Encouraging the Acceptance of Human Differences Through Children's Literature
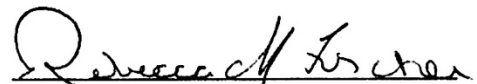

by

Hannah Berthelson

A thesis presented to the Honors College of Middle Tennessee State University in partial
fulfillment of the requirements for graduation from the University Honors College
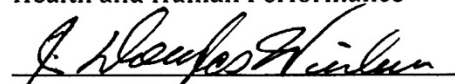

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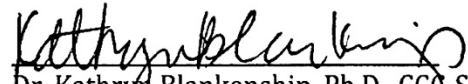
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In memory of Carol Reed, our speech superhero,

and for Chase, whose bravery showed us all what it means to go

to infinity and beyond.

Abstract

The present Honors Thesis consists of a research project utilizing a qualitative design and an accompanying creative product in which the author sought to encourage the acceptance of general human differences through children's literature. The purpose of the qualitative research component was to collect and understand the perspectives of parents and adults who have lived with a communication disorder in any way and who have experienced attending speech-language therapy for the first time. Participants included parents of children currently enrolled in speech-language therapy and adults who were enrolled in speech-language therapy as children. The emotions that the participants experienced in the face of comprehending a communication disorder and incorporating a new therapy and therapist into their routines were gathered and analyzed to shape the plot of a children's storybook. The storybook is intended to help both parents and children better understand speech-language therapy and that communication disorders are just one of many differences expressed by the population of the entire world.

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Encouraging the Acceptance of Human Differences through Children's Literature

Introduction

Every person on Earth shares a nearly identical biological makeup, with a brain that receives various electrical signals and in turn commands a complex system of nerves, muscles, veins, arteries, and organs that comprise the entire mechanism of a typical human being. However, alongside that basic fact of life is the corresponding absolute that each human is different. All individuals who contribute to the Earth's population of over seven billion people have unique personalities, smiles, skin markings, fingerprints, voices, interests, perceptions of the surrounding world, as well as countless other features. Continually educating individuals of all ages on accepting differences in others is pertinent, for some differences are not always widely understood or perceived with an open mind, especially those that make a more obvious impact on an individual's daily life.

Aside from the idiosyncrasies that make everyone who they are in appearance and personality, there are a number of individuals who express various disorders and disabilities that affect speech, language, hearing, motor, and cognitive abilities (Kim, Carlson, Curby, & Winsler, 2016). These differences vary; they may be expressed in a young person with an articulation disorder who is not understood by his or her peers at school, or through an individual with a physical disability who is avoided in the grocery store. Differences, regardless of how salient, are not always accepted or appropriately approached by society in which the norm is to be a typically developing person. Responses of fear or unacceptance can instill a negative self-perception and lowered self-

esteem within an individual who is learning to accept these differences themselves (Jerome, Fujiki, Brinton, & James, 2002).

Reduced Self-Esteem and Specific Language Impairment (SLI)

Children have much to carry as they grow older and navigate general socialization through school, home, and play. A child with a physical disability or communication disorder may struggle even more so when navigating daily life alongside peers who do not understand that disability or disorder. Clear and successful communication is a crucial aspect to establishing substantial social skills and academic success, which in turn aid the development of positive self-esteem (Glenn & Smith, 1998). Unfortunately, communication disorders have been found to be the second most common handicapping condition in school-aged children, and therefore make a significant impact on the early social interactions that shape self-concept (Glenn & Smith, 1998). Furthermore, many students with communication disorders are penalized socially by their peers, causing those students to reconsider the type and number of social interactions that they approach in order to avoid further negative experiences (Hart, Fujiki, Brinton, & Hart, 2004).

This trend of penalization for communicative differences spans a multitude of communication disorders. One communication disorder in particular that has been examined in research is specific language impairment (SLI). This communication disorder may not be as obvious in expression as other disorders, such as articulation impairment. However, SLI is characterized by impaired language skills, which can induce secondary characteristics such as social deficits caused by fewer opportunities to practice social skills because overall language ability is weaker. These social deficits may be the most significant cause of impaired social interaction in individuals who have SLI

(Hart et al., 2004). Hart, and colleagues (2004) examined the correlation between the severity of an individual's SLI and the depth of social impairment experienced by the individual. Eighty-two participants, 41 children with SLI and 41 children with typical language abilities, comprised the research sample. The group of children with SLI was divided into two subgroups: individuals who expressed a lower severity of SLI and individuals who expressed a higher severity of SLI. The Teacher Behavioral Rating Scale (TBRS) was completed by each child's teacher and the fourth edition of the Clinical Evaluation of Language Fundamentals (CELF-4) was administered to measure the participants' communication abilities. By comparing two groups of children with SLI and a group of children with typical language abilities, the researchers found that children with SLI tended to exhibit withdrawal in social settings more often than the typically developing children (Hart et al., 2004). The researchers also found an increased level of social proficiency in the subgroup of children with less severe forms of SLI and poorer prosocial ability in the children with more severe forms of SLI (Hart et al., 2004). Through rejection by peers or the work of underlying processing deficits, children with SLI may struggle significantly with social interactions and the development of their own social skills.

Furthermore, this hindrance in social function seems to make a more noticeable impact on self-esteem as age increases (Jerome et al., 2002). In early childhood, children are tremendously positive in their self-perceptions as they consider their own achievements and abilities in absolutes, and they are not yet able to compare their own capabilities to those of the children or adults around them (Jerome at al., 2002). This unrealistically positive self-evaluation prevents young children from acknowledging that

there are differences between themselves and their peers. Jerome et al., (2002) note, however, that "the risk for poor self-esteem intensifies as children enter middle to late childhood and become increasingly able both to compare themselves with their typically developing peers and to internalize the negative perceptions of others" (p. 702). At this stage, the absolutely positive self-image has dissipated as adolescents begin to notice differences in themselves and those around them, and begin comparing themselves closely to their peers. This is only exacerbated by the school setting in which these young people are grouped together with their peers daily (Jerome et al., 2002).

Jerome and colleagues (2002) examined the self-esteem of eighty children, forty with SLI and forty who were typically developing. These two groups of children were each categorized by age into two groups, a younger group of children six- to nine-years of age and an older group ten- to thirteen-years of age. Self-perception level was determined by a self-report format test. The younger group showed no significant differences between the children with SLI and the typically developing children in competence and acceptance. However, the older group of children with SLI expressed negative self-perceptions in scholastic ability, social acceptance, and behavioral conduct more frequently than the typically developing children of the same age (Jerome et al., 2002). Test results showed findings of lower self-perception in the older children with SLI, putting them at higher risk for sustained low self-esteem as they continued to age. Significant differences were also found in the area of scholastic competence, as the ratings from older children with SLI were significantly lower than those from older children who were typically developing (Jerome et al., 2002).

Challenges in the Classroom

Speech and language disorders can make a significant impact on academic achievement in students of all ages in addition to the impact on self-esteem and social competency. Beginning at the age of six-years-old, school is where children spend the majority of their time, and when a child expresses a speech or language delay, it influences their interactions with fellow students as well as their performance academically. One deciding factor in improving the quality of learning for children with communication disorders is access to support from teachers and other professionals who understand their needs. However, according to a study in British schools by Dockrell and Howell (2015), teachers lack a thorough understanding of the subsequent difficulties that children with communication disorders face, and are unaware of the social and academic challenges that result from these difficulties. Moreover, in comparison to the time devoted to naming and diagnosing communication disorders, "less attention has been given to ways in which children's SLCN [Speech, Language and Communication Needs] are identified and supported in mainstream education settings" (Dockrell & Howell, 2015, p. 412).

This study also sought to clarify the aspects of communication disorders that were most confusing and misunderstood by teachers who had students with communication disorders within their classrooms (Dockrell & Howell, 2015). The researchers found that teachers reported the terminology associated with communication disorders was the greatest deterrent in understanding students' communication disorders and how to serve them within the classroom (Dockrell & Howell, 2015). For example, participants reportedly struggled more often with understanding terms related to articulation problems

than to language problems (Dockrell & Howell, 2015). Researchers concluded that, within schools that possess an on-site speech-language pathologist, it would be beneficial for teachers of children with speech or language impairments to speak with the school speech-language pathologist about specific communication disorders and the techniques and modifications in the classroom that could be implemented by the teacher to support children's social and academic needs. The researchers also emphasized a need for better education of teachers by speech-language pathologists within the school setting. There is a distinct lack of awareness of terms used by both speech-language pathologists and researchers; awareness of key markers for speech and language difficulties; and of the problems distinguishing speech from language difficulties (Dockrell & Howell, 2015). These areas could each be clarified for teachers by professionals within the field of communication disorders.

Although language disorders have a more direct impact on academic skills such as reading comprehension, decoding, and auditory processing, disorders of articulation and speech-sound production can influence behavior and quality of learning in the classroom as well. According to Peña-Brooks and Hegde (2015), speech sound disorders are one of the more common communication disorders, and "include stuttering and cluttering, apraxia of speech, and dysarthria" (p. 1). A qualitative study of speech-sound disorders in Australian schools by Daniel and McLeod (2017) interviewed thirty-four participants that included six focus children with speech sound disorders aged five- to nine-years (5 males, 1 female) and their parents, siblings, friends, teachers and other significant adults (28 total). Each of these individuals was interviewed about the challenges faced by the focus children at school, as well as difficulties faced by the parents and teachers in meeting the

children's struggles in the academic setting. The sample included a higher number of males with speech-sound disorders rather than females, which is reflective of the generally higher prevalence of speech-sound disorders in males than females (Daniel & McLeod, 2017). Speech sound disorders ranged from mild to severe; three children had a mild hearing loss or language impairment in addition to the speech sound disorder. Consistent with a qualitative study, the interviews were semi-structured to provide parents and teachers with questions that stimulated free-flowing conversation about their perspectives and experiences with their children who expressed speech sound disorders.

After the compilation and analysis of data, results were divided into three categories: Challenges for Children, Challenges for Parents, and Challenges for Teachers (Daniel & McLeod, 2017). Challenges expressed by the children included reduced self-confidence both in social settings and learning activities in the classroom, and included speaking less frequently around peers and a reluctance to participate in classroom discussion and activities. One child expressed that he "didn't like to speak in class because it made him sad and nervous" while another child stated, "I['m] not good at speaking at my class" after refusing to participate in a class presentation (Daniel & McLeod, 2017, p. 89). These feelings were amplified by the "more dominant personalities" in the class who made comments to these children about their speech or language disorders, such as, "Why can't you speak properly?" and, "We can't understand you" (Daniel & McLeod, 2017, p. 89). As seen in this study, any reduction of self-confidence seems to be influenced by the fear and anxiety that can surround a communication disorder, not only from the child's own fears formed in their minds, but also from the vocalized perceptions of their peers. Daniel and Mcleod (2017) emphasized

the necessity for teachers and other important figures in a child's life to actively pursue an understanding of communication disorders. "That is, teachers need to be prepared with the understanding and skills required to provide learners with relevant learning experiences in an educational environment that supports the development of all children's personality, talents, and mental and physical abilities to their fullest potential" (Daniel & McLeod, p. 82). The authors maintained that the contemporary classroom is founded largely on exploratory talk and group discussion in which children are encouraged to share their own thoughts and ideas, and may be significantly more difficult and intimidating to those children whose processing and/or production of speech in impaired (Daniel & McLeod, 2017).

Harrison, McLeod, Berthelsen, and Walker (2009) performed a study that indicated that speech and language disorders are a high prevalence condition in children between the ages of four- and five-years of age. This indication was originally found in the data from the Longitudinal Study of Australian Children (LSAC) that began in 2004, and was expanded upon by Harrison et al. (2009) through a follow-up study. Harrison et al. (2009) analyzed only the Kindergarten Cohort from the LSAC, which was 3,632 of the original 10,000 children, and evaluated the progress of these four- to five-year-old children two years after the completion of the LSAC when they were attending elementary school at six- to seven-years-old. Each child's performance in school was examined for the impact of communication disorders on three specific academic outcomes: Language and Literacy, Mathematical Thinking, and Approaches to Learning. This study reported that children with language impairments not only faced difficulty in comprehending incoming language from the environment around them, but also struggled

with initiating and responding to communication with their peers. Therefore, they had to cope with the demands of school in accordance with these social struggles (Harrison et al., 2009). These academic difficulties were seen in various areas of skill, including literacy (spelling, reading comprehension, reading accuracy, phonological awareness, and writing) and mathematics (storage/retrieval of sequences, number recall, and math calculations; Harrison et al., 2009). Difficulties are seen more often in literacy and mathematics in children with language impairments or concomitant speech and language impairments, rather than speech impairment alone. These difficulties are related to the decoding skills that accompany language development and need for deciphering two major symbol systems: the written alphabet and the number system (Harrison et al., 2009).

Communication Between Parents and Clinicians

In addition to seeking support for children with disabilities in the classroom, one important factor is effective and thorough communication between parents and therapists. Donaldson, McDermott, Hollands, Copley, and Davidson (2004) examined the perspectives of both therapists in the fields of occupational therapy and speech-language pathology and parents regarding their children's progress reports. Through a qualitative design, therapists responded to open-ended questionnaires while parents participated in semi-structured, in-depth interviews that allowed for easy, open conversation and sharing of ideas (Donaldson et al., 2004). A portion of the interview questions for the current study was devoted to parent satisfaction when working with speech-language therapists, and the changes that could be made to make the professional relationship more comfortable and effective. Therapist questionnaires were designed to elicit information about the therapists'

reasons for report writing; intended audience; perceived usefulness of the report for parents; and significant factors to consider when writing for parents (Donaldson et al., 2004). Parent interviews targeted the ease and/or difficulty with which they understood the reports; perceived benefits from those experiences; and intelligibility of the structure of the written language, formatting, detail presented, grammar, and overall tone of the report (Donaldson et al., 2004).

Parents reported that they expected sufficient detail in testing and test results as well as identification of the child's difficulties and their severity; most importantly, they emphasized a need to understand the overall implications of assessment findings (Donaldson et al., 2004). Most parents stated that these expectations had been largely met in past reports. However, several parents expected additional information about the child's anticipated needs and future plans for therapy. Parents expressed a deep respect for therapists who included information about future plans for intervention and investigation of the child's difficulties. They also revered the therapists' considerations for the importance of reporting not only the child's strengths, but also his or her weaknesses in order to provide a more holistic picture of the child's abilities (Donaldson et al., 2004). Overall, this evaluation of the quality of report writing and communication between therapists and families was tremendously important for the future of therapy within all fields. Communication was a significant component in helping the children's developing skills carry over between the therapy room and their natural environment, and in helping parents understand what their children were encountering and how the parents could better cater to their children's needs in settings that were affected by their disorder or disability.

Literacy Development and Utilizing Storybooks to Increase Awareness of Differences

With the understanding of the negative impact communication disorders can have on children's perceptions of self comes the need for resources that can aid children in understanding the feelings and struggles they are encountering and in the realization that other children are having very similar experiences. One impactful resource is books, whether they are storybooks catered to young children who are not yet reading on their own or chapter books for older children. Prater and Dyches (2008) compiled a list of twenty-five books for children and young adults that depicted characters with disabilities. The disorders, disabilities, and illnesses portrayed included Attention Deficit Disorder (ADD), Autism Spectrum Disorder (ASD), learning disabilities, intellectual disabilities, orthopedic impairments, blindness, and cancer, as well as deafness, dyslexia, and other communication disorders (Prater & Dyches, 2008). This compilation was meticulously researched in order to find twenty-five examples of inclusive children's literature based on three major guidelines: Literary Quality, Illustrative Quality, and Characterization of the Characters with Disabilities. Characterization was chiefly important, as it was evaluated for a number of qualities that were presumed to provide the most valuable learning opportunities for audiences reading the story. Prater and Dyches (2008) stated,

> This guideline includes elements that are consistent with current knowledge and practices in the field: (a) accurate portrayal of the disability; (b) exemplary practices [inclusive settings, emphasis on acceptance rather than rejection, and similarities rather than differences]; (c) realistic sibling relationships, if depicted; (d) appropriate emotional reactions [respect rather

than pity, acceptance rather than ridicule]; and (e) accurate illustrations of

the disability or assistive device being used. (p. 32)

Children's literature that is inclusive of atypical populations provides a tremendous opportunity for both typically and atypically developing children to learn about the world around them. The research by Prater and Dyches (2008) resulted in a list of twenty-five books that were highly appropriate for children and inclusive of differences, which urges the question of how many other books of a similar description are available. Regardless of the answer, there is a pressing and ever-present need for growth and expansion of inclusive resources, not only for the comfort and support of children with disabilities, but for the education and awareness of children who are typically developing as well.

The call for more inclusive children's literature may seem to be counterproductive as society continues to move forward in an endless progression toward the newest state of media and technology, but books are still a significant resource in children's development. The development of a child's literacy skills requires a substantial amount of support from the child's environment, whether that be at home, at school, in the grocery store, or anywhere else that showcases print. These print-saturated environments are best supported by the child's parents and teachers who emphasize print features and sounds to foster learning in the child.

In a study conducted by Justice, Kaderavek, Fan, Sofka, and Hunt (2009), early literacy development was examined in 109 preschoolers from lower socioeconomic (SES) backgrounds as supported by teachers in 23 classrooms that heavily emphasized a print-referencing style when reading storybooks. In defining this reading style, the authors stated, "When reading with a print referencing style, teachers use verbal and nonverbal techniques

to heighten children's attention to, and interest in, print within the storybook" (Justice at al., 2009). The print referencing style of reading is highly supportive of children's print knowledge, which is a necessary precursor to the development of children's formal reading abilities (Justice et al., 2009). Print knowledge is composed of three dimensions: Print Concept Knowledge (the way print is organized and the function it serves), Alphabet Knowledge (names and distinctive features of individual letters), and Emergent Writing (expression of meaning through writing; Justice et al., 2009). The quality of teaching that children receive from parents and teachers alike in the home and school settings is largely impacted by SES, maternal education, and access to print (van Kleeck, 2006). If children are most often exposed to a high-print environment where parents frequently read books, magazines, and newspapers and children have access to books of their own that can be shared between them and a parent, they are significantly more predisposed to developing stronger print knowledge, and later, reading ability (van Kleeck, 2006). However, children with a lower SES background are less likely to have access to that high-print environment and storybook sharing, and their only opportunity to access this may be at school where resources are more abundant.

Justice et al. (2009) emphasized the benefits of saturated print referencing at school for "disadvantaged" preschoolers who were from lower SES backgrounds. In their study, teachers were selected from 23 classrooms that were designed as early education programs for children experiencing social, economic, or developmental risks. Classrooms were randomly assigned to one of two conditions: fourteen were assigned to a print referencing condition in which print was emphasized in storybook sharing, while nine were assigned to an everyday storybook sharing condition with no emphasis on print referencing.

Teachers in both conditions implemented a 30-week shared storybook reading program using a set of 30 storybooks that were provided to them. Storybooks were selected based on a high occurrence of print salient features (speech bubbles, font changes, accentuated words) as well as the appropriateness of the book for a 3- to 5-year-old audience. Teachers in the first condition were instructed to implement three distinct print referencing behaviors during storybook reading: asking questions about print; commenting about print; and tracking one's finger along the text while reading (Justice et al., 2009). The teachers within the second condition were instructed to read the storybook without implementing any print referencing behaviors. Within both conditions, teachers were asked to read the book of the week on Monday and then at least four additional times throughout the week. Data was collected on child print knowledge outcomes and the quality of the classrooms. At the end of the academic year, it was found that preschoolers in the print referencing condition made educationally significant gains in the three dimensions of print knowledge (print concept knowledge, alphabet knowledge, and emergent writing), as opposed to the preschoolers who did not receive any print referencing (Justice et al., 2009). These findings reinforced the need not only for intentional print referencing in storybook sharing at school, but also at home where these skills can be further solidified for young children who are developing their literacy skills.

While print knowledge is a significant factor in literacy development, the overall goal of reading is comprehension (van Kleeck, 2006). The necessary precursors for this goal include not only print knowledge, but also an emphasis on inferencing and prediction skills that can be underscored in storybook sharing as well. In a paper published in 2008, Anne van Kleeck explored the necessity of accentuating inferencing and prediction skills

during storybook sharing with preschoolers and ways inferencing and prediction could be implemented in the future. While decoding print is a necessary skill for comprehension at a surface level, there are more pertinent skills required for true comprehension of meaning in text (van Kleeck, 2008). Van Kleeck (2008) further stated,

> Foremost among the text-level skills important to later reading comprehension is the ability to engage in inferencing…the term used to refer to the situation in which a reader (or listener) goes beyond information that is directly provided in a text to fill in information needed to understand the text or to elaborate on the information given. (p. 628)

Education of parents and teachers alike is crucial to understanding that inferencing skills must be emphasized alongside print knowledge, decoding, and vocabulary in order for reading comprehension to develop at the rate and level that is most beneficial to the child. Van Kleeck (2008) emphasized that because educational gaps may occur before a child enters school, it is not reasonable to wait to intervene until the child is in the third or fourth grade and showing signs of difficulties in reading comprehension. Studies in cognitive science and multicultural practices have shown that preschoolers possess the capability to infer the goal of a story, infer how the characters feel about that goal, and predict what could be done to succeed at that goal (van Kleeck, 2008). In particular, it was crucial to target preschoolers who are at risk for comprehension deficits due to low SES backgrounds, second language learning, or dialect differences (van Kleeck, 2008).

Storybook sharing fosters a variety of early skills in both oral language and literacy that are tremendously beneficial to a child. Families and teachers can incorporate all of these skills into storybook sharing by reading books aloud, referencing print and print-

salient features, referring to illustrations, asking for predictions from page to page, and lastly, embedding inferencing questions throughout the story (van Kleeck, 2008). With children's literature that is inclusive of disabilities, the strategies for fostering literacy development, especially inferencing, can aid children in applying those skills to real-world scenarios that reflect the situations they have encountered in stories. This can be an incredible resource for both typically and atypically developing children in understanding their own differences as well as differences in the people they meet daily.

In summation, many factors play a role in the lives of children with disorders or disabilities. Communication disorders make a particularly significant impact on children's lives in a variety of areas. Speech-sound and/or language disorders have the potential to tremendously affect children's self esteem, especially as children age and become more aware of themselves and other children around them. Their peers may exacerbate the impact of communication disorders through insensitive comments and exclusive behaviors due to the simple fact that peers do not understand the communication disorder. This invokes a need for support from both parents and teachers for children struggling emotionally and academically. Through an emphasis on literacy skills within this support system, children with communication disorders may not only receive the support they need to successfully develop fluent reading and comprehension, but also gain the opportunity to learn from books about individuals going through similar situations. This can also benefit typically developing children who can learn from stories appropriate ways to interact with their peers who have communication disorders and other differences.

Motivating Questions for the Present Study

According to the American Speech-Language-Hearing Association (ASHA), a communication disorder is defined as "an impairment in the ability to receive, send, process, and comprehend concepts or verbal, nonverbal and graphic symbol systems" (1993, para. 2). This impairment can present in any of the areas that play a role in communication, including speech, language, hearing, or auditory processing (ASHA, 1993). Speech disorders include an impairment in the production or combination of speech-sounds, or phonemes. These can arise due to a structural abnormality in the structures necessary for producing speech, such as a cleft palate, or can be acquired following an accident or disease (Plante & Beeson, 2013). Other speech disorders include voice disorders, in which the pitch, quality, or loudness of voice is altered, as well as fluency disorders, in which the normal, smooth flow of speech is motorically interrupted (Plante & Beeson, 2013). By definition, speech disorders include impairments that can present audible differences from typical speech in the articulation and voicing of speech sounds. Language disorders do not include such audibly noticeable differences, but rather produce differences in the acquisition and expression of academic and social skills.

Regardless of how salient differences are, studies have shown that these differences still make an impact on how individuals perceive their daily environment and potentially how they perceive themselves (Hart et al., 2004; Jerome et al., 2002). Language disorders can be developmental, acquired by illness or injury, or secondary to another diagnosis, such as Autism Spectrum Disorder (Paul & Nordbury, 2012). In disorders pertaining to fluency of speech, it is known that secondary emotional and psychological behaviors, such as anxiety and avoidance, appear as a result of the speaker's perceived reactions from others

to dysfluency (Guitar, 2014). Hearing impairment is another communication disorder that can significantly impact the emotions and outlook of individuals who are deaf or hard-of-hearing (Brown & Cornes, 2015).

One increasingly popular mode of expressing the feelings and fears associated with a communication disorder is pathography, or the written expression of personal experiences living with an illness or disability (Plante & Beeson, 2013). Hawkins (1999) defines pathography as, "A form of autobiography or biography that describes personal experiences of illness, treatment, and sometimes death" (p. 1). This therapeutic activity has gained awareness through blog and website postings where individuals share their feelings and perspectives of their illness and treatment of such. A pathography may also be written as an entire book, for example, *Tuesdays with Morrie* by Mitch Albom (Plante & Beeson, 2013). An internet search alone conveys that this has been utilized by individuals expressing a variety of illnesses, disabilities, and disorders, including Autism, ALS, blindness, cerebral palsy, cancer, and many more (pathographies.blogspot.com). In the future, this tool could be tremendously helpful to individuals of all ages with communication disorders of all ages by helping them confront negative feelings and emotions related to that disorder. Not only could it aid these individuals in understanding their own feelings and how to move forward with them, but their pathographies could spread awareness to the rest of the world about the experiences and emotions surrounding communication disorders.

In spite of all we know about communication disorders, there is limited research about the emotional and psychological effects that communication disorders have on afflicted individuals. The current review of literature emphasized the research surrounding

self-esteem in children with specific language impairment because a number of studies have been devoted to the effects of SLI on self-esteem. However, there is little research devoted to the emotional impact of other communication disorders, such as speech-sound disorders and hearing impairment. While more recent studies have emerged with regard to these areas in question, researchers engaging in those studies are aware of this deficit as well. Brown and Cornes (2015) stated, "The age of onset and progression of mental health problems in children with hearing loss is little understood" (p. 80). There is still much to be explored and understood about the impact communication disorders have on the emotional and psychological well-being of affected individuals, especially children, who express them. Further research on how communication disorders shape self-esteem and self-perception in children who experience speech and language disorders could provide parents, teachers, speech-language pathologists, and audiologists with insight on how best to serve these children and understand what they are feeling and thinking.

The current study was inspired by an interest in how communication disorders make people feel and influence their daily perspectives. Through a qualitative study design, the researcher sought to gather the perspectives of parents whose children were enrolled in speech-language-hearing therapy, and of adults who were enrolled in therapy as children. The goal was to broaden the understanding not only of speech-language pathologists who are working with these individuals, but also of the general public. Interview questions specifically designed for the parents and adults were administered to examine the outlooks and emotions associated with attending speech-language therapy for the first time; working with a speech-language pathologist; and encountering individuals who did not understand communication disorders. In addition, the qualitative study examines how their

experiences shaped their views of the world and other people. By interviewing parents, the perspectives of the caretakers were better understood so that speech-language pathologists could communicate and counsel parents who harbored fear or worry about the future. By interviewing adults who were enrolled in speech-language therapy as children, the perspectives of children entering therapy for the first time could be better understood. Through these conversations, the primary researcher hoped to gain a clearer awareness of what families experienced as they lived with a communication disorder so that this information could aid speech-language pathologists and audiologists to be even more personal and understanding of future clients' needs.

Furthermore, in addition to the qualitative study, the perspectives that were gathered were used to shape the writing of a children's book for both typically and atypically developing children. The goal of the book was to help young children understand that everyone has their own differences and that these differences make individuals special and unique. The book, narrated by a character with a communication disorder, provides simple and clear examples of a variety of differences, emphasizing communication disorders and the experience of attending speech therapy for the first time. Additionally, a "Tips for Parents" section was included at the end of the book to provide tips and advice for parents who are new to communication disorders and speech-language therapy. The tips were shaped by the interviews of parents who participated in the study. Overall, the aim of this study was to understand how to aid children who are potentially worried about beginning speech-language therapy, as well as how to assuage the nerves and concerns of their parents. As a supportive tool for these families, the goal of the book was to prepare

parents and children for their new experiences with speech-language pathologists and to

develop an understanding of what to expect at the start of speech-language therapy.

Methods

The current study employed a qualitative research design in which participants were interviewed about their experiences and perspectives living with a communication disorder. The current study (designated #18-2282) was reviewed and approved by the Middle Tennessee State University Institutional Review Board.

Participants

A total of ten participants were recruited. The population from which these participants were recruited was divided into two subgroups: eight parents of children who are currently enrolled in speech-language therapy (seven mothers and one father), and two adults who participated in speech-language therapy as children. The parent participants were recruited through word of mouth by the Clinical Coordinator at the Middle Tennessee State University (MTSU) Speech-Language-Hearing Clinic, where their children were in enrolled in speech-language therapy. One of the adult participants was a student in the Speech-Language Pathology and Audiology program at MTSU and was recruited through word of mouth by professors in the program. The other adult participant was an acquaintance of the primary researcher from her hometown of Memphis, Tennessee.

Procedure

All participants underwent a brief interview process conducted by the primary researcher. Interview questions were designed specifically for each subgroup of participants. The eight parents were asked six questions and the two adults were asked seven questions (see Appendices C and D). Each interview was conducted in an office at the MTSU Speech-Language-Hearing Clinic, except for the participant in the adult

subgroup who was interviewed in a private study room at the Memphis Public Library. All interviews were audio recorded. And later transcribed, coded, and analyzed after the completion of data collection. Participants were encouraged to disclose as much or as little as they felt comfortable sharing during the interview process. The length of the parent interviews ranged from three minutes to eighteen minutes. The length of the interviews with adults ranged from three minutes to seven minutes. After the completion of all interviews, the ten audio recordings were played back and transcribed in Microsoft Word by the research assistant. When transcriptions were completed, a reliability analysis was conducted on six interviews to determine the accuracy of the transcribed information by listening through the interviews again and examining the written transcription for differences. Reliability was between 97% and 99% for the six transcripts.

Data analysis was conducted through the meticulous design and selection of A Priori, and later, Emergent Codes from each of the interviews. A Priori Codes were selected based on the themes the primary researcher felt were most often heard throughout the interviews. Emergent codes were added during the process od transcript analysis.

A Priori Codes – Parents

For the parent interviews, nine A Priori Codes were initially selected, but were later reduced to six after examination of the transcriptions. The finalized A Priori Codes included: *worry/concern*, *nervous/unsure*, *challenging*, *strengths*, *special*, and *unaware*. Originally, *proud* was included, and *worry*, *concern*, *nervous*, and *unsure* were each separate codes. After the analysis of each interview, a meeting was conducted between the primary researcher, research assistant, and research advisor to discuss the codes and

their relation to the interviews. Through the analysis of each interview, it was found that *proud* was never explicitly stated and was more often expressed in a context that fit the code for *special*, and was therefore excluded from the finalized codes while *special* remained. The definitions for each code were discussed as well, and it was found that the codes *worry* and *concern* as well as *nervous* and *unsure* could be merged due to similarities in their definitions. Definitions for the original A Priori Codes for interviews with parents may be found in Appendix E. Definitions for the finalized A Priori Codes for interviews with parents are located in Appendix F. These changes made the codes easier to understand and allowed for more concise descriptions of similarities across parent perspectives.

Emergent Codes – Parents

After the interviews with parents were analyzed for the A Priori Codes, the primary researcher developed and defined the Emergent Codes. The interview transcriptions were read through again and the Emergent Codes were pulled from information that could not be described by the A Priori Codes. The finalized Emergent Codes included: *empathy toward others*, *interaction with the outside world*, *praising differences as an emotional response*, *positive reinforcement as a therapeutic response*, and *therapy is a quick fix.* These overarching themes were developed from a larger, original list of themes that was composed based on the most obvious thoughts and feelings shared by each individual parent, and the finalized codes that were selected were those most commonly appearing in responses to all eight interviews. These final themes were also discussed and refined in the meeting between the primary researcher, research assistant, and research advisor to shape the clearest and most concise Emergent Codes

possible. The most major change that was made was in merging two original Emergent Codes, *speaking for the child* and *learned to be honest with curious strangers*, into the final code, *interaction with the outside world*. The codes *speaking for the child* and *learned to be honest with curious strangers* were each original contributions to the Emergent Code list, but were merged for a clearer theme that encompassed both of the specific behaviors that inspired the original Emergent Codes. Furthermore, *praising differences as an emotional response* was originally *praising differences across all people*, while *positive reinforcement as a therapeutic response* was originally *positive reinforcement/encouragement*. After further discussions, these two codes required specification of the intent of each response in order to distinguish the two types of occurrences involving the usage and context of praise and positive reinforcement. The definitions for the original Emergent Codes for interviews with parents may be found in Appendix G, and the definitions for the finalized Emergent Codes for interviews with parents are located in Appendix H.

A Priori and Emergent Codes – Adults

The A Priori Codes for the interviews with adults were selected in the same manner as A Priori Codes were selected for the parent interviews. Two A Priori Codes were selected: *limited memories* and *rapid results*. No changes were made to the A Priori Codes because there were only two adult interviews and the codes applied to the interviews with both participants. The Emergent Codes included: *empathy toward others*, *frustration*, and *anxiety*. No changes were made to the Emergent Codes either. These codes described feelings that were revealed by both adult interview participants.

Definitions for the A Priori Codes for interviews with adults may be found in Appendix I, and definitions for the Emergent Codes are located in Appendix J.

Post-Analysis Measures

After all interviews were completed, data analyzed, and codes collected and defined, the primary researcher distributed the following question to parent participants only. The follow-up question was, "Do you have any tips or advice that you would give to your parents who are new to speech-language therapy and new to working with a communication disorder?" and was implemented in order to gain clear parent perspectives on information they now know and would have found beneficial to their understanding when they began this process themselves. These perspectives were compiled and summarized to dorm the "Tips for Parents" portion of the children's book that was written for the creative component of this project.

Findings and Discussion

Through this series of interviews, the researcher sought to better understand the feelings and perspectives of parents and adults who live with a communication disorder and how they faced the accompanying challenges and victories. In analyzing the findings from the study, the defining question was, "What are the similarities and differences across the individual responses from parents and from adults to each of the corresponding interview questions?" With adult participants, the responses were more specifically examined for how a child feels when encountering speech-language therapy for the first time. Overall, there was a salient pattern of similar themes in participant responses to certain interview questions. The responses that were different and unique to certain individuals provided examples that alluded to the family-specific nature of communication disorders and participation in speech-language therapy.

Similar Themes Across Parent Interviews – A Priori Codes

Worry/concern.

This A Priori Code was of high interest to the primary researcher because worry and concern are emotions that are often harbored by parents for their children, and it was of particular interest how worry and concern would relate to attending speech-language therapy. This theme was identified in four of the eight parent interviews. Each time worry or concern was expressed, either through expression of the words themselves or through context, the parent was presenting these emotions in regard to how their child's communication disorder would impact his or her future.

1. *It's no longer about us because he's the one that's impacted, you know, it's him who has the struggles, that has to go to the therapies, that has the pain, that is the different one, you know?* (Interview 1)

2. *For him I guess we've been so concerned of really watching him getting made fun of and getting teased because of how he talks but he also has so many other things that might really mess up his little, you know a really fragile ego and everything.* (Interview 2)

3. *I guess when he did go to kindergarten, I was concerned that he'd be able to express what he needed to say to his teacher, you know that she'd be able to understand his needs or if he was sad about something.* (Interview 2)

4. *He hangs around- I mean even when he was in school* [with me] *I'd ask him, "Who are your friends? Who do you hang out with? Who do you hang out with?* (Interview 4)

5. *But then on the other hand you think, "Well, he's never picked that* [personal differences] *up either," so that kind of makes me sad, you know.* (Interview 6)

These responses exhibited the worry and concern that parents of children with communication disorders felt when considering the effects of those communication disorders on the state of their child's self-esteem and well-being, both currently and in the future. Not only did these responses exemplify the consistency of these emotions across parents from a variety of different backgrounds and communication disorders, but they also exhibited how these emotions arose in response to communication disorders and remained even after multiple years of experience.

Nervous/unsure.

This A Priori Code was included due to questions surrounding the experiences and emotions associated with beginning speech-language-hearing therapy for the first time. Reactions that indicated this theme were most often in response to the question, "What were your feelings for yourself and your child when encountering speech therapy for the first time?" This theme was expressed in five of the eight interviews within the

targeted context, which was nervousness and uncertainty specifically in response to attending therapy and handling the disorder both in and outside of therapy.

1. *They started with him at eight-months-old, you know, doing speech, and they would try to get him to babble and mimic signs and sounds so I didn't know what to think or expect, it was all very new to us.* (Interview 1)

2. *There's certain things that I'm like, "How much of this do I correct?"* (Interview 2)

3. [What were your feelings for yourself and your child when encountering speech therapy for the first time?] *Nervousness and kind of also a naivety maybe, or even non-acceptance, like okay this will be done in a couple weeks and we will go right through it.* (Interview 4)

4. *I had never heard of speech therapy, and seeing him go through this and transition, I was kind of skeptical about it at first and didn't quite understand how it was going to work.* (Interview 5)

5. *Well you can ask* [about what is happening in therapy] *but you're not going to get an answer; it's what did you do in speech today and then it's just kind of left up to the therapist to tell you but if you don't have eyes on what's happening, it's kind of like, can I really trust that that's happening?* (Interview 7)

This theme was very beneficial to the primary researcher's understanding of parent perspectives because the knowledge that parents faced this process with nervousness and uncertainty only further indicated the necessity for books and other resources that could support the parent and the child as they entered into this new and unknown territory. With quick tips and a simple storyline, a book outlining what to expect from speech-language therapy could potentially assuage these nerves and provide information that diminishes uncertainty.

Challenging.

This A Priori Code was chosen due to the frequency with which challenges associated with speech-language therapy and communication disorders seemed to be mentioned throughout interviews. Understanding the challenges that families faced in this process was also of key interest to the primary researcher because it offered more information about the areas that required support and more thorough communication from the speech-language pathologist. Challenges were discussed in two of the interviews. Both were in response to questions that asked how a communication disorder has changed their daily life and outlook.

1. *Yeah it's challenging, you know, and you just see other people- you see the world in a different light because once you're impacted by a child with a delay or any kind of disability that requires therapies and services it's just nothing like the norm, you know?* (Interview 1)

2. *It's gotten harder* [over the years] *with reading levels but I also think that sometimes we are pushing kids way too fast because some of the standards and some of the skills they are being asked to do, they're not mentally ready to do it…it's kind of like I'm fighting an uphill battle as a mom.* (Interview 4)

These responses shaped a depiction of the initial challenges associated with communication disorders as well as how these challenges evolved with time to impact different areas of life. For example, the first quote described how life with a child who had a delay or disability strayed so far from the norm that it altered how daily life was approached and how life was perceived as a whole. Conversely, the second quote described how new challenges arose with the passage of time, such as reading levels and new academic goals that came with an increase in age and grade level through school. These findings were supportive of how speech-language pathologists can be cognizant of each family's timeline in this process, such as researching and

understanding where a child is in his or her schooling and what factors may be impacted by their communication disorder along the way. Speech-Language Pathologists can also provide strong support and thorough communication for families who are still processing and learning how to navigate their current situation.

Strengths.

This A Priori Code was selected based on the parents' consistent portrayal of their children's strengths. This theme was an important component within the interviews because it depicted the parents' recognition of their children's gifts and talents which provided the children with a source of confidence regardless of the potentially defeating experiences the children encountered due to their communication disorder. The responses in which parents mentioned their children's strengths were often sporadic and were not consistently included in an answer to any specific question. Strengths were mentioned in two of the eight interviews.

1. *He's really good at soccer and so he's had that to feel really good about so that's been nice.* (Interview 2)

2. *He also has some skills that are amazing…I would try to focus on the stuff he's really good at; he started reading at the same time he started speaking.* (Interview 5)

There were not many concrete examples of talents or hobbies given by parents, but the incorporation of strengths in these two interviews provided clear examples of how beneficial it was to emphasize the activities that a child excelled in and enjoyed. This strengthened children's confidence in themselves and in their abilities so that they felt stronger and more capable when facing the areas where they struggled. While a communication disorder has the potential to inflict diminished self-esteem, the emphasis

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of successful talents and hobbies by parents and speech-language pathologists may be a key component to bolstering self-esteem.

Special.

This A Priori Code was shaped by the responses in which parents mentioned special qualities about their children. The incorporation of these qualities provided an emotional element that expressed how much the parents believed in their children and saw their potential to persevere through every trial they encounter. The mention of special qualities was also more sporadic and did not coincide with a specific interview question. However, this seemed to depict how parents saw their children for who they were in their character and actions rather than for the diagnostic labels that may have be placed on them. Special qualities were mentioned in all eight interviews with parents.

1. *He does work with his therapist and he knows that it's time to work, and he is a hard worker.* (Interview 1)

2. *We try to tell him all the time how beautiful he is.* (Interview 2)

3. *We talk a lot about how God has given them different gifts and that their speech problems may even be a gift to help them develop their perseverance and help them become a stronger person.* (Interview 3)

4. *He's okay with not having a best friend, he's just friendly with everybody.* (Interview 4)

5. *You know, his* [difference] *does have a name but that gives him things that are sometimes more difficult for him and some things that make him awesome. Very, very awesome.* (Interview 5)

6. *Try not to look at the disability, look at the ability.* (Interview 6)

7. *At being only five, he's very intuitive.* (Interview 7)

8. *She's come a long way since eighteen-months and we keep seeing progress in her everyday.* (Interview 8)

These responses conveyed a very hopeful and positive tone from parents who, despite all of the challenges, concerns, and uncertainty, still know their children the most deeply and see their best, strongest qualities. Acknowledging and encouraging these qualities will strengthen their children's self-confidence in their abilities so that they recognize they are not defined by their communication disorder and the weaknesses that accompany it. It is vitally important that speech-language pathologists follow the example of parents and underscore the qualities that make their children outstanding, both in and outside of therapy sessions. This explicit encouragement is crucial for the child to feel supported and successful not only in therapy, but also in their daily lives.

Unaware.

This A Priori Code was formulated from responses to the question, "How do you discuss differences with your child regarding those within themselves and in others?" While some parents reported that their child was aware of their own differences, many parents reported that their children were unaware of these differences and had yet to raise questions. Five of the eight interviews included the parent's mention that their child exhibited unawareness that he or she was different.

1. *I don't know if he's made that connection.* (Interview 2)

2. *I don't think he notices any differences and I think he's just completely fine with who he is right now.* (Interview 5)

3. *He has never asked or brought it up or said anything.* (Interview 6)

4. *I don't think he recognizes the differences yet.* (Interview 7)

5. *That's never been an issue with her.* (Interview 8)

The unawareness of personal differences exhibited by these children seemed to be related to age and level of cognitive function. Children who were still at a young age, around kindergarten and younger, did not yet possess a self-awareness on a level that allowed them to grasp that they had a communication disorder and that their communication abilities were different from the skills of other kids their age. Similarly, children who functioned at a lower cognitive level may not have possessed the self-awareness required to understand one's own differences. The children at a younger age functioning at lower cognitive levels both perceived the way they were to be just as normal as anyone else. This is a testament to the full life that can be lived without comparison or awareness of differences, as many of the parents expressed that, despite their child's unawareness, he or she was still just as happy and individualistic as any other child. It is crucial that speech-language pathologists understand that each client is unique and may or may not be aware of their differences or the disorder that has qualified them for services.

Similar Themes Across Parent Interviews – Emergent Codes

  Empathy toward others.

  This theme had a strong presence throughout parent interviews, primarily in response to the question, "How has having a child with a speech or language delay shaped how you view the world and other people?" Responses that depicted an increased empathy for others were consistent across four of the eight interviews.

1. *You get empathy. Once you go through that* [having a child with a communication disorder] *you can't help but feel for other people and their situations and then you always see other people are so much worse off, so we can see the blessings through it too.* (Interview 1)

2. *I think it makes me take more time to really listen to people.* (Interview 3)

3. *It's made me more aware that there are various speech and language difficulties than just deafness and blindness.* (Interview 4)

4. *I have more empathy and understanding with parents, like you never know what's going on with a child.* (Interview 5)

This particular theme conveyed one of the major changes that a communication disorder can bring to a family, primarily in the parents' perspectives of the world. A communication disorder can cause alterations to schedules and the structure of entire livelihoods, but it may also bring very positive changes such as a deep and personal understanding of others who may be encountering similar situations. This empathy can be a teaching tool for others who do not possess such an understanding for the people around them, as well an avenue for building community with other parents of children with communication disorders. Moreover, this theme shaped one of the tips for parents in the children's book, which states that parents should seek community with other parents of children with communication disorders so that they have a group of empathetic and like-minded individuals to share their thoughts and feelings as they continue to learn and grow through this process.

Interaction with the outside world.

This theme was observed in multiple interviews as parents detailed their experiences with strangers who did not understand their child's communication disorder or how to interact with them tactfully.

1. *I tend to speak for him due to his young age and language delay, but I always try to give him the opportunity to communicate on his own.* (Interview 1)

2. *I found myself being his translator quite a bit, but the more language acquisition he's had, the more I try to step back and let him speak for himself.* (Interview 2)

3. *I usually just end up speaking for my children, because it's just easier and it's less frustrating and now as a parent when you're talking to other parents and they don't understand, sometimes I just have to realize people don't understand and just nod and smile and carry on.* (Interview 3)

4. *I'm upfront with them and I tell them that he has a language delay and you may not understand what he says or he may not be able to get what he's saying out and he gets frustrated so just be patient with him if you don't understand him.* (Interview 4)

5. *Usually it depends on the social situation like if it's someone I'm going to know for awhile or who is going to know him, versus someone like a stranger at the grocery store checking out.* (Interview 5)

6. *I never confront them; I might give them an ugly look if they're staring at us but usually I just ignore them.* (Interview 6)

7. *I think most of the time I just speak for him and try to end the conversation.* (Interview 7)

These responses illustrated how much easier it was to simply eliminate conflict or awkwardness in interactions with strangers through the parent merely speaking for the child. However, other parents insisted that it was vital to confront the individual and be truthful about their child's speech or language abilities rather than hiding it. This may be a good model for children to then understand that they can confront their communication disorder as well, and that it is nothing to be ashamed of or to hide.

This theme shaped a portion of the "Tips for Parents" section of the children's book in the suggestion that parents of children with communication disorders be kind and patient with strangers who do not understand, even when it is hard to be. These individuals may not realize that the child has a communication disorder, or may have poor tact with people of all abilities, or may simply be having a bad day. Just as all

individuals with differences should be treated with patience and respect, so should the unknowing stranger.

Praising differences as an emotional response.

This theme appeared in interviews when parents emphasized that everyone was different and had their own strengths and weaknesses, and that having differences was nothing to be ashamed or embarrassed about. This response was typically stated in the context of a story or answer to a question from their child in which they praised their differences because that was something to be praised across all people. Three interviews included statements explicitly pertaining to this theme.

1. *We try to really praise differences instead of isolating him.* (Interview 2)

2. *We talk a lot about just that everyone's different and that's okay.* (Interview 3)

3. *I would just explain to him that everyone is unique and everyone has differences.* (Interview 4)

The perspective that everyone has their own differences and that it is okay to have those differences was of interest to the primary researcher because this supports the possibility that this concept is being taught and praised in many homes to children of all abilities. When a parent praises their own child's differences and emphasizes that this is actually a connection to all other humans, they are in turn helping their child to understand that all differences are acceptable and worthy of praise. This support can strengthen both the child's confidence in himself and his acceptance of the people around him.

Positive reinforcement as a therapeutic response.

This theme was intentionally distinguished from *praising differences as an emotional response* because praise and positive feedback seemed to be categorized into two distinct areas of expression from parents. This theme was shaped by parent responses about giving their children feedback pertaining to their speech or language. More specifically, this theme pertained to responses involving a parent's direct encouragement of the child regarding their performance in speech-language therapy and in their progress at home. Two of the eight interviews included this theme.

1. *Even on the way here, I told him, "Buddy, you're doing such a great job in speech," before we got there instead of saying, "When you get in there I need you to do a good job." We praise what he has already done, that seems to help.* (Interview 2)

2. *We just talk about the good things; we usually don't even say, "You said that wrong," we usually say, "You said the beginning of that word so well! Say it again." We really just try and emphasize positives and never say, "You did that wrong," because that's just destructive.* (Interview 3)

The use of positive reinforcement was noted because it exhibited the parents' understanding that their children may feel stressed, frustrated, fragile, defeated, and an array of other emotions as they progress toward their goal of remediated speech and language. These feelings must be met with positivity and encouragement both in therapy and at home, which is the responsibility of both the children's parents and speech-language pathologists. This positive reinforcement in concurrence with the praising of differences provides a substantial amount of support to children who are not only trying to understand their own communication disorder and the feelings that accompany it, but also the differences and feelings of the people that surround them in the world.

Therapy is a quick fix.

This theme was shaped by some of the responses to the question, "What were your feelings for you and your child when encountering speech-language therapy for the first time?" This was an intriguing response because it further exemplified instances in which there was little awareness about communication disorders and what speech-language therapy potentially entailed for individuals with a communication disorder. Of the eight interviews, three included this theme.

1. *I just thought it was something I had to do.* (Interview 3)

2. *I thought, "This will be done in a couple weeks and we'll go right through it." I didn't think it would still be going; it's kind of a slow process.* (Interview 4)

3. *I guess I thought, "Well, we're just going to go get him help; he's going to get fixed."* (Interview 6)

These responses were an indication that some parents entered their experiences with speech-language pathology under the impression that it was a brief process and an equally quick fix. This further supports the need for parent resources that generally describe what to expect from speech-language therapy, such as the potential timeline and how that timeline that can be influenced by their children's communication disorders. In the future, these resources could include pamphlets or videos designed by speech-language pathologists and parents that are developed specifically for parents so that they begin speech-language therapy with their child feeling more prepared and at ease. Not to mention, further education about effective communication between speech-language pathologists and parents would strengthen these professional relationships overall because the therapist would be more aware of the parents' initial concerns and the parents may feel more confident in asking questions.

Similar Themes Across Adult Interviews – A Priori Codes

  Limited memories.

  This A Priori Code was identified in the distinct mentioning from one of the adult

participants that the individual did not clearly remember what speech-language therapy

itself was like. Both participants recalled memories of feelings associated with that time

in their lives, but one could convey only vague recollections of their therapists and the

structure of the therapy sessions they encountered.

I don't remember too much about my experience in speech therapy. I know like why it
happened and why I was doing what I was doing but I don't remember day-to-day
activities, like what we did and stuff like that. (Interview 1)

  This theme was important in distinguishing the influence of the child's age on

memory. The quoted participant attended speech-language therapy earlier in elementary

school and emphasized throughout the interview that he did not remember specific details

of therapy itself, while the participant who attended speech-language therapy later in

elementary school retained more memories about her likes and dislikes regarding the

sessions and therapists she encountered. While this finding may indicate that a young

child may not possess enough awareness of his or her differences in order to have

negative feelings toward speech-language therapy and communication disorders,

participants' memories of their feelings related to these areas, such as frustration and

anxiety, still says otherwise.

  Rapid results.

  This A Priori Code was also only explicitly stated by one of the participants, who felt

that, although he did not remember the means to the end of his communication disorder,

he did remember the sudden difference in his speech.

All I know is that one day I couldn't speak and the next day I said, "I want a popsicle,"
and my mom was like, "What did you say?" so it happened really suddenly. (Interview 1)

This was an interesting finding in the sense that a child may not remember the
process of remediation, but the communication disorder itself and then the development
of 'typical' language are significant enough occurrences in his life that it is remembered
even after the passage of time. The interviews showed that, for some children, the
memory of overcoming such an obstacle which could emotionally impact a child of any
age, was individually a more salient remembrance than the process of speech-language
therapy.

Similar Themes Across Adult Interviews – Emergent Codes

Empathy toward others.

This theme was of key interest to the primary researcher because it was a concept
that children might learn through experiences and could also be further supported through
resources such as storybooks. However, the empathy described by these participants
developed more as they aged. Both of the adult participants incorporated this theme into
their response to the question, "How do you feel that your experience with a speech or
language delay has shaped the way you perceive the world and other people?" This was
similar to parent responses to their own experiences with communication disorders in
which they widely spoke of the increased empathy that arose alongside those
experiences.

1. *Just having that experience like I can understand other people's troubles and not*
   to particularly judge them, especially a child you can't understand, you don't
   need to push them off to the side or something like you need to keep interacting
   with them. (Interview 1)

2. *I do feel like having a speech disorder when I was younger helped me identify with my clients' feelings.* (Interview 2)

These responses underscored the widespread effects of living with a communication disorder, and how it aids in understanding what other individuals who live with disorders and disabilities may be experiencing. Moreover, the adult participant from Interview 2 was an active student within the MTSU Speech-Language Pathology and Audiology program at the time of the interview and expressed that her experiences with her own communication disorder were helping her with children on her caseload in similar situations. This is supportive of how influential empathy is on the work of speech-language pathologists, including those who have never experienced a communication disorder themselves. Empathy fosters a deeper relationship between the speech-language pathologist and the child, as well as the speech-language pathologist and the parent, because there is a mutual understanding between all parties of the challenges and emotions the family is facing.

Frustration.

This theme was found in only one of the adult interviews. The subject of frustration was explicitly stated by the participant in response to how he felt when he was young and had a communication disorder.

I think the experience can be very frustrating, like trying to say stuff I couldn't say. (Interview 1)

Frustration in response to an inability to communicate effectively is, at times, to be expected in children with communication disorders. Because a communication disorder can make it much more difficult for children to express themselves or to be understood, frustration can easily fester and intensify throughout multiple experiences of

being misunderstood or even ignored due to unclear communication. This frustration may be assuaged by parents and speech-language pathologists who implement patience, positivity, and praise throughout as many interactions as possible, especially in therapy. Family and friends in the child's life can make a more intentional and patient effort to understand the child so that, instead of frustrated, he or she feels seen, heard, and loved.

Anxiety.

This theme was influenced by the feelings expressed by a single participant who emphasized feeling more nervousness than frustration as a child with a communication disorder. This theme was also highly intriguing to the primary researcher because the emotions felt by children when facing the struggles of a communication disorder are a key component to designing effective resources with which they can resonate.

1. *Last semester I worked with a child for fluency who had a lot of secondary behaviors and was really anxious because of his communication disorder and I could definitely relate to that.* (Interview 2)

2. *When I was little I was definitely more shy but as I got closer to the end of speech I was pretty outgoing.* (Interview 2)

These feelings of shyness and anxiety in response to some experiences that were impacted by the participant's communication disorder may have been exacerbated because this child was slightly older than the other participant. Because she encountered speech-language therapy around the fourth and fifth grade, she was already at a higher level of maturity and awareness than a child in early elementary school. However, these feelings cannot be assumed to be nonexistent in younger children; at all ages, children of all abilities should have access to the opportunities and resources that can emotionally support and prepare them for the future. The anxiety with which some children may

approach speech-language therapy and daily interactions with others is a key motivator for child-appropriate resources. Moreover, the knowledge of these feelings and how they relate to experiences is also beneficial to speech-language pathologists who work with these children, so that they can adequately help the child feel comfortable and excited to work on speech and language not only on their first day, but every day of therapy going forth.

Conclusions from the Study

In conclusion, the interviews presented many similarities across parent perspectives that pertained to experiences with speech-language pathologists and communication disorders. These perspectives not only provided a common ground for parents of children with communication disorders, but also exhibited how the unconditional love that parents feel for their children is expressed through so many other emotions, such as concern, uncertainty, positivity, and encouragement.

Conversely, the adult interviews presented differences in the overt feelings surrounding their experiences, which could be due to the slight age difference between the two participants and small sample size. Nonetheless, these responses showed that children can harbor negative feelings toward their own communication disorders and, at least initially, toward the accompanying remediation process.

The most striking similarity across all interviews, both parent and adult, was in the acquisition of deepened empathy. This quality enhanced these individuals' acceptance of differences in other people, and especially as parents, bolstered the teaching of this acceptance at home. These findings supported the necessity of an increased production of accessible and simplistic resources that can aid parents and children in their preparation

to begin speech-language therapy. Overall, these perspectives provided insight into the feelings of parents and children that speech-language pathologists everywhere may apply to lesson planning and communication with families so that everyone involved feels seen, heard, and informed as they venture into the new and unknown.

Suggestions for future research include examination of the acquisition and application of empathy in children as a result of their experiences with communication disorders, and whether empathy appears at that stage or if it more consistently emerges in retrospect at an older age. Furthermore, future research may consider the distinct ways in which parent perspectives change over time. Parents who have been involved with speech-language therapy for several years may have different perspectives as compared to parents who are beginning therapy. A study of the benefits that parents find from having a resource, such as the "Tips for Parents" section of a storybook for their child, and the effectiveness of those benefits in preparing for speech-language therapy would be an interesting follow-up to the current study.

The Call to Create

A little over two years ago on a cozy December evening, I was sitting on my parents' couch conversing idly with my mother. In the throes of late night conversation, we found ourselves reminiscing on the passage of time, and its unfortunate tendency to be all too rapid. My younger brother, Chase, would soon be graduating from high school, and with this jarring reality we found comfort in the memory of a much younger Chase, one who loved Buzz Lightyear and was in desperate need of two front teeth. "To ininity and eyon!" I still hear his small voice as he ran down the hall in his Buzz costume shouting that famous declaration of adventure: To Infinity and Beyond. Despite having the typical dentition of a toddler, Chase's articulation of speech was significantly impaired beyond a mild lisp that can be easily caused by missing teeth. Early on in his development, Chase was afflicted with ear infections of such a severe degree that he perceived the sounds in his world as if they were under water. By the age of three, his speech was expressed in a manner that reflected his hearing ability to such an unintelligible degree that people who were not a member of his immediate family did not understand him, and he was often ignored or written off by peers and adults alike. When our little sister, Hope, came along, Chase became her immediate playmate and she learned to speak by his example, causing her to develop a lisp as well. Her speech impediment was significantly less severe, but I was still provided with another individual's perspective of speech therapy. Hope's self esteem and confidence in her young personality remained intact, while Chase's self perception grew more and more fragile. As my mother and I thought about that little boy and the shattered confidence he carried, we looked at each other with misty eyes. "I wish there had been something I

could have shown him or read to him to help him understand what he was going through," Mom remarked, "To help him understand that speech therapy is not scary, and that a lot of other kids go through the same situation." With this heartfelt statement came the illumination of every figurative light bulb inside my brain: I was going to write a children's book.

Growing up as Chase's older sister, I was able to watch his growth and progression from before speech therapy through to his completion of speech therapy in its entirety. This was not growth strictly pertaining to his progress in the therapy room, but the progress that shone through his newfound confidence and mended self-esteem that accompanied his newfound voice. Before this healed state was found, however, I saw the way my little brother hid behind my mother's legs when people spoke to him. I watched his face fall mid-sentence as people turned away from him because they had given up on attempting to understand his speech. I heard the stories my mother brought home from his Mother's Day Out teacher expressing his troubles socializing and how the other kids did not play with him because they could not communicate with him easily. This undertone of fear and heartbreak that was beginning to color my brother's demeanor is something I carried in my heart long after he was reunited with his confidence. Inspired by Chase's speech pathologist, Mrs. Carol, I chose speech pathology as my own career path with the dream to instill confidence in children with communication disorders as she did for my brother. Knowing that this is how one young child felt when dealing with a communication disorder that he had no control over at the start of his journey through speech therapy only motivated me to find ways to make this easier for every child who may experience these feelings in similar situations. It is my hope to instill confidence and

a sense of individualism in every client I encounter through my practice as a speech language pathologist, not only just in accordance with their communication disorder, but also as a life skill in which they learn to accept their own differences as well as those in the people around them. With that notion comes the very heart of this children's book: accepting human differences within ourselves and others, for those person-to-person differences are the fundamental beauty of this life.

Whether difference is found in a communication disorder, a medical diagnosis, a birthmark, hair color, freckles, intellect, skin color, or a dialect, each and every human being expresses a variety of intrinsic differences that formulate who they are as an individual. Just as no two fingerprints are the same, no two individuals are the same in appearance or personality or mindset. This understanding of individualism not only helps shape social skills, but it also helps an individual develop a stronger self-esteem and sense of self-awareness. This is applicable to all ages and lifestyles, but it is an especially important value to learn as a child.

The goal of this story book is to aid parents in helping their child understand their own differences as well as the differences observed in people that share their day-to-day environment. With a storyline narrated by a child who expresses a communication disorder, the book does place an emphasis on understanding speech-language therapy and accepting the influence of a communication disorder in a child's life, both personally and socially. However, the plot also explores many other differences through the main character's friends and classmates at school in order to depict a wider variety of differences that children may encounter in themselves and others. It was my goal to show the audience that differences come in many different forms; some are more obvious and

can be seen on the outside, while some are invisible because they are a part of our

insides. The ultimate moral is that everyone is different, but in that is strength and

similarity because we can share and appreciate our differences positively, rather than as

something to be ashamed of.

WE CAN ALL BE FRIENDS

Written by Hannah Berthelson

Illustrated by Jenny Nazarova

There are over 7 BILLION people
in the whole world...

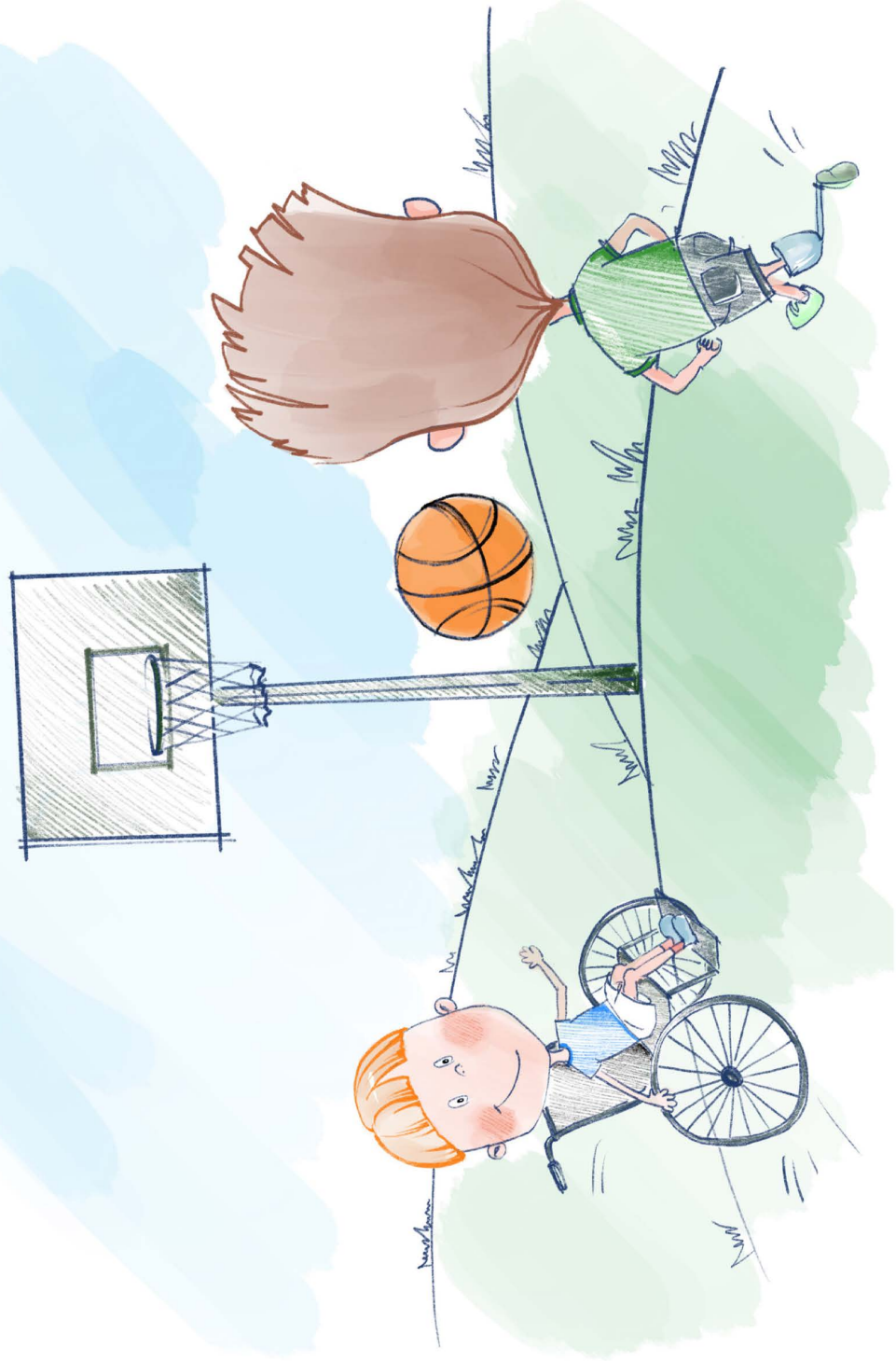Some differences we can see on the outside.
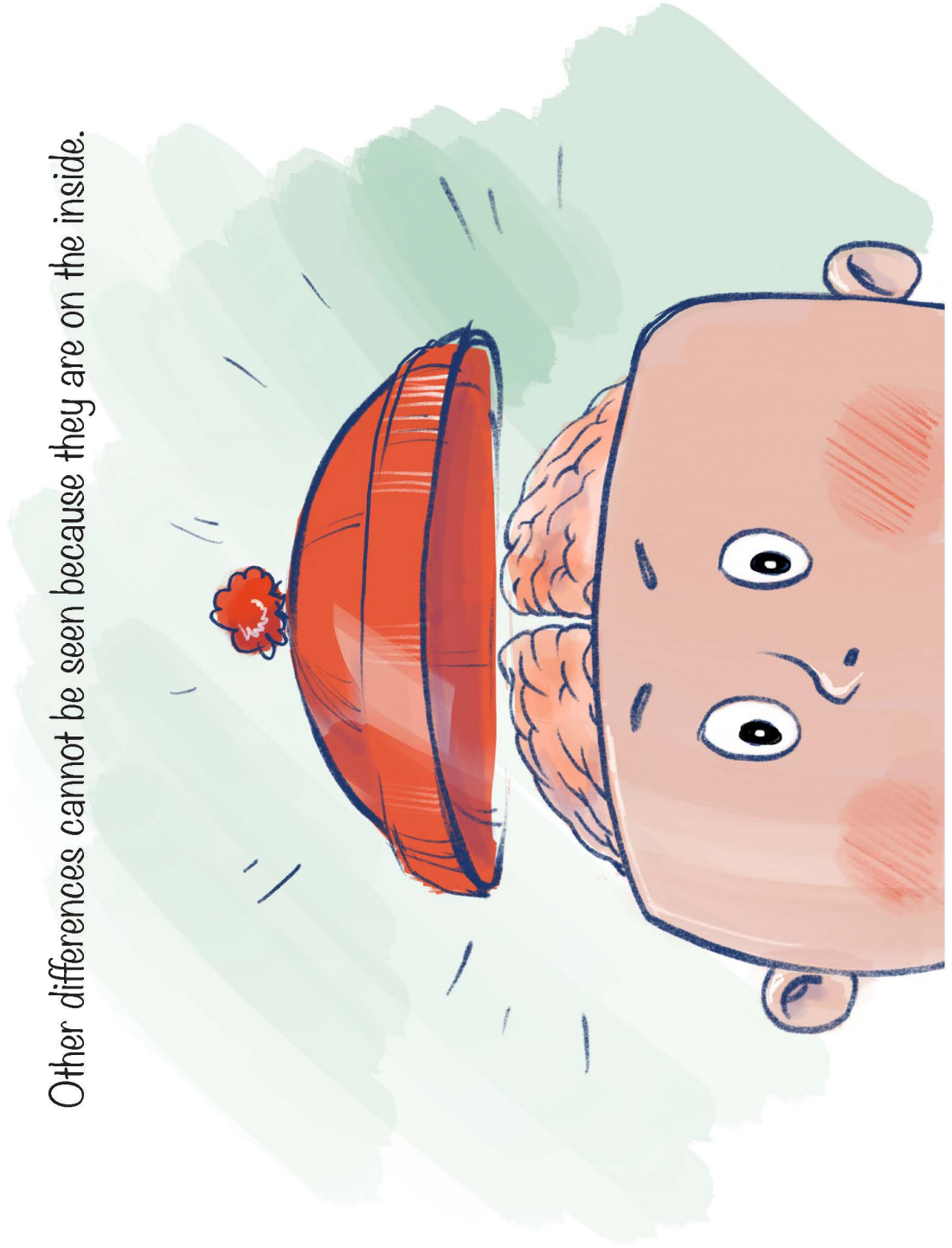
Like beautiful birthmarks...

...and freckles that cover you like hundreds of stars...

...or in how you move from place to place!

Other differences cannot be seen because they are on the inside.

Like having a brain
that needs special time
to take a break
and be alone before
returning to a routine.

...of life all around!

Or needing some help to hear the sounds and music...

Another invisible difference is in how people communicate.
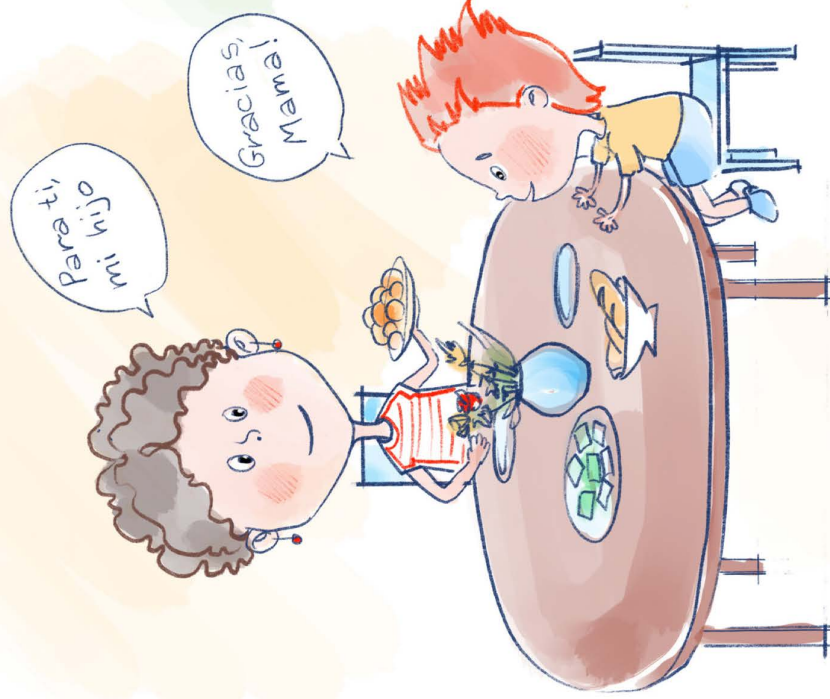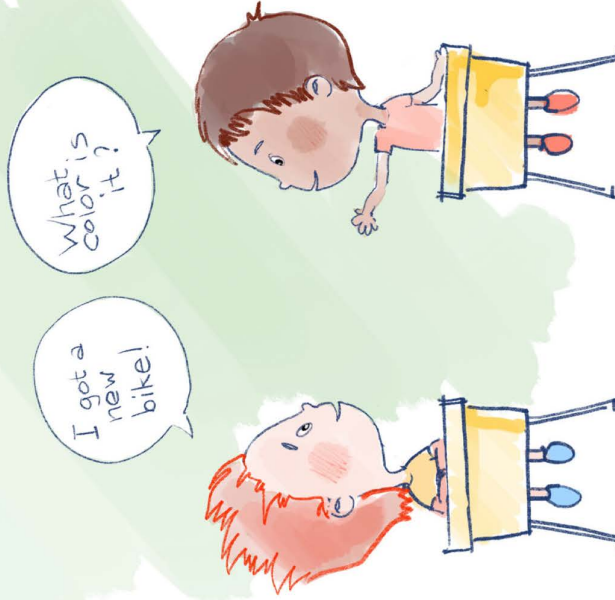
Some speak more than one language and may switch languages depending on where they are.

Or speak only English and say words differently because of where they live.

61

But others say their sounds for speech differently and can be hard to understand, so they need a little help!

I really want to ride bikes with you guys! Wait for me!

Why don't they try to listen to me?
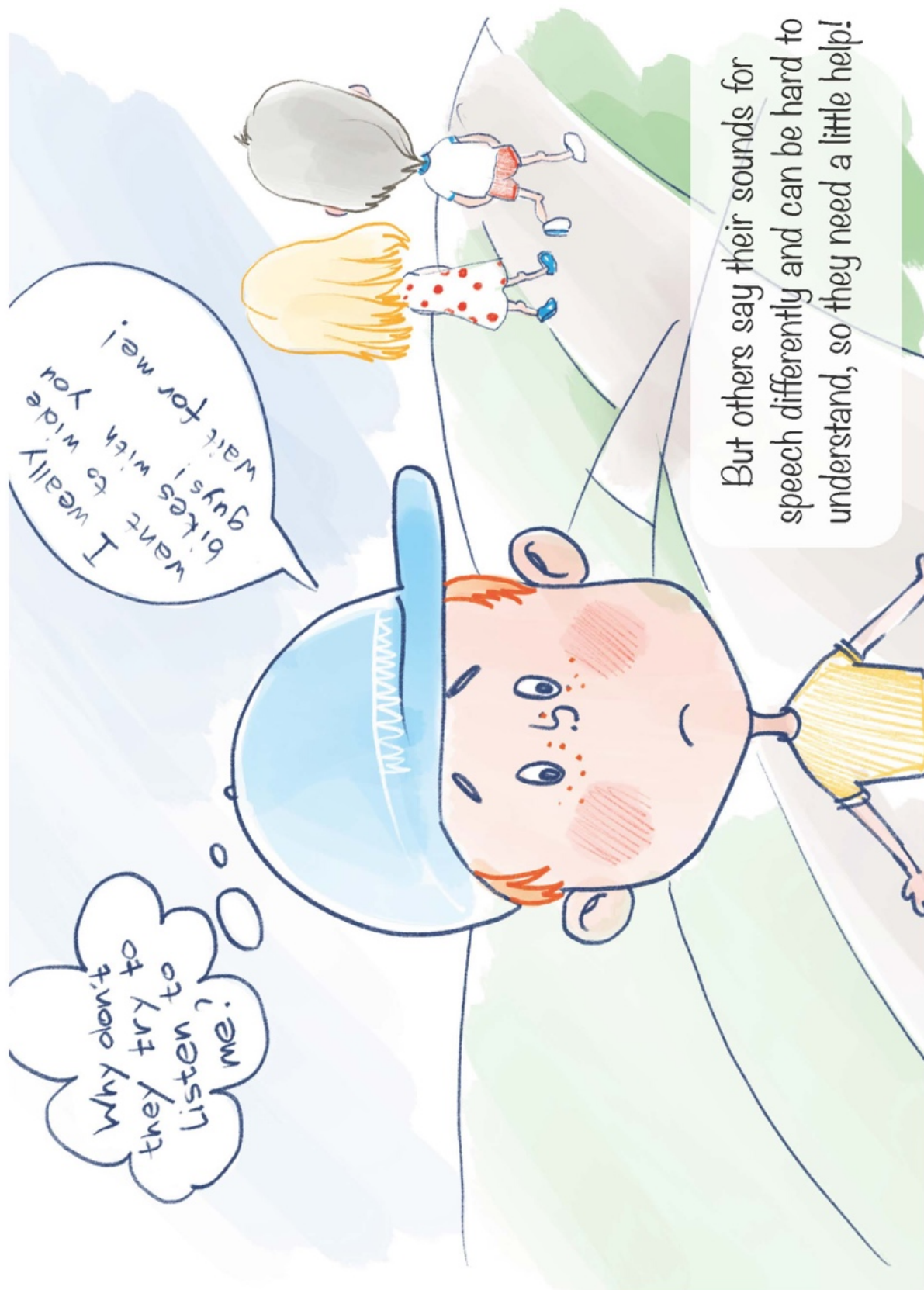
Like me!
My name is Sam,

but when I say it,
it sounds like Tham.

I go to speech therapy, where my speech therapist helps me practice my "s" sound.

Her name is
Ms. Carol,
and she is a
speech superhero!

Other kids my age do not always understand what I am trying to say, but instead of asking, they just walk away.

When I found out
I was going
to speech therapy,
I was not sure
what that meant.
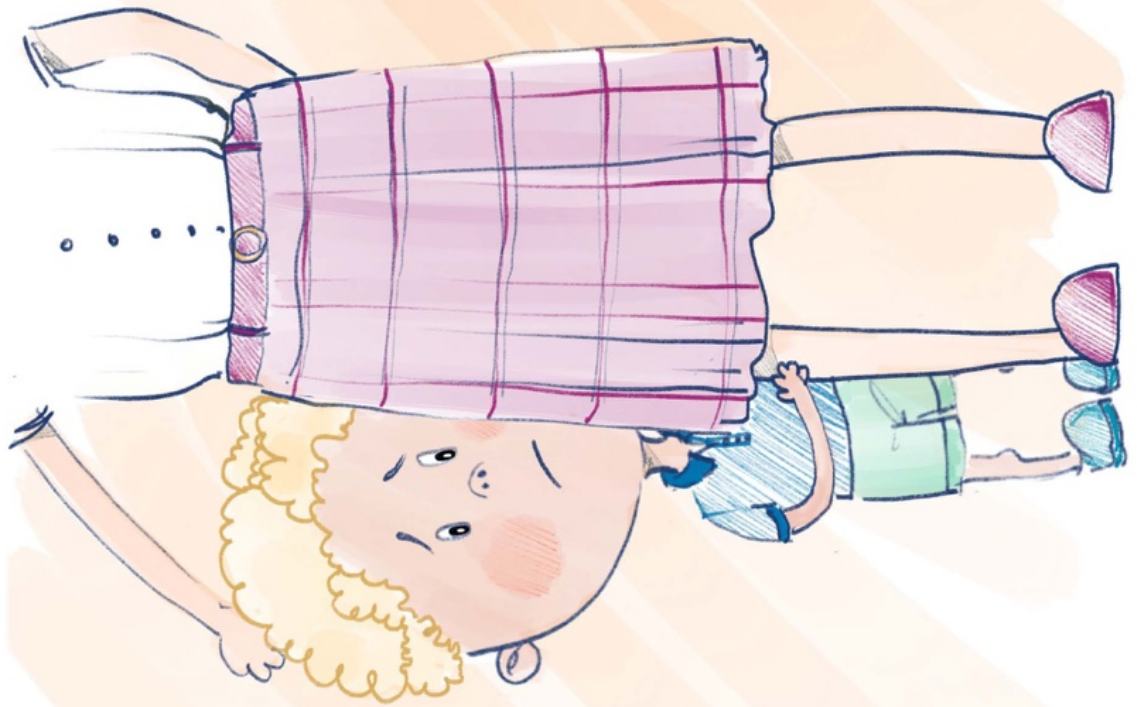
But after I went to my first day of speech, I realized there was no reason to feel nervous after all!

We practice with lots of words, but while playing lots of games!

Ms. Carol helps me learn how to move my mouth to make my "s" sound.
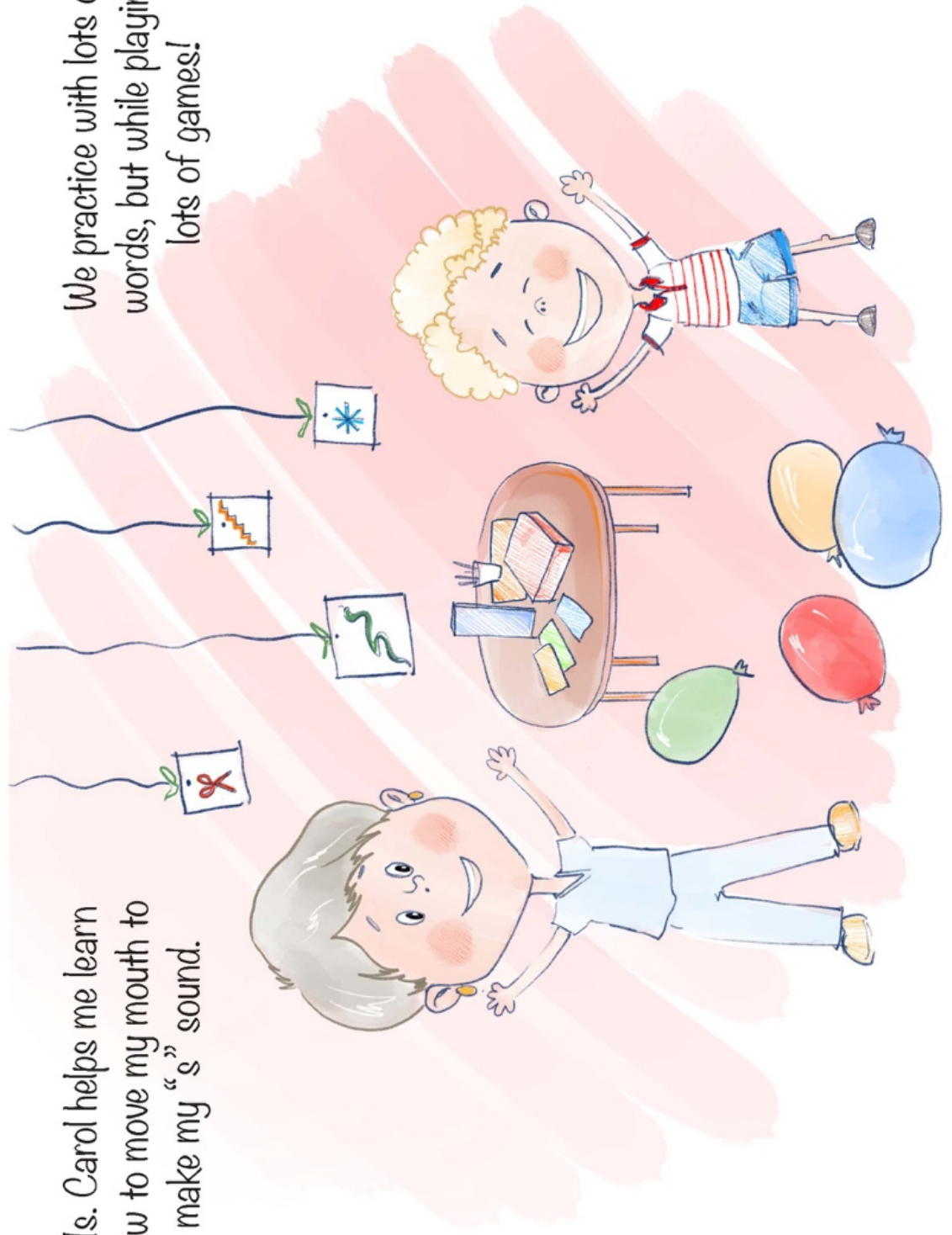
Speech therapy is FUN!

Ms. Carol helps
me feel brave
like a superhero,
even though my
speech sounds different.

I have even made lots of friends at speech therapy who sound different when they talk, just like I do!

Everyone in the whole world is different,

I AM...

BEAUTIFUL

KIND

AWESOME

SPECIAL

GENEROUS

FUNNY

FRIENDLY

INSPIRATIONAL

SMART

but those differences make us who we are.

We can always find other people who share some of our differences,
so we can all be special together!
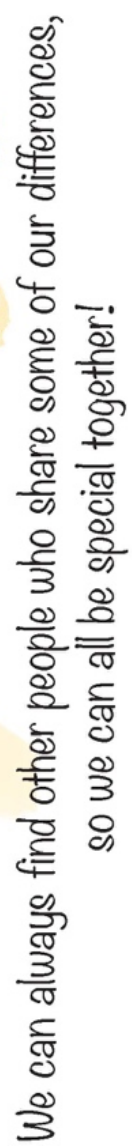
Everywhere we go, it is important to love the people around us,
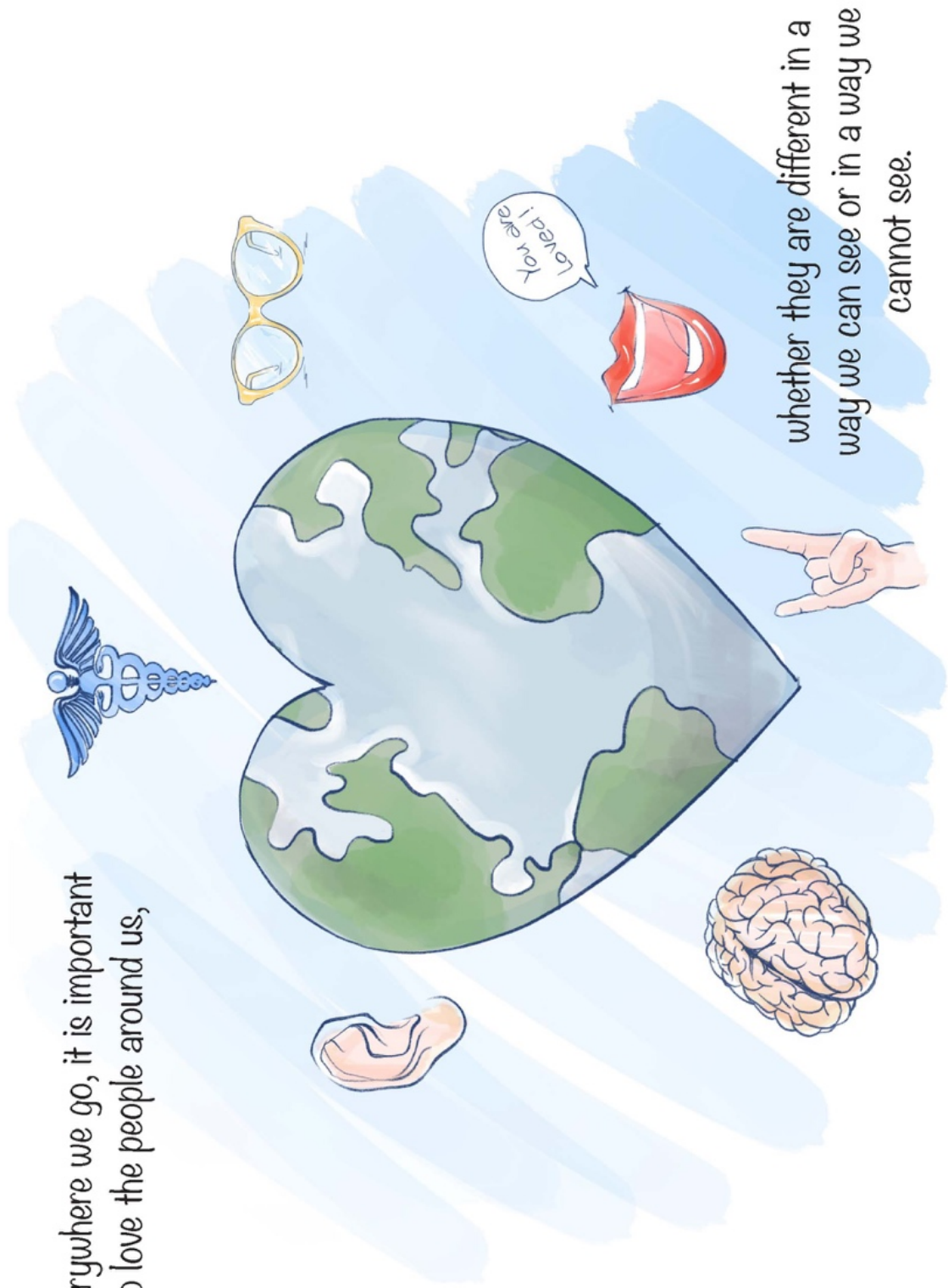
whether they are different in a way we can see or in a way we cannot see.

You are Loved!

Because no matter what, we can all be friends!

Tips for Parents of Children in Speech-Language-Hearing Therapy

Based on real tips from real parents!

1. Be patient. This process takes time, but it is a worthy effort!

2. Praise all progress. Encourage your child for even the littlest victories!

3. Ask questions. Communicating with the therapist is vital for success. They are there to help!

4. Test the waters. Ensure that your child enjoys spending time with his or her speech therapist! This is a crucial component to your child's willingness and motivation to work and learn.

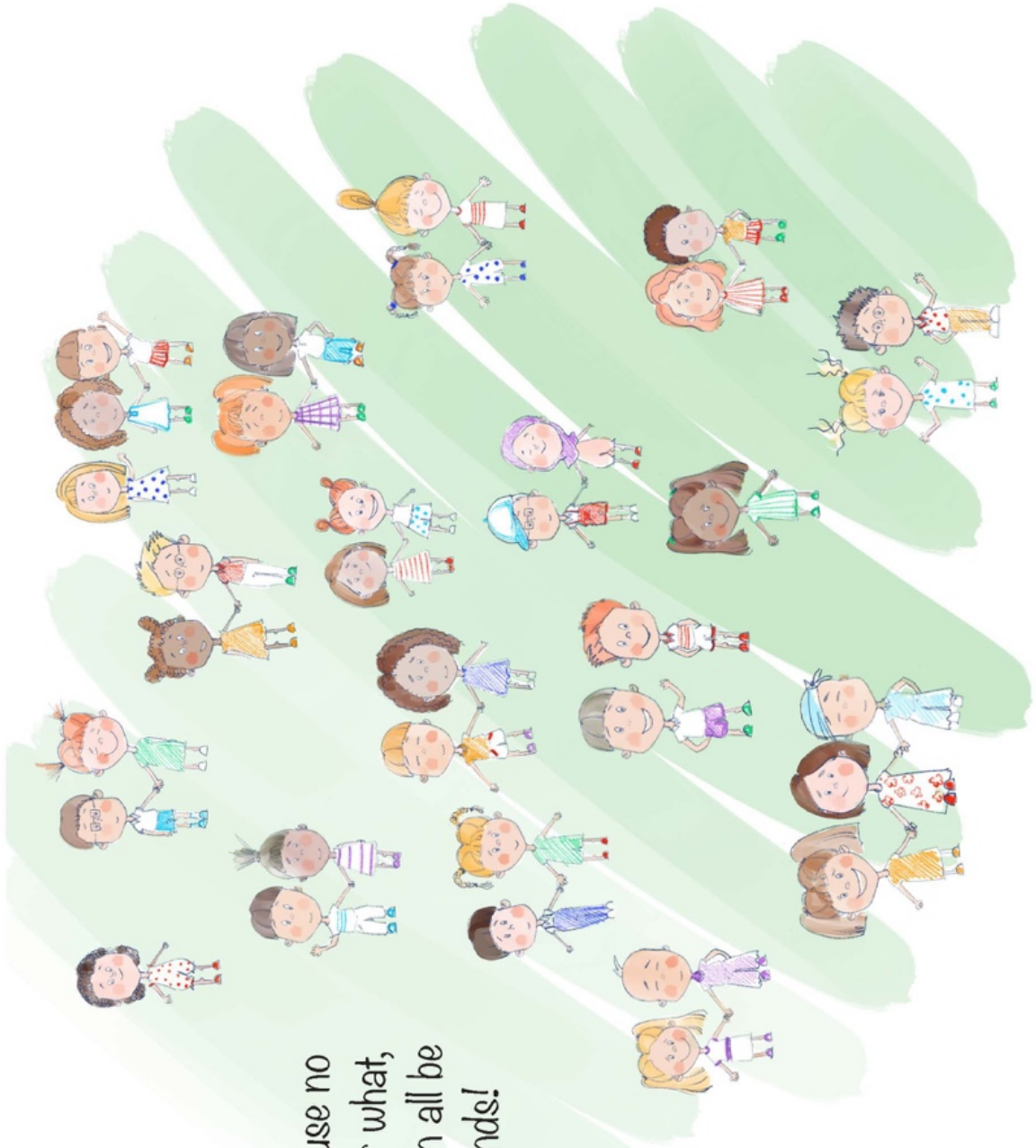5. No comparison. Every family has a different experience in this process. Go at your own pace and find what works best for your family in therapy and home routines.

6. Seek community. Find fellow parents of children with communication disorders and talk about your victories and concerns. This will encourage and validate the feelings of all families involved.

7. Be consistent. Follow through with homework and carrying over practices from therapy to home. This will aid progress simply through more consistent exposure to the targeted skill.

8. Don't push it. Incorporate support for speech and language at home, but be cognizant of the line between laziness and frustration. When a kiddo shuts down, progress goes out the window.

9. Go with the flow. Be kind to strangers who do not understand your child's speech or language delay, even when that is hard to do.

Conclusion

Overall, the intent for this project was to understand the perspectives of individuals who have been influenced by a communication disorder and to utilize those perspectives to shape a resource for individuals who encounter similar situations in the future. Through interviews with parents and adults, a deeper, more personal understanding was obtained of what daily life looks like for individuals with communication disorders and how their emotions are influenced by their experiences. *We Can All Be Friends!* was written under the impression of those emotions to be a resource for families feeling uncertain, worried, nervous, or confused about what is to come when facing speech-language therapy for the first time. The "Tips for Parents" portion of the book is especially important, because it provides direct encouragement and advice to parents who read the book with their children through tips that were each inspired by the response of a parent who had already experienced similar situations and emotions.

The book was written to be a learning resource for all children as well. The portrayal of multiple differences as well as communication disorders allows for children who are typically developing to learn about a number of disorders and disabilities, and physical differences that they may express themselves. This was inspired by the participants' experiences with individuals who did not understand their communication disorders, and how a more generalized understanding of these invisible differences could shape responses from society to be more appropriate in the future. In all, this project was implemented to seek the emotional component of life with communication disorders and speech-language therapy so that speech-language pathologists and audiologists in the future are equipped with this deeper understanding of emotion and can harbor a better

understanding of how to best empathize, prepare, encourage, and communicate with client families. This can begin through the presentation of resources, such as *We Can All Be Friends!*, that can benefit the entire family in a lighthearted yet meaningful way that depicts both the challenging and fun aspects of speech-language therapy.

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Appendix A

IRB Approval Letter

IRB
INSTITUTIONAL REVIEW BOARD
Office of Research Compliance,
010A Sam Ingram Building,
2269 Middle Tennessee Blvd
Murfreesboro, TN 37129

MIDDLE TENNESSEE STATE UNIVERSITY

IRBN001 - EXPEDITED PROTOCOL APPROVAL NOTICE

Wednesday, August 29, 2018

Principal Investigator	**Hannah Berthelson** (Student)
Faculty Advisor	Rebecca Fisher
Co-Investigators	Hannah Owens
Investigator Email(s)	*hrb3m@mtmail.mtsu.edu; heo2e@mtmail.mtsu.edu; rebecca.fisher@mtsu.edu*
Department	Health and Human Performance
Protocol Title	***Perspectives of adults on communication disorders and speech therapy***
Protocol ID	**18-2282**

Dear Investigator(s),

The above identified research proposal has been reviewed by the MTSU Institutional Review Board (IRB) through the **EXPEDITED** mechanism under 45 CFR 46.110 and 21 CFR 56.110 within the category *(7) Research on individual or group characteristics or behavior*. A summary of the IRB action and other particulars in regard to this protocol application is tabulated below:

IRB Action	**APPROVED for ONE YEAR**		
Date of Expiration	**8/31/2019**	Date of Approval	8/29/18
Sample Size	10 (TEN)		
Participant Pool	Primary Classification: **Healthy Adults (18 or older)**		
	Specific Classification: **Clients of MTSU speech and hearing clinic**		
Exceptions	1. Collection of identifable personal information for non-research project administration purpose is permitted. 2. Voice recording for data collection is allowed.		
Restrictions	**1. Mandatory signed informed consent; the participants must be provided with a copy of the informed consent document signed by the PI. 2. Identifiable personal information must be removed once data are collected and the patients may not be identified unless approved by IRB. 3. Voice data must be destroyed once data are processed.**		
Comments	NONE		

This protocol can be continued for up to THREE years (**8/31/2021**) by obtaining a continuation approval prior to **8/31/2019**. Refer to the following schedule to plan your annual project reports and be aware that you may not receive a separate reminder to complete your continuing reviews. Failure in obtaining an approval for continuation will automatically result in cancellation of this

protocol. Moreover, the completion of this study MUST be notified to the Office of Compliance by filing a final report in order to close-out the protocol.

Post-approval Actions

The investigator(s) indicated in this notification should read and abide by all of the post-approval conditions imposed with this approval. Refer to the post-approval guidelines posted in the MTSU IRB's website. Any unanticipated harms to participants or adverse events must be reported to the Office of Compliance at (615) 494-8918 within 48 hours of the incident. Amendments to this protocol must be approved by the IRB. Inclusion of new researchers must also be approved by the Office of Compliance before they begin to work on the project.

Continuing Review **(Follow the Schedule Below:)**
Submit an annual report to request continuing review by the deadline indicated below and please be aware that REMINDERS WILL NOT BE SENT.

Reporting Period	Requisition Deadline	IRB Comments
First year report	7/31/2019	The protocol is currently scheduled to expire on 08/31/2019 if CR is not requested before the deadline
Second year report	7/31/2020	NOT COMPLETED
Final report	7/31/2021	NOT COMPLETED

Post-approval Protocol Amendments:
Only two procedural amendment requests will be entertained per year. In addition, the researchers can request amendments during continuing review. This amendment restriction does not apply to minor changes such as language usage and addition/removal of research personnel. .

Date	Amendment(s)	IRB Comments
NONE	NONE.	NONE

Other Post-approval Actions:

Date	IRB Action(s)	IRB Comments
NONE	NONE.	NONE

Mandatory Data Storage Requirement: All of the research-related records, which include signed consent forms, investigator information and other documents related to the study, must be retained by the PI or the faculty advisor (if the PI is a student) at the secure location mentioned in the protocol application. The data storage must be maintained for at least three (3) years after study has been closed. Subsequent to closing the protocol, the researcher may destroy the data in a manner that maintains confidentiality and anonymity.

IRB reserves the right to modify, change or cancel the terms of this letter without prior notice. Be advised that IRB also reserves the right to inspect or audit your records if needed.

Sincerely,

Institutional Review Board
Middle Tennessee State University

Quick Links:
Click here for a detailed list of the post-approval responsibilities.
More information on expedited procedures can be found here.

Appendix B

Consent Form for Interviews

Principal Investigator: Hannah Berthelson
Study Title: Encouraging the Acceptance of Human Differences Through Children's Literature
Institution: Middle Tennessee State University

Name of participant: _____ Age: _____

The following information is provided to inform you about the research project and your participation in it. Please read this form carefully and feel free to ask any questions you may have about this study and the information given below. You will be given an opportunity to ask questions, and your questions will be answered. Also, you will be given a copy of this consent form.

Your participation in this research study is voluntary. You are also free to withdraw from this study at any time. In the event new information becomes available that may affect the risks or benefits associated with this research study or your willingness to participate in it, you will be notified so that you can make an informed decision whether or not to continue your participation in this study.

For additional information about giving consent or your rights as a participant in this study, please feel free to contact the MTSU Office of Compliance at (615) 494-8918.

1. **Purpose of the study:**
   You are being asked to participate in a research study because you are the recipient of, or the parent of a child who received speech and hearing therapy. I am interested in finding out about your experiences as a parent or child who was enrolled in speech and hearing therapy.

2. **Description of procedures to be followed and approximate duration of the study:**
   I will be interviewing two groups of people: parents of children who participate in speech therapy, and adults who participated in speech therapy as children. My objective is to understand your experiences with speech therapy and with a speech or language disorder. I am also interested in your suggestions of what could have made those experiences easier for you. The interview will consist of a series of questions about your experiences. These interviews will be audio recorded so that I can transcribe them at a later time. Your name, your child's name, and the names of any other people will not be disclosed in any publications of the study.

3. **Expected costs:**
   No cost is necessary.

4. **Description of the discomforts, inconveniences, and/or risks that can be reasonably expected as a result of participation in this study:**
   The interview questions will be targeting personal experiences living with a child who has a communication disorder, or as a child who has a speech or hearing disorder. You may experience slight discomfort if you find it uncomfortable to talk about your experiences. If talking about your experiences becomes too uncomfortable, you may choose to not answer a question or to end the interview at any point in time.

5. **Compensation in case of study-related injury:**
   There is no risk of study-related injury so related compensation is not offered.

6. **Anticipated benefits from this study:**
   Participants will not receive any direct benefits through this study. The potential indirect benefits from participation in this study would be in contribution to science and humankind in helping speech language pathologists and audiologists better understand how persons in therapy feel about their experiences, their relationship with the therapist, and their experiences with other people unfamiliar with communication disorders.

Middle Tennessee State University Institutional Review Board
Informed Consent Document for Research

7. **Alternative treatments available:**
Treatment is not a component of this study so there are no alternative treatments available.

8. **Compensation for participation:**
Compensation is not offered for participation.

9. **Circumstances under which the Principal Investigator may withdraw you from study participation:**
If any irrational behavior or slanderous language is used in any way during the consent or interview process, the researcher will withdraw you from the study.
If you feel that it is to uncomfortable or stressful to answer these questions at any point during the consent or interview process the researcher will withdraw you from the study.

10. **What happens if you choose to withdraw from study participation:**
If you feel that it is too uncomfortable or stressful to answer these questions at any point during the interview, you may choose to omit a question or to withdraw from the study.   Your data will be omitted and destroyed.

11. **Contact Information.**
If you should have any questions about this research study or possible injury, please feel free to contact **Hannah Berthelson** at **901-491-3340** or my Faculty Advisor, **Dr. Rebecca Fischer** at **615-904-8541.**

12. **Confidentiality.** All efforts, within reason, will be made to keep the personal information in your research record private but total privacy cannot be promised. Your information may be shared with MTSU or the government, such as the Middle Tennessee State University Institutional Review Board, Federal Government Office for Human Research Protections. If you or someone else is in danger or if we are required to do so by law.

13. **STATEMENT BY PERSON AGREEING TO PARTICIPATE IN THIS STUDY**
I have read this informed consent document and the material contained in it has been explained to me verbally. I understand each part of the document, all my questions have been answered, and I freely and voluntarily choose to participate in this study.

_____   _____
Date   Signature of patient/volunteer

Consent obtained by:

_____   _____
Date   Signature

                                        _____
                                        Printed Name and Title

Appendix C

Questions for Interviews with Parents

1. How has having a child with a disorder shaped how you view the world and other people?

2. What were your feelings for yourself and your child when encountering speech therapy for the first time?

3. How do you handle encounters with individuals who do not understand your child's disorder?

4. How do you discuss differences with your child, regarding those within themselves and in others?

5. Does your child ever raise questions about their speech or language delay, and if so, how do you explain to your child that they are not like everyone else? How do they receive it?

6. Over the years, how has your perception of your child's diagnosis and how it influences their daily life changed?

7. What has your experience with speech therapy been like? What have you appreciated and disliked when working with a speech therapist?

Appendix D

Questions for Interviews with Adults

1. What do you feel makes you who you are? In other words, how are you unique from your peers? In what ways do you think you are the same as your peers?

2. When you were a child, what did you feel made you different from other people?

3. How do you feel that your communication disorder has shaped the way you perceive the world and other people?

4. How do you feel that your communication disorder has influenced the way you feel about yourself?

5. What kind of advice would you give to a child entering speech and hearing therapy for the first time?

6. What was speech therapy like for you? Specifically, how did you get along with your speech therapist? What did you like and dislike about your experience?

Appendix E

Definitions for Original A Priori Codes for Interviews with Parents

1. *Worry*- Parent is worried about child's social, medical, and emotional well-being due to possible influence of communication disorder.

2. *Nervous*- Parent and/or child is nervous about beginning speech therapy.

3. *Concern*- Parent is concerned for the future and what the child is going through in the present.

4. *Unsure*- Parent is unsure of what is causing the communication disorder and how to confront it at home.

5. *Challenging*- The learning process of encountering a communication disorder is challenging and presents difficulties/hardships that the families must face.

6. *Strengths*- Child has strengths that he or she finds confidence in and that are emphasized by the parents

7. *Special* – Parents emphasize special qualities in their children.

8. *Unaware* – Child is unaware of his or her own differences.

Appendix F

Definitions for Finalized A Priori Codes for Interviews with Parents

1. *Worry/concern* – Parents harbor worry about the child's current and future social, medical, and emotional well-being due to the possible influence of the communication disorder.

2. *Nervous/unsure* – Parent and/or child nervous about beginning therapy due to overall uncertainty about the disorder and how to confront it outside of therapy.

3. *Challenging* – The learning process in encountering a communication disorder is challenging and presents difficulties/hardships that families must face.

4. *Strengths* – Child has talents and activities in which he or she finds confidence that are emphasized by the parents.

5. *Special* – Parents emphasize special qualities about their children.

6. *Unaware* – Child is unaware of own differences, which can be due to young age or cognitive differences.

Appendix G

Definitions for Original Emergent Codes for Interviews with Parents

1. *Increased understanding*- The parents expressed a heightened understanding for the troubles and challenges that other people face, primarily when living with a disorder or disability.

2. *Speaking for child*- The parent spoke for the child to quicken conversations and avoid awkward encounters with strangers.

3. *Praising differences across all people*- The parents praised the fact that everyone is different to encourage the children to accept their own differences.

4. *Positive reinforcement/change*- The parents provided positive remarks about the children's progress to reinforce or correct behaviors.

5. *Therapy is a quick fix*- The parents believed that therapy was a brief process and the children wouldn't be enrolled for long before they were remediated.

6. *Learned to be honest with curious strangers*- The parents claimed to being upfront, honest, and kind to strangers who do not understand the client's communication disorder.

Appendix H

Definitions for Finalized Emergent Codes for Interviews with Parents

1. *Empathy toward others* – A deepened understanding of others who live with a disability or disorder as well as the potential struggles other people may face that are unknown by those around them.

2. *Interaction with outside world* – Interactions with strangers in public who do not understand the child's communication disorder, in which the parent either felt the need to speak for the child or had negative experiences with those individuals who did not know how to appropriately interact with the child.

3. *Praising differences as an emotional response* – Praising differences in the child by praising the fact that everyone is different and that is okay.

4. *Positive reinforcement as a therapeutic response* – Supplying positive reinforcement and encouragement as a direct response to the child's performance in speech-language therapy and the progress they are making with therapy goals at home.

5. *Therapy is a quick fix* – When entering speech-language therapy for the first time, the parent believed that it would be a quick and simple process that would "fix" the child with ease, but found that it takes time.

6. *Child is unaware of own differences* – Many of the children of parents interviewed were described as being oblivious that they have a communication disorder or that it sets them apart from their peers in any way.

Appendix I

Definitions for A Priori Codes for Interviews with Adults

1. *Limited memories* –The participant has a limited memory of his or her time in speech-language therapy as a child.

2. *Rapid results*- The participant recalls rapid and sudden changes in his or her speech and/or language abilities after time in speech-language therapy.

Appendix J

Definitions for Emergent Codes for Interviews with Adults

1. *Empathy toward others*- The participants feel that they better understand the situations and feelings of children and adults who experience life with a communication disorder because they have had similar experiences.

2. *Frustration*- The participants recalled feeling frustrated when unable to communicate what they wanted too and when others did not understand them easily.

3. *Anxiety*- The participants recounted experiencing anxiety due to their communication disorder in knowing that what they were saying sounds different to other people.