the data and identify possible correlations between participants characteristics and their disability language preference.

RESULTS

The present study used descriptive research methods to examine the disability language preferences of parents with young children. During the course of the study, the researcher attempted to answer four central questions through an online, researcher-created survey. After responses to the survey were coded into SPSS, descriptive statistics and bivariate correlations (Pearson r) were used in an effort to answer the questions.

1. What form of disability language do parents choose to adopt for their preschool-aged child immediately following a diagnosis and prior to their child's ability to assist in the decision-making process?
2. What factors influence the decision-making process of parents while deciding what form of disability language to use when referring to their preschool-aged child with special needs?
3. How does the disability language preference of parents relate to the intensity or frequency of services their child receives during preschool programs (Section 619)?
4. How does the disability language preference of parents relate to the short-term goals they have created for their child?

4.1 Disability Language Choice

Participants overwhelmingly chose person-first as their language of choice when referring to their child with special needs ($n = 12, 85.7\%$), as seen in Table 2. One participant (7.1%) reported using identity-first language exclusively, while another preferred to use both identity-first and person-first language interchangeably. However,

only 28.6% of participants described their decision as intentional. Out of the 12 participants who preferred person-first language, four (28.6%) described feeling ‘somewhat uncomfortable’ and two (14.3%) participants felt ‘extremely uncomfortable’ when someone referred to their child using identity-first language.

Table 2
Disability Language Choices

Disability Language	Frequency	Percent
Person-first	12	85.7
Identity-first	1	7.1
Both	1	7.1
Total	14	100.0

4.2 Influential Factors

When given a set of choices about what influenced their decision to use the preferred language, four (28.6%) out of the fourteen participants indicated that their child’s diagnosis was the only influence, and one (7.1%) indicated that the parent’s opinion of disability language was the only influence among the choices provided. Beyond their child’s diagnosis and opinion, participants described a combination of factors that influenced their decision. A parent’s level of education combined with a nondisclosed factor was reported by three (21.4%) participants as influential, followed by a parent’s opinion, education, and their child’s diagnosis (n = 2, 14.3%).

Table 3
Influential Factors

Factors	Frequency	Percent
Child's diagnosis only	4	28.6
Parent opinion only	1	7.1
None	3	21.4
Parent opinion, parent education, child's diagnosis	2	14.3
Parent opinion, other	1	7.1
Parent education, other	3	21.4
Total	14	100.0

Note. Participants could choose multiple responses.

4.3 Intensity and Frequency of Services

Intensity—referring to the number of services a child is enrolled in—of services was compared with disability language choice in a bivariate correlation. The number of services each participant's child was enrolled in was identified ($M = 4.50$, $SD = .94$). Results of the Pearson correlation revealed there was no significant relationship between the intensity of services received by a child and the disability language used by their parent, $r = 0.317$. The frequency of services—defined as the number of services received on a weekly basis—was reported by two of the fourteen participants and therefore no subsequent analyses were run. Although there was no statistically significant relationship between the two variables, more than half of participants (57%) described their child's service provider as using person-first language.

4.4 Short-term Goals

Because of the small sample size, a bivariate correlation could not be used to compare the short-term goals a parent made for their child and their disability language preference. Participants were asked to describe the goals they hoped their child would achieve before attending kindergarten. Response options included safety, more communication, self-help skills, improved social skills, pre-academic skills, and other.

Participants could choose as many options that applied. Half of the participants ($n = 7$, 50%) chose all five of the goals. Five participants (35.7%) chose four goals and the remaining two participants chose two goals (7.1%) and six goals (7.1%) respectively. Communication was chosen unanimously amongst the participants ($n = 14$, 100.0%), followed by social skills ($n = 13$, 92.9%) and safety ($n = 12$, 85.7%). Table 4 shows the frequency of each goal.

Number of Goals	Frequency	Percent
Two	1	7.1
Four	5	35.7
Five	7	50.0
Six	1	7.1
Total	14	100.0

DISCUSSION

Due to the lack of research on parent preferences of disability language, the purpose of this study was exploratory. Previous research on disability language preferences often involved adult participants with the same disabilities or included professionals who, because of their work, may have had biases (Bickford, 2004; Dupré, 2012; Fernald, 1995; St. Louis, 1999). This study was the first to examine what disability language is being used to refer to children with special needs who are between the ages of three and five. In addition, multiple disabilities were represented in the sample, with some comorbidity amongst the participants. Despite several attempts to reach larger participant pools, the final sample contained 14 participants.

The results revealed the majority of participants prefer person-first language when speaking about their child. Only one participant reported using identity-first language. This supports research conducted by Bickford (2004), DeMieri (2013), and St. Louis (1999). Of those surveyed, four indicated their decision was intentional. Participants were given the choice of five potential factors that influenced their decision—their child's diagnosis was indicated the most, followed by parent's opinion, parent's education, and 'other'. One possible explanation for the overwhelming support of person first language is semantics. There are some diagnoses that do not translate easily from person-first language into identity-first language, some of which were represented in the study's population. These include but are not limited to Apert syndrome, 22q deletion syndrome, and unspecified behavioral problems. Furthermore, the age of the child when they received their diagnosis may have also been an influential factor. The majority of the participants' children were diagnosed between birth and two years of age.

After reporting their disability language preference and the factors that influenced their decision, participants were asked what their comfort level was when someone used either person-first or identity-first language when speaking about their child. With the majority of participants preferring person-first language, a small number of participants reported feeling somewhat or extremely uncomfortable when someone referred to their child using identity-first language. Considering the frequency of services the participants' children received and that more than half of service providers being described as favoring person-first language, it is plausible to hypothesize that having person-first language being modeled more frequently by professionals could have influenced the parents to do the same. These results are similar to those found by DeMieri (2012) and St. Louis (1999) in that current or future service providers preferred person-first language. Research conducted by Jensen et al. (2013) further supports the current study's findings by recommending professionals in the mental health field use person-first language when referring to their patients.

Due to the open-endedness of the question that asked participants to report the intensity and frequency of their child's current services, many parents chose not to answer in detail how often their child received various therapies. When a Pearson correlation was run between the number of services and disability language preferences, the result was not statistically significant. This could have been affected by the study's small sample size. Although Pearson correlations do not require a specific *n* size to achieve a significant result, a small sample size does reduce the power of the test (McMillan, 2016). Future research should focus on more attractive recruitment methods in an attempt to boost the number of participants. Another possible cause for the lack of

significant results lies in the word choice for the corresponding question on the survey. Not only did participants not report the frequency of services, but ‘EC preschool program’ was not included as a service option. Ten of the fourteen participants were recruited directly through an EC preschool program in which their child could receive speech, occupational, and physical therapies. With this many possible therapies occurring during the school day, it is reasonable to believe that many children do not need or have time for additional services. Therefore, when asked to report any outside services, their options were limited.

A bivariate correlation was attempted but unsuccessful at finding a significant relationship between a parent’s disability language preference and the short-term goals they had created for their child. This question should be revisited in future studies with larger participant pools. Long-term goals should also be addressed, as they were examined in this study but were not emphasized.

5.1 Limitations

As previously predicted, a lack of participants was a major limitation for this study. After the original phase of the study concluded with only ten participants, efforts were made to change the recruitment methods and re-open the survey to a new and larger participant pool. Because of the small number of participants, the results of the study are not generalizable. Despite representing one of the most diverse populations belonging to a study on disability language, several categories of disabilities are not included (i.e., physical disabilities, mood disorders). The recruitment methods themselves were also a limitation. In the preschool setting, potential participants received the recruitment flyer during their child’s open house or during a planned home visit. The original thought

behind this tactic was that parents would be paying more attention to the paperwork coming home in their child's folder and were less likely to throw out the flyer. However, because the flyer did not require immediate action, it is possible that parents disregarded it entirely and instead focused on the papers that needed their attention. There was also no accountability for the reminder emails that needed to be sent out to families while the survey was open. Although the researcher created the email and forwarded it to teachers, there is no guarantee that the teachers sent the email to families. One benefit to the preschool, though, was everyone who received a recruitment flyer automatically met the study's criteria. During the second phase of recruitment, the methods were adjusted so a larger number of potential participants could be reached. A parent organization was asked to post the recruitment flyer on their social media pages. Anyone who followed the organization on Facebook or Twitter had access to the post and the link to the survey. Therefore, individuals who did not meet the criteria for the study were able to attempt the survey. This resulted in multiple incomplete surveys. Out of the 25 responses from the parent organization, only six were useable. Finally, the lack of previous research leading to a novel, researcher created survey being used was a final limitation. Although the survey was piloted prior to the study beginning, only five parents agreed to take the survey—none of which provided feedback that would have added to the survey's social validity.

5.2 Future Research and Implications

Similar to other studies, additional research is needed to further our knowledge on disability language. The current study added a new dimension to previous research by examining the preference of parents and combining multiple disabilities into one sample.

The results were not found to be statistically significant, but because of the novelty of the subject matter, they hold a great deal of practical significance. Of the fourteen parents that participated, person-first language was overwhelmingly preferred. Their decision to use person-first was not premeditated (71.4%) but instead was influenced by factors such as the child's diagnosis, and parent education/opinion. This information can be used to assist service providers as they encounter families with different disability language preferences however, until more information is available, person-first language should still be used unless otherwise specified by the families.

Future research should focus on using qualitative methods so a database of information on disability language can continue to be built. Interviews should also be added as a method of data collection so individual answers can be studied more in depth. Researchers should consider using more attractive methods of recruitment such as offering incentives for turning in completed surveys or using paper and pencil surveys—as opposed to online—because they have higher return rates. Limiting participant criteria should be kept at a minimum so a variety of disabilities can be included. Finally, longitudinal studies could also be considered. Learning how a parent's preference of disability language can influence a child's preference as they become able to make their own choice would benefit several fields but would take many years of research.

CONCLUSION

For centuries, society has moved through various conceptual models as their views on individuals with disabilities has evolved. Until recently, person-first language was thought to be the only language appropriate and sensitive enough to address those residing in disability culture. There now exists a highly individualized debate amongst professionals and stakeholders regarding which language is best: person-first or identity-first. However, although there are people who use self-reflection to decide which language is best for themselves, children are having the choice made for them. Parents of children with disabilities are faced with the task of choosing between the two disability languages, a decision which could impact their child as they continue to grow. This study sought to answer several questions in an attempt to discover more about this process: What factors are influencing a parent's decision?, and What disability language are they choosing for their child? Furthermore, how does the preferred disability language affect the services a child receives in addition to the short-term goals a parent has for their child? While these questions were answered, a small sample size limited the generalizability of the results.

The findings of this study provided practical significance as well as implications for future research. Parents of young children with special needs favor person-first language over identity-first language. No differences were found between the child's diagnosis and disability language, although this was reported as a major influence as parents were making their decision. Apart from the hypotheses, anecdotal evidence regarding the parent's decision (e.g., short and long-term goals, comfort with both languages) can be used to inform future research. As these findings join those of past

research studies in building a foundation for disability language, professionals will gain a resource to help them consider and search for a more inclusive language.

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Appendix A

Parents,

My name is Lindsay Alpaugh and I am an EC Teacher Assistant at a preschool and a graduate student at the University of North Carolina at Charlotte. Through the graduate school, I have created a research study entitled “Examining Parent Preferences on Disability Language Regarding Their Preschool-Aged Child With Special Needs” that I will begin conducting at your child’s school and the ECAC during September 2017. This study has the approval of a committee of faculty members employed at UNCC and the Institutional Review Board. The purpose of the study is to examine the disability language preferences of parents with preschool-aged children with special needs. Past research discusses the importance of individuals choosing between person-first (e.g., child with Autism, child with Epilepsy) or identity-first language (e.g., Autistic child, Epileptic child) for themselves however there is currently no research examining how young children are introduced to disability culture or how a disability language is chosen for them.

The data collected will serve several fields of academia with preliminary information concerning preschool-aged children and their parents in addition to allowing the participants of the study reflect on their child through the lens of disability culture. To collect data, an electronic survey will be sent in one week by your child’s teacher. Only one parent/guardian per family will be asked to volunteer to complete the survey and all answers will be anonymous to both the researcher and the child’s teacher. Because participation is voluntary, you may refuse to participate at all or may choose to end your participation once you have begun the survey. Any emotional distress participants may receive after reviewing their child’s diagnosis will be connected with the appropriate resources (e.g., therapists, support groups) via the researcher or the responsible faculty member. Once the survey is started, it will not take more than 10 minutes to complete. This study aims to give participants total anonymity. The researcher will be the only one with access to the survey which will not provide any identifiable information including your email, name, or your child’s name. Similarly, your child’s classroom teacher/ECAC representative will be the only individual with access to your email address but will not have access to your survey answers. If you have any questions regarding myself or the study, please do not hesitate to email me at lindsay.alpaugh@cabarrus.k12.nc.us, my supervising faculty member JaneDiane Smith (jdsmith@uncc.edu), or to contact the Institutional Review Board for Research with Human Subjects (704.687.1871)

Thank you,

Lindsay Alpaugh

Appendix B

Examining Parent Preferences

Parents,

Thank you for participating in my survey. This survey is meant to examine your preference of disability language (person-first or identity-first) regarding your child with special needs. The survey will not take more than ten minutes to complete. However, the survey will remain active for six weeks so feel free to complete the survey as needed. If you have any questions about a specific question or want more information on the study I am conducting, please do not hesitate to contact me at lalpaug1@uncc.edu or my Faculty Advisor at jdsmith@uncc.edu. Thank you again for your time!

The purpose of this study is to examine which disability language (person-first or identity-first) parents use when speaking about their preschool-aged child. Person-first language involves the speaker mentioning the person before they talk about their impairment/disability. In other words, the person comes first, the disability/impairment is second. To use person-first language, use the following sentence structure: (Child's name /My child) has/is diagnosed with (name of impairment/disability)

Person-first language examples:

- John has Autism
- Bobby is diagnosed with Fragile X Syndrome
- My child with Epilepsy
- Sarah has a Visual Impairment
- Julie is diagnosed with a Developmental Delay

When a speaker uses identity-first language, they mention the disability/impairment before the person. The disability/impairment comes first, the person is second. To use identity-first language, use the following sentence structure: (Disability/impairment) child

Identity-first language examples:

- Autistic child
- Downs child
- Epileptic child
- Blind/Visually Impaired child
- Developmentally Delayed

1 What gender do you identify with?

- Male
- Female
- Prefer not to answer

2 What is your age?

3 What is your highest level of education?

- Less than high school
- High school graduate
- Some college
- 2-year degree
- 4-year degree
- Professional degree
- Doctorate

4 What ethnicity do you identify with?

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Hispanic
- Other _____
- Prefer not to answer

5 What is your marital status?

- Married
- Widowed
- Divorced
- Separated
- Never married
- Prefer not to answer

6 How many children do you have?

7 What is the age of your child currently?

- Younger than 3 years
- 3 years
- 4 years
- 5 years
- 6 years or older

8 What is your child's diagnosis?

9 How old was your child when he/she received their diagnosis?

- Diagnosis was received prenatally
- Birth to 1 year
- 2 years old
- 3 years old
- 4 years old
- 5 years old

10 What disability language (person-first or identity-first) do you use when speaking about your child? Person-first language involves the speaker mentioning the **person**

before their impairment. Identity-first language involves the speaker mentioning the **impairment before the person.**

- Person-first language (examples: Child with Autism, Child with Down Syndrome, Child who is Blind, Child with Epilepsy)
- Identity-first language (examples: Autistic Child, Down's Child, Blind Child, Epileptic)
- Both interchangeably

11 How did you decide which disability language to use with your child? Was the decision made consciously or did you use the disability language that came naturally while interacting/thinking about your child?

- Yes, my decision was intentional
- No, my decision was not premeditated

12 Does everyone in your household refer to your child with the same disability language?

- Yes
- No

13 What factors, if any, influenced your choice of disability language? Click all that apply

- Your Ethnicity
- Child's diagnosis
- The opinions of others (family, friends, service providers)
- Your level of Education
- Other _____
- None of these

14 What services is your child currently receiving outside of the EC program? (food therapy, ABA, occupational therapy, speech therapy, etc.) Please specify all of the services your child has received in the last 90 days.

15 Do you, your child, or your family members attend or support any diagnosis specific activities in the community? (The Buddy walk for Down Syndrome, Autism Charlotte,

Fragile X Foundation, etc.) If yes, please specify what activities you have been involved with.

- Yes _____
- No

16 Does anyone else in your family have a disability or impairment? If yes, please specify your relation to the family member (i.e., sister, cousin, uncle) and their disability.

- Yes _____
- No

17 What are short-term goals you hope your child will achieve before entering kindergarten? Choose all that apply.

- Safety Awareness
- Communicate more (Verbally or non-verbally)
- Self-help skills (i.e., dressing, eating, pottyng)
- Improved social skills (i.e., turn taking, sharing)
- Pre-academic skills (i.e., letter recognition, pre-writing skills)
- Other (please specify) _____

18 What are your long-term goals for your child? Choose all that apply.

- Obtain a job
- Live independently
- Maintain social relationships
- Other (please specify)

19 What is your comfort level when someone uses person-first (child with Autism, child with Down Syndrome, child who is Blind, child with Epilepsy) language to refer to your child?

- Extremely comfortable
- Somewhat comfortable
- Neither comfortable nor uncomfortable
- Somewhat uncomfortable
- Extremely uncomfortable

20 What is your comfort level when someone uses identity-first (Autistic child, Blind child, Epileptic child) language to refer to your child?

- Extremely comfortable
- Somewhat comfortable
- Neither comfortable nor uncomfortable
- Somewhat uncomfortable
- Extremely uncomfortable

21 Have you ever experienced a service provider use disability language when speaking about your child? For example, how does a therapist or teacher refer to your child? If yes, did they use person-first or identity-first language?

- Yes _____
- No

22 Did their use of disability language influence your disability language preference?

- Yes
- No

Appendix C

Teachers/Administrators,

Thank you again for helping me contact families for my study. Please copy and paste the bolded paragraph into a new email and individually send it to all English-speaking families with a child in your classroom who is enrolled in the Exceptional Child program.

Families,

You should have received a copy of the recruitment letter from your child's classroom teacher last week. If you still have questions regarding the nature of the study, please contact Lindsay Alpaugh at lalpaug1@uncc.edu or Jane Diane Smith at jdsmith@uncc.edu. Below is the link to the survey. The survey will remain open for six weeks so please feel free to complete it as you are able. Overall, the survey should not take more than ten minutes of your time to complete. Again, any participation in this study is voluntary and can be stopped at any time without any notice to the researcher. Thank you again for your consideration!

Lindsay Alpaugh

[Examining Parent Preferences Survey](#)

Appendix D

Please copy and paste the following message onto your social media page.

WHICH LANGUAGE DO YOU PREFER?



Attention Families with children between the ages of 3 and 5: Your input is needed!

Our organization is pleased to share information about this unique research project being conducted by a UNC Charlotte graduate student. She is examining the preferences of disability language of parents who have a child between the ages of three and five with special needs. Disability language refers to person-first language (person with autism, child with Epilepsy) and identity-first language (Autistic person, Epileptic). The data collected from this study will provide novel information to several fields of academia. Any information provided by participants will be completely anonymous. This study has the approval of UNCC, the Institutional Review Board, and the organization's Executive Director. All participation is voluntary but if you wish to participate, we ask that you have a child with special needs between the ages of three and five, speak English, and have access to the internet. Only one parent from each family should participate. If you meet this criterion and wish to participate, please click on the link at the end of the post to access our survey. The survey will take less than ten minutes to complete. Thanks for your consideration!

[Examining Parent Preferences Survey](#)

Appendix E

Please copy and paste the following message onto your social media page. These should be sent out with three weeks left into the study and with one week left.

Families,

Just a reminder! There are only (insert time left) week(s) left to complete the Examining Parent Preferences Survey.

[Examining Parent Preferences Survey](#)