Knowledge and Treatment of the Down Syndrome Population in Speech-Language Pathology: A National Survey

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Abstract

The purpose of this study was to determine the extent to which speech-language pathologists possess both knowledge of Down syndrome and confidence in their clinical abilities to treat the population and their families. Data was collected through an anonymous 39-question, web-based survey designed for practicing speech-language pathologists. A total of 260 completed responses were received. The results indicated the participants in the study possessed a foundational knowledge of Down syndrome, characterized by general knowledge of the disorder and evidence-based ideals; however, a lack of knowledge on the communicative characteristics associated with Down syndrome was exhibited. Further, participants' confidence in their abilities to treat individuals with Down syndrome was shown to increase in relation to increased experience. While some elements of family-centered practice were reported, implementation across multiple domains of treatment was limited. From this, it can be concluded that emphasis may be placed on clinical experience with Down syndrome, knowledge of the communicative characteristics associated with the disorder, and ways to implement family-centered practice for the population in the future.

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Chapter 1

Introduction

Professionals in the field of speech-language pathology are responsible for appropriately, efficiently, and effectively treating individuals with a variety of disorders. Whether assessing or treating speech, language, voice, swallowing, or cognitive skills, speech-language pathologists are required to have an in-depth level of knowledge on each disorder in which they come into contact. As the field's scope of practice continues to increase, the demands placed upon the professionals also expand. No matter the setting, speech-language pathologists must consistently and explicitly work to increase their knowledge on the characteristics of the disorders in which they interact by reviewing the most recent research published on the subject and integrating it into their practice when appropriate.

A variety of low-incidence disorders require the services of speech-language pathologists, and Down syndrome is no exception. The associated deficits often make individuals with Down syndrome excellent candidates for speech and language therapy throughout the entirety of their lifespans, further illustrating the likelihood of speech-language pathologists coming into contact with clients with Down syndrome regardless of the setting in which they work. Although the disorder is relatively rare in comparison to autism spectrum disorder or general language delays, it is the most common chromosomal condition in the United States (March of Dimes, 2016). The need for competent and confident speech-language pathologists to treat the population is present.

Because a variety of medical, physical, cognitive, and behavioral symptoms are often associated with Down syndrome, specific skills and knowledge are required in order to treat the population and their families. Specifically, individuals with Down syndrome may exhibit lower

levels of cognition, challenging behaviors that are characterized differently throughout childhood, greater risks of medical conditions, lower speech intelligibility, and/or decreased linguistic knowledge and skills (CDC, 2017; Evans & Gray, 2000; Feeley & Jones, 2006; Fidler, 2005; Te Kaat-Van Den Os et al., 2015; Kumin, 1994; March of Dimes, 2016; Pinto & Schub, 2015; Wright et al., 2013). To manage such deficits, a variety of treatment methods have been developed and considered. While each intervention method considers a particular skill or area of deficit, one characteristic of Down syndrome that is consistently evaluated in treatments throughout the literature is visual memory (Cleland, Timmons, Wood, Hardcastle, & Wishart, 2009; Knight et al., 2015; Wood, Wishart, Hardcastle, Cleland, & Timmins, 2009). Individuals with Down syndrome typically exhibit higher visual memory skills than verbal memory skills. Thus, treatment of the population often involves visual elements, or in the least, ways to augment the decreased verbal memory skills with the addition of visual supports.

In addition to treating the individual with Down syndrome, speech-language pathologists must also consider him or her in the context of his or her family (Bernheimer & Weisher; 2007; Van Hooste & Mass, 2003; Viana Pereira & Parlato Oliveira, 2015). Because parents and siblings interact with the individual with Down syndrome every day, their ability to shape his or her communication should be considered (Hedov et al., 2000; Hsiao, 2014; Van Riper, 2007; Viana Pereira & Parlato Oliveira, 2015). This may look different for each family. Some caregivers may need to be educated on the communicative characteristics associated with the disorder while others may require interactional models and ways to integrate therapy into everyday routines. Regardless, the role of the speech-language pathologist is both large and dynamic in the treatment of the Down syndrome population.

Ultimately, there are a few ways speech-language pathologists can become educated on different elements of Down syndrome and the most effective, research-based treatment methods. Dependent upon their undergraduate and graduate training experiences and clinical caseloads, speech-language pathologists may either feel fully prepared to treat the population or feel they are in need of more training. In these instances, they may take initiative and complete their own research or enroll in related continuing education courses. However, the possibility exists that some speech-language pathologists may treat individuals with Down syndrome and their families without the necessary knowledge and training. The purpose of this study was to explore the scope of knowledge on the Down syndrome population and the prevalence of confident and competent professionals prepared to treat individuals with Down syndrome and their families in the field of speech-language pathology.

Chapter 2

Review of the Literature

This chapter describes literature relevant to the research purposes of the thesis. It is organized in the following sections: a) Down Syndrome Overview, b) Role of the Speech-Language Pathologist, c) Personnel Preparation

Down Syndrome Overview

Down syndrome is a genetic disorder diagnosed at or before birth. It results in a wide array of intellectual and physical deficits as well as increases the risk for other medical conditions. Currently, there is no cure for Down syndrome. Its symptoms may only be treated throughout the affected individual's lifespan. Nonetheless, research is ongoing and ways in which Down syndrome may be potentially cured and treated are continuing to be examined.

While the cause of Down syndrome is related to nondisjunction (error in cell division at conception), the cause of the nondisjunction is unknown (NADS, 2016). In typically developing individuals, 46 chromosomes are present; 23 chromosomes come from each parent. In individuals with Down syndrome, 47 chromosomes are present. There is one extra copy of chromosome 21 in all or some cells of the body. Chromosomes contain the genetic material necessary for cells to develop. Therefore, the presence of the extra copy of chromosome 21 influences both the anatomical and intellectual development of the individual. Additionally, there are three distinct types of Down syndrome: Trisomy 21, Translocation, and Mosaicism. Trisomy 21 is the most common form of Down syndrome, making up approximately 95% of the population. In this type, the extra copy of chromosome 21 is completely separate from the other two copies and is included in every cell in the body. In Translocation however, the additional copy of chromosome 21 is attached to another chromosome (typically chromosome 13, 14, 15,

21, or 22). This type affects approximately three percent of the population and can be passed down hereditarily. The third type of Down syndrome, Mosaicism, is unique in that only some cells of the body contain three copies of chromosome 21. As such, some cells in the body contain a typical 46 chromosomes resulting in less severe symptoms than those seen in individuals with Trisomy 21 or Translocation. Mosaicism occurs in approximately 2% of the population. Regardless of the specific type of Down syndrome, all cases are often referred to as 'Trisomy 21' in everyday discourse.

Both screening and diagnostic tests are available to help expecting mothers determine if their children have Down syndrome. Screening tests, such as the combination of blood tests and ultrasound images, are used to help determine the baby's likelihood of having Down syndrome. If a risk is found to be present, a mother may decide to partake in a diagnostic test, which will either confirm or reject the Down syndrome diagnosis. However, these tests are invasive and increase the risk of miscarriage (March of Dimes, 2016). The types of diagnostic tests include chorionic villus sampling (assessing the placenta), amniocentesis (assessing the amniotic fluid), and percutaneous (assessing blood from the umbilical cord) (CDC, 2017). These tests are effective because blood and tissues yield chromosomal information through karyotypes (NADS, 2016). Karyotypes are pictures that show chromosomes grouped by their size, shape, and number. To diagnose Down syndrome, physicians and researchers are looking for an additional copy of chromosome 21. If a baby was not diagnosed with Down syndrome while in utero, he or she may be diagnosed immediately after birth through a blood test. Once again, a karyotype can be created and the extra presence of chromosome 21 can be determined.

A British physician named John Langdon Down is credited with discovering Down syndrome in 1866, hence the name "Down" syndrome (Irvine, 1986). Since then, the disorder

has continued to be explored. Although less than one percent of babies born in the United States have Down syndrome, it is the most common chromosomal condition in the United States (CDC, 2017; March of Dimes, 2016). Approximately one out of every 700 babies in the US are born with the disorder, accounting for around 6,000 births per year. The likelihood of having a child with Down syndrome increases with maternal age, notably beginning at age 35. This can be further represented by the different levels of risk present across a span of ages. For instance, one out of every 1,340 babies born to a 25-year-old mother will have Down syndrome (March of Dimes, 2016). For babies born to 30-year-old mothers, one out of every 940 will have Down syndrome. For babies born to 35-year-old mothers, one out of every 353 will have Down syndrome. Then, the likelihood of having a child with Down syndrome becomes significantly higher. At age 40, one out of every 85 babies have Down syndrome, and at age 45 the risk becomes one in every 35 babies (March of Dimes, 2016). Although the etiology behind the presence of the extra copy of chromosome 21 is unknown, it is evident that maternal age plays a significant role in the likelihood of its appearance. In addition, it should be noted that the influence of maternal age was shown to change dependent upon ethnicity. For instance, maternal age was shown to play the largest role in the Mexican American and African American populations and the smallest role in the non-Hispanic White American population (Khoshnood et al., 2000). Across all cultures, however, 80% of babies with Down syndrome were born to mothers younger than 35 years of age, illustrating that it should not be assumed that a child with Down syndrome was born to an older mother (NADS, 2016).

Characteristics associated with Down syndrome. While there is no singular profile attributed to those with Down Syndrome, certain traits and characteristics are associated with the diagnosis of the disorder. Certain physical traits and cognitive deficits are commonly highlighted

when Down syndrome is discussed or thought of in everyday environments. In addition, trends in speech-language development and behavioral traits have also been noted in the literature. The ways in which all of these components combine and affect the individual further influence how he or she participates in the world and in his or her family unit.

Physical characteristics. There are many recognizable physical characteristics of individuals with Down syndrome. While some individuals may possess many of the characteristics, others may possess only a few. The most common of these include a flat bridge of the nose, short stature, almond-shape eyes that slant up, palmar crease (line through the palm of the hand), and hypotonia (low muscle tone) (CDC, 2017; NICHCY, 2010; March of Dimes, 2016). Other characteristics include a small neck, head, and oral cavity, large tongue (macroglossia), spotted irises of the eyes, and folding ears. The combination of these physical characteristics may lead many to be able to discern whether an individual has Down syndrome without ever having interacted with them. Furthermore, some individuals with Down syndrome experience co-occurring medical conditions. Approximately 75% of the population experiences hearing loss and 60% require glasses to see or exhibit eye diseases (e.g., cataracts; Shott, 2006). Additionally, obstructive sleep apnea is experienced by 50-75% of the population and a similar range (50-70%) experience ear infections. Congenital heart defects are also commonly experienced by individuals with Down syndrome since close to 50% are born with some form of a heart defect (CDC, 2017; March of Dimes, 2016). Less commonly found in the population but certainly notable are blood disorders (e.g., anemia or a leukemia), slowly developing or absent teeth, microcephaly (i.e., a smaller head than peers), intestinal blockages such as those found in Hirschsprung Disease, hip dislocations, spine or neck issues, and problems with the thyroid (e.g.,

hypothyroidism) (CDC, 2017; March of Dimes, 2016). Most physicians will monitor individuals with Down syndrome for any and all of these conditions throughout their lifetimes.

Cognitive phenotype. Research has been completed looking at specific cognitive characteristics present among individuals with Down syndrome. Specifically, by understanding the cognitive phenotype, a more holistic view of Down syndrome may be created. As mentioned previously, cognition is certainly affected by Down syndrome. On average, intellectual quotients for this population fall between 20 and 80 (Pinto & Schub, 2015). While a diagnosis of Down Syndrome does relate to a range of intelligence quotients, the term cognition can be used in a much broader context. According to Silverman (2007), cognition constitutes all of the mental processes involved in every conscious and subconscious action one completes. More specifically, cognition has been defined as including attention, memory, and executive functioning (Kimbarow, 2016). When impairment in any one of these areas is present, the others are likely to be affected as well; cognitive processes are interrelated with one another. In a systematic review, Silverman (2007) reviewed the cognitive characteristics of the Down syndrome population. Most notably, it was found that processing speed and verbal memory were lowered. The implications of these deficits can be far reaching. For instance, when an individual requires more time to processes information, he or she may fall behind in social, academic, and vocational endeavors. It is not a lack of knowledge or intelligence that is causing these individuals to fall behind; rather it is a lack in the speed of their ability to process information they have just heard or seen. This ideal is crucial when treating these individuals in various contexts. Furthermore, the deficits in memory should be highlighted. Memory impairments are noticeable in childhood and extend throughout the lifetime. Silverman (2007) reported that individuals with Down syndrome have greater trouble with verbal memory than visuospatial

memory, signifying an increased obstacle with understanding what has been said to them. Therefore, children with Down syndrome have been found to struggle with completing tasks requiring a strong verbal working memory (Silverman, 2007). With slower processing speeds and challenges related to verbal memory, the individual with Down syndrome may have a much harder time participating in conversations and following instructions than their typically developing peers. Furthermore, memory and processing speeds are also related to speech and language abilities. The ability to learn and use language and communicate verbally is dependent upon remembering what one has said, understanding the words spoken, and formulating a message to send back. With deficits in verbal working memory, it would be expected that this population might experience communicative obstacles related to their cognitive phenotype.

In a longitudinal study published by Couzens, Haynes, and Cuskelly (2012), various aspects of cognition among individuals with Down syndrome were studied. Eighty-nine participants with Down syndrome were included in the study from the ages of four years to 30 years, and subtest scores from the Standford-Binet IV were used to acquire the data. The purpose of the study was to explore both the rate of cognitive development as well as the factors influencing the cognitive differences between the participants. While there are similar cognitive characteristics present in the Down syndrome population, the severity of the characteristics is quite variable. Some individuals may experience less severe cognitive deficits than others. In regard to the rate of cognitive development, the mood of the participant, presence of a persistent personality, maternal education level, and experiences at the elementary school level were found to be the most influencing factors. Evidently, similar factors influenced the differences between cognitive development. Overall temperament, maternal education, medical conditions, and school experiences were found to influence the differences in cognitive development between

participants. Regardless of these factors however, individuals in the study experienced greater cognitive development when provided consistent learning opportunities early in their childhood and /or had a higher level of cognition from the beginning of their lives. Thus, their already high memory skills, processing speeds, attention abilities, and executive functioning may have allowed them to further their development. It is also likely that mothers who attained a higher level of education provide their children with more opportunities to learn due to the language rich environment they are able to create. Thus, the factors mentioned previously indirectly create more learning opportunities which further affects cognitive development (Couzens, Haynes, & Cuskelly, 2007).

In line with information presented previously from Silverman's (2007) research, the authors of the longitudinal study suggest that intervention for individuals with Down syndrome should emphasize verbal memory as well as problem solving skills. As Silverman (2007) mentioned, individuals in this population have slower processing speeds as well as deficits in verbal working memory. The research aligns to represent the cognitive deficits present within the population. Interestingly, Couzens, Haynes, and Cuskelly (2012) add to this ideal by suggesting negative affect be targeted along with those cognitive skills. As they found, temperament, the personality trait of persistence, and overall mood relate to the rate of cognitive development as well as the differences between such development. Therefore, by adding the element of mood and temperament into the understanding of the cognitive phenotype, a more comprehensive view can be attained. Additionally, language abilities are often believed to be embedded within an individual's cognitive abilities (Kimbarow, 2016). Thus, research points to the ideal that language intervention may need to target the underlying cognitive processes of verbal working memory, processing speed, and overall mood and attitude rather than specific language targets.

This way, greater language gains may be seen through a strong, research-based understanding of the cognitive phenotype.

Communicative characteristics. Aside from the physical and intellectual aspects of Down syndrome, speech and language development is also frequently affected. The intellectual deficits discussed above may affect the adaptive skills, communicative abilities, and learning processes possessed by individuals with Down syndrome and can often create challenges for these individuals in everyday life and activities of daily living. Specifically, the American Speech-Language-Hearing Association (n.d.) highlighted the deficits present within the element of communication. In a systematic review completed by Kent and Vorperian (2013), elements of verbal communication were considered. They suggested that a mild form of dysphonia is exhibited within the population and that voice production is often perceived as rough and/or breathy and is associated with a low signal-to-noise ratio. Further, affected individuals have been found to utilize their vocal folds atypically during vibration as well as produce abnormal resonances. When all of these elements combine to create the vocal production necessary for speech, intelligibility can be affected. Another element reviewed by Kent and Vorperian (2013) was speech sound disorders. They found that the severity of speech or verbal challenges was not related to the severity of challenges in the areas of language and cognition. Further, delayed and disordered speech patterns were shown to have appeared by age 3 for individuals in this population with inconsistent errors noted throughout the lifespan. In regard to fluency and prosody, limitations were noted in both. It was reported that 10-45% of the Down syndrome population exhibits stuttering and/or cluttering behaviors. While this range is very wide, only 1% of the typically developing population stutters. Therefore, even if the lowest number in the range for the Down syndrome population truly stutters (10%), it is vastly different from the 1%

exhibiting dysfluent speech in the general population (Kumin, 2010). Additionally, individuals with Down syndrome were found to have a harder time adjusting the prosody of their speech than their typically developing peers. Through abnormal vocal fold vibration and resonances, inconsistent speech errors, a high percentage of stuttering behaviors, and limitations in prosody, overall intelligibility is lowered for individuals in this population. Unfortunately, this low level of intelligibility extends throughout the individuals lifespan, affecting communication with others, educational and vocational pursuits, and overall quality of life.

In addition to lowered speech intelligibility and cognitive levels, individuals with Down syndrome also experience notable deficits in expressive language and syntax (Roberts, Price, & Malkin, 2007). As expected, the population generally has higher receptive language abilities than expressive language abilities, which allows them to understand more than they are able to produce. Further, their language productions may be confounded by their deficits in verbal communication (e.g., inconsistent errors, low signal-to-noise ratio, etc.). Similarly, just as expressive language presents more challenges than receptive language, syntax (the combination and organization of words) has been found to be more challenging for individuals in this population than the elements of semantics (understanding words and developing a lexicon) (Fidler, Most, and Philofsky, 2008). Regardless of these deficits however, individuals with Down syndrome experience less challenges with pragmatic language and may be able to use this strength to alleviate deficits in other areas (Kumin, 2010).

Behavioral phenotype. Aside from evaluating the physical characteristics and potential medical conditions possessed by individuals with Down syndrome, there are also behavioral characteristics present within the population. These characteristics are described by the term "behavioral phenotype" and represent the set of behaviors related to social-emotional, motor,

personality motivation, and cognitive-linguistic functioning (Fidler, 2005). Attributes of this phenotype are present early in development for individuals with Down syndrome, representing the connection between Down syndrome and specific behaviors as opposed to behaviors relating to the ways in which care is provided or individual temperament. The behavioral phenotype is consistent across the lifespan, although certain behaviors are exhibited more frequently at different ages.

The literature shows that individuals with Down syndrome are more likely to experience and exhibit challenging behaviors than their typically developing peers (Feeley & Jones, 2006; Fidler, 2005). These behaviors can further affect their family members, caregivers, and friends in a variety of ways. Thus, the consistency of these behaviors across the lifespan and across the population highlights the need for the behavioral phenotype to be understood by caregivers and professionals who work with the population. The over-arching behaviors of challenge seen in individuals with Down syndrome include avoidant and attention-seeking actions (Povee, Roberts, Bourke, and Leonard, 2012). These actions are further paired with the personality traits of stubbornness and the likelihood to be disobedient (Feeley & Jones, 2006; Fidler, 2005; Povee, Bourke, & Leonard, 2012). It is important to note that these behaviors are present within the population regardless of who is interacting with them. More specifically, it is not a lack of discipline or poor provision of support that causes these behaviors to occur. Rather, individuals with Down syndrome are born with the inherent likelihood to participate in these challenging behaviors, represented by their actions in even the earliest developing years (Fidler, 2005). In addition, Anzivino and colleagues (2013) suggest that such challenging behaviors are further shaped by the variety of deficits associated with having the disorder. For instance, the physical and cognitive deficits shown in the Down syndrome population may present barriers for

individuals in the population to communicate their wants and needs effectively. The resulting frustration may act as a driving force for challenging behaviors to occur.

Additionally, individuals with Down syndrome often exhibit a propensity to create and actively participate in routine and compulsive behaviors (Povee et al., 2012). For instance, they may decide that certain tasks should be completed in a specific order before going to bed. Once this routine has been established, individuals may compulsively ensure that it is followed correctly. Furthermore, these behaviors lend themselves to the challenging behaviors mentioned previously. If routines cannot be followed correctly, disobedient and attention-seeking behaviors could arise. While the phenotype is consistent throughout the lifespan, some ages lend themselves to specific characteristics. In childhood, individuals with Down syndrome are more likely to partake in both oppressive and aggressive behaviors. In adolescence however, individuals are more likely to lessen their social interactions by withdrawing from social situations and in turn decrease their social behavior entirely (Evans & Gray, 2000; Povee et al., 2012). In a study completed by Fidler, Hodapp, and Dykens (2002), a survey was sent to parents of individuals with Down syndrome inquiring information on their knowledge of the Down syndrome behavioral phenotype. The results showed that while parents did have an awareness of some behaviors, their awareness related to the more obvious characteristics, such as a weaker ability to express language than to understand language. The extent of parent knowledge did not typically extend to a deep, research-based level. While the authors of this research related the information to family functioning, these results also emphasize the overall absence of knowledge on the specific behavioral characteristics associated with the disorder.

Another interesting area of the behavioral phenotype includes the actions individuals with Down syndrome have been shown to complete when presented with difficult tasks. Wishart

(1993) found that individuals in the population withdraw from difficult activities, even if the activities are only slightly above the individual's current level of ability. In turn, they end up using inappropriate social behaviors and may actually miss out on opportunities to learn and gain new skills (Feeley & Jones, 2006; Wishart, 1993). This pattern of avoiding hard tasks (i.e., avoidant behavior – a main contributor to the behavioral phenotype) has been shown to begin in infancy (Fidler, 2005; Wishart, 1993). Thus, its interference with the learning process is crucial since a vast amount of baseline learning takes place during the early developing years.

While a vast portion of the phenotype involves rather challenging behaviors, individuals with Down syndrome have also been shown to possess strengths within their personalities. Individuals in this population are often praised for their ability to connect with others as well as their ability to show empathy. Further, regardless of their more challenging behaviors, they have still been described as having charming and affectionate personalities (Fidler, 2005). This attribute is quite substantial because it can potentially make up for the more challenging behaviors also exhibited by individuals in the population. In a study completed by Fidler, Barret, and Most (2005), children with Down syndrome were found to smile more than children with other intellectual disabilities. This aligns with the idea that charming personalities and the ability to connect with others are strengths for this population. Interestingly however, it was shown that the amount of smiling decreased as age increased. A key attribute of the phenotype in adolescence is the withdrawal from social behaviors, so a decrease in smiling with age would be consistent with that ideal (Povee, Bourke, & Leonard, 2012). Other areas of the behavioral phenotype mentioned in the literature included a limit in both gross and fine motor functioning and a higher likelihood of completing off-task activities (Fidler, 2005; Wishart, 1993). Although every characteristic of the behavioral phenotype is not present in every individual with Down

syndrome, the over-arching themes of the characteristics are important to understand and can allow friends, families, and professionals the opportunity to better understand the individual with Down syndrome.

Outcomes for the individual. Just as typically-developing individuals experience new challenges at each stage of their lives, individuals with Down syndrome also experience such road blocks. While a variety of circumstances play into the type of challenges each individual with Down syndrome and his or her family face, there are trends that can be seen across the population as adults with Down syndrome navigate through the remainder of their lives. One of the main concerns about adulthood that both individuals with Down syndrome and their caregivers hold relates to daily activities. While typically-developing adults are societally expected to fill their days with employment activities, the deficits experienced by individuals with Down syndrome can make attaining such employment opportunities challenging. Whether seeking the opportunity itself or simply the necessary vocational training necessary for coordinating later employment, individuals with Down syndrome and their parents have been shown to report a shortage of available resources in this realm (Tomaszewski, Fidler, Talapatra, & Riley, 2018). In a study examining the employment rates of adults with Down syndrome, Kumin and Schoenbrodt (2016) found that 30.2% were unemployed. In addition, they found that 42% participated in volunteer-related work. They used this finding to represent a dichotomy sometimes present in the Down syndrome narrative. While this relatively high percentage of volunteers represents the contribution individuals with Down syndrome make to their communities, it also represents the challenges they face to find paid employment opportunities (Kumin & Schoenbrodt, 2016). Essentially, opportunities for paid employment can be limited, so individuals with Down syndrome may look to volunteer-based activities as a next step.

Additional day-to-day activities may include day programs and/or a combination of both paid and volunteer work (Kumin & Schoenbrodt, 2016; Tomaszewski et al., 2018).

In a study completed by Tomaszewski, Fidler, Talapatra, and Riley (2018), relative strengths and weaknesses were evaluated in relation to individuals with Down syndrome's executive functioning abilities and their relation to employment. While the individuals in the study exhibited a strength in emotional control and organization, their difficulty in working memory presented challenges for holding a job; individuals with greater working memory abilities were more likely to hold a job than those who experienced less working memory deficits (Tomaszewski et al., 2018). Thus, it can be concluded that while there are trends across the population, there are also individualized elements that contribute to whether an adult with Down syndrome attains a paid employment position or pursues other avenues.

Another outcome faced by individuals with Down syndrome and their families comes in the form of early aging. Those in the Down syndrome population have a propensity to experience the medical, physical, and functionality effects associated with aging earlier than their typically-developing peers (NDSS, 2013). Unfortunately, this often occurs while their central caregivers (typically parents) are also experiencing the effects of aging. Research shows that the largest impact of caregiving falls upon the mothers of adults with Down syndrome, which is then followed by the fathers, and then by the siblings (Holmes & Carr, 1991). Once parents are unable to be the primary caregivers for the adult with Down syndrome, whether by aging, illness, or other circumstances, it is likely that the siblings will take on full-time care of the individual (Burke, Taylor, Urbano, & Hodapp, 2012). Through this, the element of familial contribution can be illustrated. Family members often work together to create the best outcomes and provide the most appropriate care for the member with Down syndrome. As individuals with Down

syndrome become adults, their lives are often adjusted as caregiving responsibilities shift within the context of their families.

Role of the Speech-Language Pathologist

Communication intervention. In addition to care from family members, the wide array of deficits exhibited by individuals with Down syndrome often leads the population to come into contact with professionals from many different disciplines throughout their lifespan. For instance, they may receive treatment from occupational therapists, physical therapists, cardiologists, endocrinologists, speech-language pathologists, and any number of other specialists. Although each individual with Down syndrome is different in their specific deficits and abilities, care from a variety of specialists can act as a factor in improving the overall quality of life for this population.

Based on the literature, treatment from a speech-language pathologist has been shown to be effective for improving a variety of necessary communicative skills in individuals with Down syndrome (Knight, Kurtz, & Georgiadou, 2015; Sepúlveda, López-Villaseñor, & Heinze, 2013; Te Kaat- van den Os, Jongmans, Volman, & Lauteslager, 2015; Van Bysterveldt, Gillon, & Foster-Cohen, 2010; Wright, Kaiser, Reikowsky, Roberts, & Oetting, 2013). Through the provision of explicit treatment with the purpose of improving intelligibility, language acquisition, language use, literacy skills, and many other areas, individuals with Down syndrome and their families are often able to experience benefits from therapy. Whether treatment is provided individually, in a group, or centered around the family, speech-language pathologists work to provide effective speech and language treatment for any and all clients who receive their services. However, McDaniel and Yoder (2016) suggest there is a disconnect between the treatment methods found to be effective in the research and the methods actually being used in

the field. Thus, the extent to which evidence-based practice is currently being used for this population is questionable. Nonetheless, there is a strong research base of studies providing helpful guides for developing treatment methods for this population.

Regardless of the specific speech and language treatment provided, McDaniel and Yoder (2016) discuss the importance of using precision therapy to treat individuals with Down syndrome. They suggest that precision therapy, which calls for adjusting treatment to the individual, be implemented by creating treatment goals and activities that align with the behavioral phenotype of Down syndrome. By developing an understanding of how the individual's speech and language abilities relate to the behavioral phenotype, speech-language pathologists may see greater linguistic gains in their clients with Down syndrome. In line with this train of thought, Wishart (2001) emphasized the importance of being aware of the stereotype of Down syndrome, which is often different from the actual behavioral phenotype (McDaniel & Yoder, 2016). It has been found that professionals across an array of different disciplines believe individuals with Down syndrome are consistently loving, joyous, and adaptable. This belief can create a barrier for treatment due to the disconnect between what is expected and what is actually occurring in the treatment session. Thus, precision therapy combined with the consideration of the behavioral phenotype is crucial for the treatment of both speech and language in individuals with Down syndrome (McDaniel & Yoder, 2016; Faught, Conners, Barber, & Price, 2016).

Speech. Across multiple ages and levels of functioning, intelligible speech is important for one to be able to participate in everyday activities of his or her daily life. If one is producing speech but it is not understood by the others around him or her, its effectiveness is lost. Thus, intelligibility holds the key to the underlying results of the act of communication: connection, sending messages, feeling understood, etc. Due to a variety of associated deficits (e.g., low

muscle tone, decreased motor coordination) individuals with Down syndrome often struggle to produce entirely intelligible speech. In a study completed by Kumin (1994), parents of individuals with Down syndrome were surveyed about their children's speech. As a result, 95% reported their children have exhibited some difficulty being understood by others. More specially, 80% reported trouble with articulation and 49% reported difficulty with the rate of speaking (Kumin, 1994). Through this, it becomes evident that speech-language pathologists may emphasize intelligibility with their clients with Down syndrome.

The question then becomes, by what methods do speech-language pathologists use to target intelligibility with their clients with Down syndrome? Before digging into specific methods, though, overarching elements of speech development in children with Down syndrome should be highlighted to allow for clinicians to determine where their clients fall on the developmental path. Through this, treatment of specific, unrelated skills can be avoided to allow for the treatment of developmentally appropriate skills that will build upon one another and improve the speed and efficacy of treatment. Through analysis of 62 individuals with Down syndrome aged four to 40 years, it was determined that intelligibility greatly improved with age from four years to 16 years (Wild, Vorperian, Kent, & Austin, 2018). Additionally, both consonants and vowels affected intelligibility, instead of mostly consonants as exhibited in typically developing individuals. Further, the vowels /i/ and /u/ were seen to develop before /æ/ and /a/. Thus, if intelligibility is low, one should consider the impact of vowels and vowel development to determine a starting point. Additionally, individuals with Down syndrome were also reported to struggle with initial and final consonant clusters in words and contrasting tongue posture, control, and timing during their productions and combinations of vowels and consonants in words (Wild et al., 2018). By understanding the development and typical problems in the

speech of this population, speech-language pathologists can tailor treatment toward habilitating the speech of an individual with Down syndrome rather than habilitating the speech of a typically developing child with low intelligibility. The differences in development must be understood.

In line with the thought of considering attributes specific to Down syndrome, it has been suggested that the strength in visual memory present among individuals with Down syndrome be emphasized throughout treatment (Cleland, Timmons, Wood, Hardcastle, & Wishart, 2009; Knight et al., 2015; Wood, Wishart, Hardcastle, Cleland, & Timmins, 2009). Because verbal memory is typically weaker than visual memory, the use of electropalatography (EPG) to increase articulatory abilities has been studied. EPG is a technological device that illustrates the individual's tongue while speaking. With this, the placement of the tongue becomes evident and the associated visual representation can be used in therapy and during assessment (Wood et al., 2009). Although not studied extensively, EPG has been shown to be effective in the literature base (Cleland et al., 2009; Gibbon, McNeill, Wood, & Watson, 2003). Gibbon and colleagues (2003) used the EPG to target velar fronting. Over a fourteen-week span of treatment, benefits were shown by eliminating the substitution of /t/ for /k/. At the end of treatment, 87% of participants exhibited correct velar productions of /k/, illustrating the potential for use of the EPG as visual feedback in therapy. In addition, Cleland and colleagues (2009), used the EPG to provide visual supplements to therapy for many phonemes. By administering pre- and post-tests using the Diagnostic Evaluation of Articulation and Phonology (DEAP), it was concluded that the EPG can act as a helpful tool in intelligibility therapy.

Another element found to be helpful for treatment of the intelligibility in individuals with Down syndrome is reading/letter knowledge (Knight et al., 2015; Van Bysterveldt et al., 2010).

Because reading involves visual representations of sounds and individuals with Down syndrome possess a stronger visual memory than verbal memory, Knight and colleagues (2015) suggested the inclusion of reading tasks in therapy may improve intelligibility. Their study found that children with Down syndrome were more intelligible when reading than when completing naming or imitation tasks. Thus, it became evident that the ability to read can positively affect intelligibility therapy. In line with this thought, Van Bysterveldt and colleagues (2010) studied the effectiveness of an intervention strategy that emphasized letter knowledge and phonological awareness in order to increase appropriate sound productions. For instance, if the child's target sound was /m/ in the initial position, activities based upon the letter "m" were implemented through letter knowledge and phoneme blending tasks. Ten children with Down syndrome were used in the study within the age span of four years four months to five years five months. The intervention contained three components, which included a home program employed by the parents, clinical program employed by speech-language pathologists, and an additional computer program. Intervention lasted approximately 18 weeks. The results showed a significant increase in speech abilities. Additionally, a total of 60% of the participants improved their letter knowledge while 90% improved their awareness of phonemes in the initial position of words. However, no improvement in phonological awareness was shown. The authors concluded that interventions based upon increasing letter knowledge and phonological awareness may have positive benefits for increasing the speech abilities and subsequent intelligibility of preschool children with Down syndrome (Van Bysterveldt et al., 2010).

While the integration of elements related to phonological awareness has been shown to be beneficial for individuals with Down syndrome, another body of evidence shows that Broad Target Speech Recasts (BTSR) can further facilitate speech intelligibility (Yoder, Camarata, &

Woynaroski, 2016). In a study completed in 2016 (Yoder at al.), 51 children with Down syndrome in the age range of five to 12 years were randomly assigned to receive treatment that implemented either BTSR or the Easy Does It for Articulation program (a more traditional approach). Broad Target Speech Recasts involved recasting the child's utterance so that it was stated with appropriate sounds, pitch, intonation, and stress. The Easy Does It for Articulation program did not involve recasts. Rather, it emphasized the child's production of targeted phonemes through a set number of trials and the provision of a variety of cues necessary to prompt the correct production. Each treatment session was completed individually and lasted one hour. The treatment sessions occurred twice a week for approximately six months. The results of the study showed that speech comprehensibility can be improved for the population and highlighted the ideal that if a child with Down syndrome exhibits abilities related to verbal imitation, BTSR may be an appropriate intervention method to utilize. Additionally, the authors highlighted the importance of providing an increased number of recasts as well as providing such recasts in a conversational context (Yoder et al., 2016).

Another area necessary for consideration includes the growing evidence supporting an often undiagnosed connection between Down syndrome and childhood verbal apraxia. As approximately 95% of parents with children with Down syndrome reported their children struggled with being misunderstood (Kumin, 1994), the ways in which the population's speech errors occur become a necessary topic to explore. Based upon a study which included 1620 parent surveys, it was found that approximately 15 percent reported their children had been diagnosed with childhood verbal apraxia (Kumin, 2006). However, based upon the report of each child's specific errors, it was shown that a greater percentage showed signs of childhood verbal apraxia than the 15 percent who had received the diagnosis. These results suggest that a clinical

gap may exist between the exhibition of symptoms related to childhood verbal apraxia and the actual provision of the diagnosis. Children residing in the gap may not be receiving the appropriate treatment. The most common symptoms reported by the parents in the study included difficulty sequencing oral actions, inconsistent speech errors, and a decrease in intelligibility as the length of utterances increases (Kumin, 2006). In addition, it was shown that children with Down syndrome who began speaking after the age of five received lower intelligibility ratings by their parents than did children who began speaking before the age of five. Childhood verbal apraxia has been connected with speaking abilities beginning at later ages, which may explain the decrease in intelligibility for children with Down syndrome who begin speaking after age of five and the potential connection between childhood verbal apraxia and Down syndrome for those individuals. While approximately 60% of parents reported their children had received a diagnosis of oral motor difficulty, the authors raised the question of whether a percentage in that group should have received a childhood verbal apraxia diagnosis. By knowing this information, clinicians may be more equipped to provide accurate diagnoses that lead to more appropriate and effective treatment.

Nevertheless, the element of technology present in the intervention put forth by Van Bysterveldt highlights an increasing body of research being completed on the positive effects technology can have on individuals with Down syndrome (Ortega-Tudela & Gomez-Ariza, 2006; Felix, Mena, Ostos, R., & Maestre, 2017). It has also been shown that a vast majority of the Down syndrome population across the world uses elements of technology in their daily lives for both recreational and educational purposes (Fritz, 2017). By using the technological components already being used by individuals with Down syndrome in their everyday lives, speech-language

pathologists may increase both the naturalistic context of therapy and the likelihood of generalization while simultaneously capitalizing on their strength of visual memory.

Language. Another element of communication often impacted by Down syndrome is language. While speech intelligibility is the foundation for verbal communication, language is also a key element involved in possessing adequate communicative abilities. Typically, language therapy will be implemented alongside speech therapy for clients with Down syndrome, and it will target a variety of different concepts. Whether designed to improve components of semantics, syntax, morphology, or pragmatics, language therapy may elicit just as many communicative benefits as speech therapy.

The first step in providing language therapy is to determine where the individual's language abilities currently lie. Although it is known that there will likely be a language deficit, the severity of the deficit and the extent to which it will affect each person with Down syndrome's life is relatively variable across the population. However, research has shown that individuals who possess both Down syndrome and congenital heart defects typically have lower levels of language than do their peers in the Down syndrome population without congenital heart defects (Visootsak, Hess, Bakeman, & Adamson, 2013). This ideal can be used by speech-language pathologists to form a baseline or initial hypothesis for both assessment and treatment purposes. As both procedures get refined based upon each individual's needs, it is important for clinicians to understand the impact of congenital heart defects on language. While such deficits can only be explained to an extent by associated congenital heart defects, they illustrate an important connection between language and other medical and/or cognitive deficits associated with Down syndrome.

One of the most well-known treatment methods for language suggested for individuals with Down syndrome is Enhanced Milieu Training (EMT) (Hancock & Kaiser, 2006) combined with joint attention, symbolic play, and emotional regulation (JASPER) (Kasari, Freeman, & Paparella, 2006). In 2013, Wright and colleagues researched the efficacy of the treatment for four young children with Down syndrome. Throughout 20 play-based treatment sessions, clinicians produced spoken words and signs to communicate while implementing elements of EMT and JASPER. The results showed that while the intervention did not appear to increase spoken language, it did increase expressive language throughout the use of signs. In addition, it was reported that all participants continued to use their signs in settings outside of therapy (Wright et al., 2013). Thus, it was concluded that using signs with spoken language while also implementing components of EMT and JASPER is effective at increasing expressive language in individuals with Down syndrome.

In line with this thought, Te Kaat-Van Den Os and colleagues (2015) advised clinicians and parents to combine verbal communication with gestures to increase the child with Down syndrome's utterance length. Because children with Down syndrome develop expressive language abilities in the same way as typically developing individuals, just at a slower rate, it was advised support be provided in visual ways through gestures. As mentioned previously, individuals with Down syndrome typically have stronger skills in visual memory than in verbal memory. Thus, by providing visual information for communication through gestures, clinicians and parents can capitalize on such strengths to improve expressive language (Te Kaat-Van Den Os et al., 2015; Wright et al., 2013).

Another treatment element important for increasing language abilities was related to choosing the appropriate targets to include in language therapy. Through analyzing a variety of

naturalistic language samples, researchers developed a list of core vocabulary words for the Down syndrome population in the age range of two to seven years (Deckers, Van Zaalen, Van Balkon, & Verhoeven, 2017). A little over half of the words included in the list were related to illustrating a function while the rest were related to illustrating content. While each client's vocabulary list targeted in therapy may look different based upon family preferences and individual needs, it can be drawn from this research that speech-language pathologists should ensure they target a collection of both function and content words, with a slight emphasis on function.

This ideal aligns with another study completed in 2004 that highlighted the effects of naturalistic intervention on increasing verb usage (Vilaseca & Del Rio). If a child left out a verb in a statement while playing, the speech-language pathologist encouraged the parents to recast the statement and include the omitted word. Additionally, the parents were encouraged to place specific emphasis on the omitted word while not providing any explicit feedback on whether the child's statement was right or wrong. This way, the child was given the opportunity to learn in the naturalistic context of communicating with his or her parents without any indication that his or her speech was being analyzed. While a major component of the efficacy of the therapy was parent involvement, its impact on verb development should not be overlooked. In addition, this type of treatment may be used to target a variety of other types of language objectives.

While mentioned previously in the context of improving speech intelligibility, reading may also influence language development. Within the academic context, children are often required to read in order to gain information on a variety of different topics. This type of skill can have a drastic influence on the development of language skills as it exposes children to vocabulary words and linguistic concepts that may not have been received aurally. Teaching

children with Down syndrome to read, however, can present specific challenges. However, with appropriate treatment methods, reading improvements may be exhibited (Baylis & Snowling, 2012; Lecas, Mazqud, Reibel, & Rey, 2011). Through strategies based upon teaching the alphabet, rhyming, and whole word reading (within the context of short books), children with Down syndrome were shown to improve their ability to read words (Baylis & Showling, 2012). Furthermore, Burgoyne, Duff, Snowling, Buckley, and Hulme (2013) designed a program to teach phoneme blending and single-word reading. Through 10-15 minute daily sessions which occurred over a six-week span, individuals with Down syndrome were introduced to new letter sounds. The activities used in each session involved blending aural stimuli and/or visual stimuli (letters) to create words that were two to three phonemes in length. Improvements in both word reading and phoneme blending were shown throughout the intervention.

To improve verbal comprehension of stories, Lecas and colleagues (2011) emphasized the importance of teaching children with Down syndrome to use visualization strategies. They followed a path which included first teaching rehearsal strategies within the context of a story with familiar characters. Next, they taught the participant to draw what he or she understood from parts of the story. Then, he was taught to make those drawings in his head. Through this, the steps and skills necessary for adequate visualization were explicitly taught, allowing for a deeper understanding of the target ability. It was concluded that the strategies were related to improvements in verbal memory and comprehension of presented stories (Lecas et al., 2011).

An interesting study completed by Wilkinson, Carlin, and Thistle (2008) highlighted the effects of color distribution on the use of augmentative and alternative communication devices by children with Down syndrome. The results showed that when symbols were grouped by color, individuals with Down syndrome located their targets with greater speed and accuracy. While the

use of AAC devices for the population should be facilitated by speech-language pathologists, the results of the study extend far beyond its specific domain. Because of the strength exhibited by individuals with Down syndrome in visual memory over verbal memory, the results of the study highlight the importance of considering aspects of color when treating clients with Down syndrome. Even if using small picture cards, the distribution of the colors and/or the ways in which they could be perceived should be measured. Although language therapy can take many different paths, it can have great benefits for individuals with Down syndrome.

Family-centered practice. When treating clients with Down syndrome, it is often necessary to understand the ways in which the family operates and how the child fits within the family unit as a whole. As mentioned previously, Down syndrome impacts more than simply the individual with the disorder. Rather, the associated cognitive and behavioral phenotypes have indirect effects on parents, siblings, and extended family members (Hedov, Anneren & Wikiblad, 2002; Gerstein et al., 2009; Hedov et al., 2000; Hsiao, 2014; Marchal et al., 2016; Mulroy et al., 2008; Roach et al.,1999; Sander & Morgan, 1997; Van Riper, 2007).

Effects of Down syndrome on the family. While the individual with Down syndrome may be the only person in his or her family to experience the physical and mental effects directly related to the disorder, his or her family members may be indirectly affected due to the caregiving responsibilities required to raise an individual with such deficits. Thus, research has been completed on the effects of Down syndrome on various elements of the family unit. According to Povee et al. (2012), families typically experience increased levels of stress and greater difficulty making adjustments when the child with Down syndrome is young. However, Hsiao (2014) suggests that as the child gets older, the family learns to adapt to the child's needs, and the overall level of the family's ability to function improves. Van Riper's (2007) research

expanded upon such adaptations. In his study, mothers of individuals with Down syndrome were surveyed on their family's level of functioning. It was found that three variables were associated with family adaptation: the demands placed on the family, the resources available to the family, and the family's problem-solving communication. From this research, it can be concluded that although families experience effects of Down syndrome that may lower their overall well-being, adjustments can be made within the unit to improve their resiliency (Hsiao, 2014; Povee et al., 2012; Van Riper, 2007).

In light of this, the idea of a "down syndrome advantage" has surfaced throughout the literature. As such, it has been shown that when compared to families of children with other developmental disabilities (e.g., autism spectrum disorder) families affected by Down syndrome appear to have higher levels of well-being (Dumas, Wolf, Fisman, & Culligan, 1991; Fidler, Hodapp, & Dykens, 2000; Hodapp & Urbano, 2007; Sander & Morgan, 1997). Nonetheless, their well-being when compared to families with typically-developing children is still decreased (Sander & Morgan, 1997). Thus, while a family's ability to function is certainly affected by Down syndrome, the extent to which it is affected may be viewed a benefit of the disorder. Nonetheless, parents and siblings continue to experience a wide array of effects as a result of their child or brother/sister with Down syndrome (Gerstein, Crnic, Blacher, & Baker, 2009; Hedov, Annerén, & Wikblad, 2002; Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008)

Parental effects. Caring for an individual with Down syndrome can place a variety of demands on different areas of an individual's life. Whether monitoring elements of development, behavior, school/vocational activity, or overall health, caregivers are required to provide their child with increased levels of care and attention at all hours of the day. For instance, Smith (2016), a mother of a child with Down syndrome, described her experience as, "A bit of a

minefield, and [she has] been working hard on stepping only on the little bombs. So much to learn. So many mistakes to apologize for. So much love to give." Additionally, the level of care needed to raise a child with Down syndrome can extend beyond what is typically expected and last all the way through the child's lifespan or the rest of the parent's lifespan. Thus, it has been found that the quality of life and overall well-being of caregivers is often impacted. Specifically, research shows that parents of individuals with Down syndrome exhibit higher levels of stress than parents of typically developing children (Gerstein, Crnic, Blacher, & Baker, 2009; Hedov, Annerén, & Wikblad, 2002; Marchal, Maurice-Stam, van Trotsenburg, & Grootenhuis, 2016; Roach, Orsmond, and Barratt, 1999). The ways in which the stress manifests, however, depends upon a variety of variables.

In a research study completed in 2016 (Marchal et al.), the health of mothers and fathers who have children with Down syndrome was evaluated. The study found that both mothers and fathers reported poor relationships with their spouses and decreased social networks. Additionally, fathers appeared to have decreased responsiveness and organization when compared to the mothers. On the other hand, overall health quality of life did not change depending upon the child with Down syndrome's age (6-8 years and 11-13 years were the age categories used in the study). The authors described the possible causes for this decreased health quality of life by highlighting the demands often placed upon parents of individuals with Down syndrome. These included adapting to the diagnosis, learning how to provide appropriate care, coordinating services, managing finances, and understanding societal attitudes toward individuals with Down syndrome. As mentioned previously, demands placed on the family have been shown to influence their overall ability to function (Van Riper, 2007). Thus, as demands

such as these increase, it is likely elements of the family's health as well as their overall ability to make the necessary adaptations to function decreases (Marchal et al., 2016; Van Riper, 2007).

In line with the element of health, it has also been found that mothers of children with Down syndrome exhibit poorer overall well-being than exhibited by their spouses and even mothers of typically developing children. Thus, it can be concluded that while fathers of individuals with Down syndrome show poorer responsiveness and organization, mothers experience a lower level of general health (Hedov, Annerén, Wikblad, & Annerén, 2000; Van Riper, 2007). The consequences of caring for a child with Down syndrome can be pervasive, and just as different areas of health are affected, other elements of life may be influenced by Down syndrome and caregiving activities as well. Similarly, in a study completed by Gerstein et al. (2009), it was found that the stress associated with raising a child with Down syndrome increased over time for mothers yet remained the same for fathers. This highlights the differing roles and expectations placed on mothers and fathers and their perceptions of care. Further, it can be concluded that while the family as a whole makes adaptations to achieve a higher level of functioning and well-being, mothers and fathers participate in such familial adaptations in different ways (Gerstein et al, 2009; Hsiao, 2014).

In comparison to families with solely typically developing children, families affected by Down syndrome often differ (Hedov et al, 2002; Roach et al., 1999). In a study completed by Hedov et al (2002), employment activities were evaluated for families of children with Down syndrome and families of typically developing children (average age of 4.7 years). It was found that while there were no overall differences in employment rates between families of Down syndrome and families of typically developing children, mothers of children with Down syndrome exhibited greater part-time employment than mothers of typically developing children.

Additionally, the parents of children with Down syndrome did not report an increased amount of time spent on caregiving activities. However, they did report a greater perception of stress than the group with typically developing children (Hedov et al., 2002). This finding was further supported and expanded upon in a study completed by Roach et al. (1999). It was shown that while parents of individuals with Down syndrome perceive greater difficulty with caregiving, the difficulty arises from two categories: child-related stress and parent-related stress. In child-related stress, the parents were found to be concerned of their child's distractibility and/or demanding and socially inappropriate behavior. In parent-related stress, parents were concerned of incompetence about caring for a person with Down syndrome, mental health disorders such as depression, overall health and well-being, and role-restrictions. When these two elements of stress combine, the influence of Down syndrome on various elements of caregivers' lives becomes evident (Roach et al., 1999).

Although parents of children with Down syndrome experience many negative effects on their health and well-being, positive effects can be exhibited as well. Van Riper (2007) explained the experience of raising a child with Down syndrome as paradoxical. While major stressors are certainly present, joy can be experienced as well. In a study completed by Skotko, Levine, and Goldstein (2011), parents of children with Down syndrome were surveyed about their feelings toward their lives. Among 2,044 respondents, 99% reported love for their child, 97% were proud of them, and 79% felt their outlook on life was more positive because of them. A smaller percentage, however, felt embarrassment toward their child (5%) and reported regret for having them (4%). Regardless of all of the relatively negative effects experienced by caregivers in this population, it is evident that a vast majority are able to find joy and experience positive emotions

throughout the process of raising their child even if the positive emotions occur alongside negative effects.

Sibling effects. Just as parents are affected by Down syndrome, siblings are also influenced. While the extensity of the influence will depend upon a number of variables (e.g., older versus younger age status, care required during activities of daily living, range between ages, cultural beliefs, etc.), it is expected that typically developing siblings of children with Down syndrome experience a range of effects as a result of their sibling. In a study completed by Mulroy, Robertson, Aiberti, Leonard, and Bower (2008), parents of both typically developing children and children with Down syndrome were surveyed about their typically developing children's experiences growing up around their special siblings. Parents reported both advantages and disadvantages. While the advantages were all related to personality characteristics (some have a greater propensity to provide care, exhibit increased resilience, etc.), the disadvantages spread across multiple domains. The reported disadvantages were related to parental time constraints, difficulty with relationships and decreased opportunities for socializing, emotions exhibited by their parents, overall restrictions, and the burden of helping (Mulroy et al., 2008). These advantages and disadvantages are likely to influence a sibling with Down syndrome throughout his or her childhood and length of time around his or her sibling. Interestingly, greater disadvantages were reported by large, two-parent families who were socioeconomically advantaged. This is a key factor in determining the influence of Down syndrome on a family unit.

Furthermore, siblings of individuals with Down syndrome have been found to experience courtesy stigma throughout adolescence and adulthood (Fulk, 2014). Courtesy stigma involves experiencing the prejudice and discrimination often given to individuals with Down syndrome as

a result of their relation. For example, typically developing siblings may be stereotyped as less capable because they are related to an individual who requires additional help to complete daily activities. Such courtesy stigmatization increases as siblings with Down syndrome exhibit challenging behaviors or experience heightened communicative challenges (Fulk, 2014). Through this, it is evident that the effects of having a sibling with Down syndrome can be long lasting and have different types of impacts. While caregiving responsibilities would certainly influence the lives of typically developing siblings, other types of effects are related to social elements and rooted in societal perceptions of disabilities.

Although the previous studies reported a plethora of disadvantages surround typically developing siblings who have brothers or sisters with Down syndrome, positive factors can also be present. In one study, 95% of parents of individuals with Down syndrome reported good relationships between their typically developing children and their child with Down syndrome (Skotko, 2011). Even with disadvantages such as increased care taking and parental time constraints present, the quality of the relationship has been shown to experience less negative effects (Mulroy et al., 2008; Skotko, 2011). Further, while the disadvantages may also lead one to believe typically developing siblings will exhibit adjustment difficulties, Cuskelly and Gunn (2006) found that having a sibling with Down syndrome does not elicit any trouble with making adjustments. While this finding it specific, it supports the notion that siblings of Down syndrome likely adapt in their own ways and discover the most appropriate processes for caring for their sibling and participating in their family units (Hsiao, 2014).

Because of the strong, positive relationship found to be present between typically developing siblings and siblings with Down syndrome, researchers have begun assessing the influence of the typically developing sibling on the child with Down syndrome's communication

skills. In a study completed in 2015 (Singh, Iacono, & Gray), twelve children with Down syndrome ranging in age from one year ten months to five years four months were observed during three different play situations. In the first instance of play, the interaction was between the mother and the child. In the second instance of play, the interaction was between the sibling and the child. And in the third instance of play, the interaction was between the mother, child, and the sibling. The results of the study showed that the child exhibited the most pre-symbolic communicative behaviors in the interaction involving only the mother and child; the second most in the interaction involving the mother, child, and sibling; and the least in the interaction involving just the child and the sibling. The authors suggest this occurred because the siblings did not provide as many opportunities for turn-taking or responding to initiations as the mothers did (Singh, Iacono, & Gray, 2015). Nonetheless, both siblings and mothers are able to interact with the child and understand his or her wants and needs based on their ability to adapt to the child with Down syndrome's early attempts to communicate. This research one again encourages the notion that families make adaptations to improve their ability to function (Hsiao, 2014; Singh, Iacono, & Gray, 2015).

In light of the importance of sibling interactions, Trent-Stainbrook, Kaiser, and Frey (2007) completed a research study that included typically developing siblings in the intervention process. In this study, siblings who were older than their brother or sister with Down syndrome were taught responsive interaction strategies to use with their sibling. The results showed that the young siblings with Down syndrome increased their intentional communicative behaviors after their older siblings were trained on such strategies. Additionally, at the one-month follow-up, it was found that the older siblings were continuing to use the responsive interaction strategies that they learned. While communication increased, a more positive and reciprocal relationship was

exhibited by the sibling pairs in the study (Trent-Stainbrook, Kaiser, & Frey, 2007). Because siblings play an important role in the child with Down syndrome's life, they may need to be recruited to help and provided basic education about communication development during the intervention process (specifically family-centered intervention). This way, the child will be receiving the stimulation he or she needs from the most significant people in his or her life. Just as siblings experience many negative and positive effects from Down syndrome, they too can influence their sibling in a variety of ways.

Practice. To meet the demands presented by having a child with Down syndrome, family units often make adaptations to increase their ability to function (Bernheimer & Weisner, 2007; Hsiao, 2014). While treating the child with Down syndrome in the context of his or her family is a common practice when he or she is three years of age or younger (early intervention period), the nature of speech and language treatment becomes more individualized as all clients, including those with Down syndrome, progress throughout their childhood. However, because children with Down syndrome are cared for by parents and siblings for much longer than typically developing individuals, the need for family-centered practice throughout the individual with Down syndrome's early and late childhood (and adulthood if therapy is still sought) is highlighted.

Bruder (2000) defines family-centered early intervention as "both a philosophy of care and a set of practices" (p.105). In terms of more general family-centered practice throughout an individual with Down syndrome's childhood, this requires the clinician consider more than simply the family's immediate needs and concerns. Rather, the clinician should attempt to understand the daily routines, attitudes, strengths, and challenges of each family and make the appropriate therapeutic adjustments to meet the greatest needs set forth by the individual in the

context of his or her family (Bernheimer & Weisner, 2007). Whether this involves educating parents on communicative symptoms associated with Down syndrome or targeting a more obscure language goal because it will have the greatest impact on the child's participation in the family unit, it takes both an underlying understanding of the family's ways of operating alongside the child's speech and language abilities. While many speech-language pathologists likely set out to consider the family in treatment, it has been noted that there may be a disconnect between the family-centered attitude and genuine family-centered practice (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). Interestingly, when mothers of children with Down syndrome perceive they have a family-centered relationship with their care-provider, they are more likely to be satisfied with the care they are receiving and are more likely to seek additional care (Van Riper, 1999). Because parents are often the individuals who implement the therapy goals in the child's everyday settings and have the greatest influence on generalization, their belief in therapy and subsequent participation in the process is crucial. Family-centered practice works to establish a positive therapeutic relationship, target the goals that are most important, and add meaning to the intervention process. Through this, speech-language pathologists are more likely to provide efficacious care to the population.

In order to determine the family's true therapeutic needs, Bernheimer and Weisher (2007) suggest speech-language pathologists complete an ethnographic interview by asking the parents to describe a typical day. More explicitly, they advise asking parents to explain what happens from the moment they wake up to the moment they go to bed. This way, clinicians can gain an understanding of how the family operates, what they value throughout the day, how they make adaptations for their child with Down syndrome, and where/why any communicative breakdowns may be occurring. In addition, they can determine where and how intervention can

be placed into the family's daily routine. To take a deeper look into the ways in which families of those with disabilities operate, Bernheimer and Weisher (2007) conducted a longitudinal research study which followed families of children with disabilities throughout their childhood. At various intervals, they asked the parents to describe their typical day. Through this, Bernheimer and Weisher (2007) noted an overarching and consistent theme of adaptations. Each family adjusted their daily routine based upon the difficulties or caretaking duties they experienced at each stage. In addition, six different categories of daily difficulties which required adaptation were discovered. They were related to behavior, medical needs, communicative challenges, social conduct, level of activity, and responsiveness. These categories shed light on the ideal that families of individuals with disabilities, particularly Down syndrome, experience a multitude of different obstacles that require a new way of thinking and living. By reviewing the adaptations each family is making dependent upon the difficulties they are experiencing, speech-language pathologists can refine intervention to meet the child and family's true needs rather than the skills appearing deficient through tests. In addition, each family's resilience, strength, and daily dedication to help their child may be emphasized throughout the intervention process (King, Baxter, Rosenbaum, Zwaigenbaum, & Bates, 2009).

While treatment in therapy rooms creates the foundation for school-age intervention for children with Down syndrome, another element to consider is the way in which the parent and child interact within their daily routines (Mahoney, Boyce, Fewell, Spiker, & Wheeden, 1998; Marchal et al., 2016; Te Kaat-van den Os et al., 2015; Van Hooste & Mass, 2003; Viana Pereira & Parlato Oliveira, 2015; Vilaseca & Del Rio, 2004). As part of family-centered practice, it is important speech-language pathologists educate parents on the big picture of family interaction and its impact on their child's development (Van Hooste & Maes, 2003). For instance, parents

should be aware that the environment in which they live and interact with one another, their attitudes, the support they receive, and the ways in which they cope with stress all have an impact on their child with Down syndrome's speech and language development. For a child to truly make gains in these areas, therapy must extend beyond the treatment room and into everyday life. While the specific goals included in the intervention plan are important to discuss with parents, speech-language pathologists should also encourage them to look at communication with a broader view. Because there are a variety of components that affect speech and language development, the clinician can help parents review each variable in order to create a better communicative environment for their child.

In a related context, Viana Pereira and Parlato Oliveira (2015) highlighted the impact of the family's environment and routines on their child with Down syndrome's communicative skills. In their study, it was found that families who exhibited greater organization, stricter routines, and a more predictable schedule were related to children with Down syndrome who used an increased amount of verbal utterances, specifically related to making comments and requesting actions. In addition, it was found that as children with Down syndrome participated in more scheduled activities, their narrative abilities increased (Viana Pereira & Parlato Oliveira, 2015). Thus, the ideal that parents should be educated on the influence of their everyday activities and environments on their child with Down syndrome's communicative abilities is reinforced (Van Hooste & Maes, 2003; Viana Pereira & Parlato Oliveira, 2015). As speech-language pathologists provide family-centered practice, it is important they analyze the family's daily life to provide advice on creating everyday routines that are facilitative to communication (Bernheimer & Weisher, 2007; Viana Pereira & Parlato Oliveira, 2015).

Another way to help parents create an enhanced communicative environment is to increase and refine their responsiveness to their child's communicative attempts (Mahoney et al., 1998; Marchal et al., 2016; Vilaseca & Del Rio, 2004). Mahoney and colleagues (1998) believe that without this step, effects from treatment are not likely to be experienced. In addition, it has been shown that fathers exhibit less responsiveness than mothers to their child with Down syndrome's communicative behaviors. Thus, it becomes evident that providing family-centered care to this population requires individualized education on responsiveness. Instead of delivering basic information to all family members, each parent's strengths and weaknesses should be considered and treated accordingly (Marchal et al., 2016). Once an appropriate level of responsiveness has been achieved, speech-language pathologists may seek to provide parents with more specific information, such as pairing verbal communication with gestures to increase their child's utterance length (Te Kaat- van den Os et al., 2015). By first providing information on general responsiveness and then adding specific behaviors into the parents' communication, speech-language pathologists are able to avoid overloading the parents with too much information and risk making no change in responsiveness.

In all, a child with Down syndrome's family members play a large part in providing their everyday care. While speech and language treatment becomes more individualized for typically developing individuals as they progress throughout school, such treatment for children with Down syndrome does not always follow the same path. Rather, family-centered practice should be the standard for treatment of this population. By analyzing the daily routines of families affected by Down syndrome, needs related to communication and areas in which intervention may be provided are highlighted. Through parent education and implementation of objectives in the home environment, greater benefits are likely to be exhibited. As speech-language

pathologists develop an understanding of the impact made by the family on the child with Down syndrome (and vice versa), effective and individualized care may be provided.

Personnel Preparation

To become a speech-language pathologist who works with individuals with Down syndrome, one must take many steps and meet a plethora of requirements set forth by the American Speech-Language-Hearing Association (ASHA). After obtaining a bachelor's degree, one must attend graduate school to earn a master's degree in speech-language pathology or communication disorders. Because the scope of the field is continually expanding to include a greater number of responsibilities, the graduate programs are often very rigorous. Classwork is combined with clinical experiences so that students enter the field with both a strong knowledge base and adequate clinical skills. While learning about a variety of different disorders and the ways in which individuals with such disorders should be evaluated and treated, students in speech-language pathology graduate programs learn to collaborate with other professionals, document session outcomes, and meet the needs of the clients they have been assigned. A total of 400 hours of direct client contact must be documented in order to graduate. To achieve such experience, students participate in various internships and are supervised in their treatment and evaluation of clients 25-100% of the time (ASHA, 2008). In addition, students must pass the praxis exam, which is used to test their knowledge in the field of speech-language pathology and represent their competency as clinicians. Once their graduate programs have been completed, students partake in nine months of clinical fellowship. During this time, their work is overseen by more experienced clinicians who act to guide them into the field and refine their clinical skills and problem-solving abilities. Only after all of these requirements have been completed do the individuals become fully fledged speech-language pathologists with all the associated privileges

and responsibilities. Although it appears that the process would leave a vast amount of available time to discuss special populations, research shows that many clinicians do not feel they were adequately prepared to treat a variety of disorders (Brisk, Healey, & Hux, 1997; Compton, Tucker, & Flynn, 2009; Hux, Walker, & Sanger, 1996).

Because speech-language pathologists are licensed to treat individuals from birth to the end of their lives, they must possess a wide variety of knowledge on normal and disordered development and aging. However, throughout four years of undergraduate work, two years of graduate work, and nine months of clinical fellowship, every disorder cannot be discussed in depth. Aside from unique clinical experiences, speech-language pathologists in-training may only be exposed to information on Down syndrome a few times, and it may focus on the symptoms associated with the disorder rather than the ways in which the symptoms should be treated. While it is certainly possible for clinicians to receive the opportunity to treat or evaluate an individual with Down syndrome throughout their educational careers, many speech-language pathologists may not experience Down syndrome in the clinical setting until after their educational endeavors have been completed. Thus, the knowledge they apply to the treatment of this population comes from those few instances in which Down syndrome was discussed. Nonetheless, learning about new and rare disorders is a part of the field. Training in speech-language pathology highlights the importance of taking initiative and gaining knowledge on the disorders presented. However, there is often a challenge in truly preparing clinicians for such endeavors (Whitmire & Eger, 2004).

To combat this, some universities have created specialty tracks in which their students who are interested in particular areas or groups of clienteles are able to forgo a more general education and dive deeper into their particular interests. These tracks range from areas such as

voice to hearing, etc. (Brown & Quenin, 2010; San Jose State University, 2000). While wonderful opportunities, there are rarely specialty tracks in which Down syndrome or even intellectual disabilities are the main focus. Thus, gaining an understanding of research-based treatment ideals for individuals with Down syndrome often requires explicit initiative from the clinician. Essentially, training programs in speech-language pathology teach young, developing clinicians to use the literature and other resources to obtain information on uncommon disorders or communicative challenges. In regard to treating clients with Down syndrome, preparation likely centers more upon teaching clinicians how to acquire their own knowledge on the disorder rather than teaching them how to specifically treat the population.

To illustrate this ideal, the literature based upon preparation for treating individuals in other special populations, such as autism spectrum disorder, may be evaluated. Multiple studies have found that professionals in the field of speech-language pathology hold beliefs about characteristics of autism spectrum disorder that do not reflect the most recent research published on the disorder (Heidgerken, Geffken, Modi, & Frakey, 2005; Stone, 1987; Schwartz & Drager, 2008). Since professionals are expected to appropriately and effectively treat individuals in the autism population, this could elicit a variety of concerns from clients about the ethics and knowledge level of the professionals in the field. Thus, it becomes evident that personnel preparation for speech-language pathologists may need to include ways in which they can remain updated on current research-based thoughts about a variety of disorders in which they treat.

In addition to attaining knowledge on different disorders, the ways in which personnel in the field of speech-language pathology are prepared to provide family-centered practice is also of interest. Although involving the family in therapy is a relatively common ideal, Crais (1991) encouraged clinicians to change the ways in which they think about such relationships by

developing a habit of determining their place in the family's life instead of taking a passive role during interactions with them. In a recent study completed by Bruder and Dunst (2005), it was found that while family-centered practice was highlighted in many training programs for speech-language pathologists and professionals in related disciplines, there was less of an emphasis placed on coordinating family-centered services and collaborative, multidisciplinary teams. Thus, it can be illustrated that while family-centered practice is being taught in training programs, the depth of information provided throughout the training process and the associated extent to which it is being used clinically may be variable. In line with this, Campbell, Chiarello, Wilcox, and Milbourne (2009) encouraged training programs to alter the ways in which methods for family-centered practice are taught to better prepare young clinicians to meet the needs of their young clients. Although developing speech-language pathologists are provided an extensive amount of information throughout their undergraduate and graduate careers on a variety of disorders and treatment topics, gaps may still exist between the ways in which clinicians are prepared for the field and the skills required to be an effective clinician.

Chapter 3

Justification

As illustrated by the literature, the effects of Down syndrome can be both pervasive and numerous. The ways in which each individual is impacted can further affect the ways in which the family unit is able to function and meet the needs of the disabled individual (Bernheimer & Weisner, 2007; Hsiao, 2014). As speech-language pathologists hold the responsibility of working to improve the individual with Down syndrome's communicative abilities, this often involves including the family members. Whether educating them on facilitating communicative behaviors or simply acting to understand their concerns, speech-language pathologists must possess knowledge on different elements of Down syndrome, the most recent research published on the subject, and the most effective ways to transfer their knowledge to the clinical setting.

Due to the rarity of Down syndrome, instruction in undergraduate and graduate preparation programs in the field of speech-language pathology is likely to include ways in which clinicians can attain their own knowledge rather than explicit instruction on elements of Down syndrome and effective treatment methods. It becomes evident then that a gap may exist between the ways in which speech-language pathologists treat clients with Down syndrome and their knowledge level on various characteristics of the disorder and associated research-based treatment methods. Although Down syndrome is relatively rare, it is the most common chromosomal disorder in the United States. It is likely that professionals will treat at least one, if not more, individuals within the population throughout their careers (CDC, 2017; March of Dimes, 2016). Speech-language pathologists are responsible for using the information they learned from their undergraduate and graduate experiences to provide the most efficacious care for their clients and their families. Thus, it becomes necessary to inquire about the knowledge

level of practicing professionals, their confidence in treating the Down syndrome population, and the extent to which the evidence-base is considered. With this information, the adequacy of preparation and any associated gaps of knowledge may be highlighted and a more appropriate climate for treatment may be created. The purpose of this study was to explore the scope of knowledge speech-language pathologists possess on Down syndrome and the extent to which they are trained and subsequently view treatment for the population and their families. The questions of the study are delineated below.

Questions of the Study

1. What academic and clinical training have speech-language pathologists received to prepare them for working with the Down syndrome population?
    - Hypothesis – Preparation will consist of a combination of academic and clinical instruction during school and experiences after graduation, such as continuing education courses and reviews of the literature.
2. To what extent do speech-language pathologists possess knowledge on the different elements associated with Down syndrome?
    a. Sub-category: overall knowledge of disorder
        - Hypothesis – The majority of participants will provide correct answers to at least four of the seven questions that address this topic.
    b. Sub-category: knowledge of communicative characteristics
        - Hypothesis – Less than half of the participants will provide correct answers to four or more of the seven questions that address this topic.
    c. Subcategory: evidenced-based intervention practices specific to Down syndrome

    - Hypothesis – Less than half of the participants will provide correct answers to four or more of the six questions that address the topic.

3. How confident do speech-language pathologists feel in treating clients with Down syndrome?
    - Hypothesis – Participants will report varied levels of confidence in their abilities to treat individuals with Down syndrome, with confidence level related to experience.
4. To what extent are speech-language pathologists including the families in their treatment of individuals with Down syndrome?
    - Hypothesis – The majority of participants will report including the family in treatment activities; however, only a small percentage will report considering the client in the context of his or her family before treatment begins.

Chapter 4

Methodology

Participants

A total of 260 respondents completed the survey. To meet inclusion criteria, respondents were licensed and certified speech-language pathologists who were currently treating or had treated a client with Down Syndrome within the past five years. Individuals who did not meet inclusion criteria were taken to the end of the survey, and their answers were excluded as their responses may have detracted from the validity of the results.

Materials

To answer the questions of the study, the investigators created an electronic, web-based, 39-item survey via Qualtrics software (see Appendix 1) to address questions in five main areas: (a) Background/demographic information, (b) Training experiences (c) Knowledge of Down syndrome, (d) Knowledge of the communicative characteristics of Down syndrome, and (d) Intervention practices.

- Part I questions were used to obtain information on the demographics of the participants. As such, the aim was to learn about each participant's educational background and current practice.
- Part II questions inquired as to each participant's clinical and educational training for treatment of individuals with Down syndrome. The ways in which Down syndrome was discussed throughout undergraduate and graduate training experiences was evaluated.
- Part III questions were created to obtain information regarding the level of knowledge each participant possessed about general elements of Down syndrome. Knowledge of the

genetic cause, occurrence statistics, associated medical conditions, behavioral phenotype, and basic facts was assessed.

- Part IV questions inquired about the level of knowledge each participant exhibited related to the communicative characteristics associated with Down syndrome. As such, questions assessed the areas of speech, language, cognition, and voice.
- Part V questions were used to obtain information on the participants' knowledge of research-based intervention practices, the extent to which they had reviewed the literature base, and the ways in which they include the family in their treatment of the population.

Survey construction and distribution. While technological advances have allowed for the use of electronic surveys and provided further avenues to recruit potential participants, these same advances have also increased the likelihood that potential participants might ignore or overlook these electronic recruitment attempts (Dillman, Smyth, & Christian, 2014). To increase the likelihood of obtaining a response, various recommended cautions were observed.

Social exchange theory. By implementing aspects of the social exchange theory into the survey construction and dissemination procedures, the rate by which respondents completed the survey might have been increased (Dillman et al., 2014). According to this theory, "people are more likely to comply with a request from someone else if they believe and trust that the rewards for complying with that request will eventually exceed the costs of complying" (Dillman et al., 2014, p. 24). Essentially, investigators obtaining data via an electronic survey must adjust their instrument and procedures so that the request draws respondents to the cause and eases any associated concerns or barriers that would keep them from participating. Because the implementation of this theory may occur in various ways, the specificity of the precautions that

were taken in accordance with the social exchange theory throughout this investigation are delineated below.

Specific measures. As dissemination occurred through social media groups containing professionals who treat the population, elements of the social exchange theory were used in various ways. In order to increase trust and emphasize appreciation for completion of the survey, the associated message was kept relatively short and clearly stated the purpose of the survey (Dillman et al., 2014). To further implement these ideals in social media groups, investigators introduced themselves and the purpose of the study while simultaneously communicating appreciation and the need for participation. In addition, investigators used the estimation put forth by Qualtrics to provide the time commitment associated with taking the survey.

Another important aspect involved with survey construction and dissemination depended upon the reputability of the participation request. In accordance with the social exchange theory, it was critical that participants trusted the individuals/organizations conducting the research and did not believe any associated risks had the potential to outweigh the benefits of their participation (Dillman et al., 2014). Thus, investigators ensured all respondents that their participation in the study was anonymous and that their specific answers would be kept confidential. In no way would their name be associated with the study or their particular answers. This was especially important for the nature of this study. Because there were large knowledge-based components (knowledge of Down syndrome, knowledge of communicative characteristics, and knowledge of evidence-based methods), honest answers were imperative. Language that promoted acceptance, compassion, and professionalism was used to ease participant fears and increase their beliefs in the anonymity and confidentiality associated with participation in the survey.

Procedures

Before large-scale dissemination of the survey, the current instrument was piloted with a faculty member at another university who was familiar with the Down syndrome research, as well as fellow colleagues in the field. Through this, feedback was provided in order to improve the content, structure, and validity of the survey. Once the survey was finalized, participants were obtained through two methods. Initially, a message containing a brief description of the survey and its purpose was posted on the primary investigator's Facebook page. The post was made public so that it could be shared by anyone on Facebook. An invitation was also posted in Facebook groups specific to speech-language pathology in which the primary investigator and/or faculty advisor were members. According to Dillman and colleagues (2014), participants are less likely to respond if contacted in the midst of other responsibilities. Thus, the posts to Facebook were made after typical work hours and meal times, ranging between 6:30 p.m. – 7:30 p.m. In addition, the link to the survey was also posted on discussion boards within ASHA's Special Interest Groups 16 (School-Based Issues) and 1 (Learning Language and Education). These special interest divisions were selected due to their focus on service provision to school-age individuals and the resulting probability that many of their members might have worked with individuals with Down syndrome. The survey was administered using the survey tool Qualtrics, which is a secure Internet-based software program. All data was collected anonymously and analyzed via Qualtrics and SPSS. Participants were informed that all responses were confidential, and that no personal identifying information would be included in the computer-generated dataset other than the date and time they completed the online study.

Chapter 5

Results

Data Analysis

Survey responses were filtered for completion. To determine a mean response for each item, the responses for all individuals who participated were averaged. In cases where some participants chose not to respond to a question, the averages were calculated using the number of participants who responded to that item, as opposed to the number of participants who completed the survey.

Demographics

The online survey was initiated by approximately 367 participants. Upon consideration of the inclusion criteria, 107 participants were excluded from the study due in part by their current practicing or certification status, highest degree attained, and/or lack of experience with Down syndrome in the past five years. Thus, the results were drawn from the 260 participants who met the inclusion criteria and subsequently completed the survey. Participants were made aware of the survey through posts on the discussion boards of ASHA's Special Interest Groups 1 and 16 (18%; $n = 47$), posts on Facebook (76%; $n = 197$), and/or unspecified connections (e.g., word of mouth; 6%; $n = 16$).

Participant background. The majority of the participants identified as female (98%; $n = 255$), while the remaining participants (2%; $n = 5$) identified as male. Participants were queried with regard to race in accordance with the format of the U.S. Census (U.S. Bureau of the Census, 2018). Of the 258 participants who responded, the majority identified as white (93%; $n = 239$) with 19 respondents reporting their race as either Black or African American, American Indian or Alaskan Native, Asian, or Other/Multiple Races. To view the exact breakdown, see Table 1.

In addition, participants were also asked to provide information as to whether they were of Hispanic or Latino origin. A total of 239 of the 257 (93%) participants who responded reported they were not of Hispanic, Latino, or Spanish origin. Those who did indicate such an origin provided more specific information (see Table 1).

Participants were also queried as to the region in which they currently practice. The majority of respondents reported practicing in the Southern region of the United States (i.e., Texas, Arkansas, Louisiana, Oklahoma, Mississippi, Alabama, Georgia, Kentucky, Tennessee, South Carolina, Florida, North Carolina, Virginia, West Virginia, Maryland, or Delaware), while the remaining reported the Midwest (i.e., North Dakota, South Dakota, Nebraska, Kansas, Missouri, Iowa, Minnesota, Wisconsin, Illinois, Indiana, Ohio, or Michigan), Northeast (Pennsylvania, New York, New Jersey, Massachusetts, Connecticut, Rhode Island, Vermont, New Hampshire, or Maine), and West (Washington, Oregon, California, Montana, Idaho, Wyoming, Nevada, Utah, Colorado, Arizona, New Mexico, Hawaii, or Alaska). With regard to age, slightly under 2/3 of participants identified between 19 and 39 years of age, while the remaining participants indicated they were above 39 years of age (See Table 1).

Field experience. With regard to year of graduation, the largest percentage of respondents reported graduating in 2010 or after (49%; $n = 127$). Responses of the remaining participants ranged from before 1980 to 2009 (see Table 2). Next, participants were asked to report their length of experience. Slightly over a third of participants (34%; $n = 88$) reported practicing less than one to five years, while 19% ($n = 49$) reported six to ten years of experience. Even further, 17% ($n = 43$) reported practicing 11 to 15 years, and 10% ($n = 27$) reported 16 to 20 years. A total of 21 years of experience or greater was reported by a fifth of the participants ($n = 53$).

Table 1

Participant Demographics

Category	*n* (%)
Race (N = 258)	
White (only)	239 (93%)
Black or African American (only)	5 (2%)
American Indian or Alaskan Native (only)	1 (0.3%)
Asian (only)	1 (0.3%)
Native Hawaiian or Other Pacific Islander (only)	0 (0%)
Other or Multiple Selections	12 (5%)
Origin (N = 257)	
Not of Hispanic, Latino, or Spanish origin	239 (93%)
Mexican, Mexican-American, or Chicano origin	10 (3.3%)
Puerto Rican origin	1 (0.4%)
Cuban origin	2 (0.8%)
Other Hispanic, Latino, or Spanish origin	5 (2%)
Age (N = 260)	
19-29 years	78 (30%)
30-39 years	85 (33%)
40-49 years	44 (17%)
50-59 years	29 (11%)
60-69 years	21 (8%)
70-79 years	3 (1%)
Location (N = 260)	
West	24 (9%)
South	165 (63%)
Northeast	30 (12%)
Midwest	41 (16%)

Note. N = number of total respondents; *n* = number of respondents per choice; % = percentage of total respondents

Respondents also shared the primary setting in which they currently worked, and approximately half of the 259 participants who responded reported working in a school. Almost a quarter of participants reported working in a private practice, and the remaining 28% (*n* = 186) reported working in the following settings: early intervention, hospital, university clinic, skilled nursing facility, home health, rehabilitation facility, or unspecified location. Within these settings, participants were queried as to their current caseloads and asked to select all that

applied. The largest number of participants reported currently working with clients from 3:1 to 10:0 years of age, followed by 10:1 to 20:0 years of age, birth to 3:0 years of age, and older than 20:0 years of age.

Table 2

Participant Experience

Category	*n* (%)
Year of Highest Degree (N = 260)	
Prior to 1980	8 (3%)
1980-1989	22 (8%)
1990-1999	34 (13%)
2000-2009	69 (27%)
2010 or after	127 (49%)
Employment Setting (N = 259)	
Private practice	56 (22%)
Early intervention program	21 (8%)
Hospital	17 (7%)
Skilled nursing facility	6 (1%)
School	130 (50%)
Rehabilitation facility	5 (2%)
Home health	6 (2%)
University clinic	7 (3%)
Other	11 (4%)
Current Caseload (N = 259)	
Birth-3:0	103 (40%)
3:1-10:0	199 (77%)
10:1-20:0	148 (57%)
Older than 20:0	69 (27%)

Note. N = number of total respondents; *n* = number of respondents per choice; % = percentage of total respondents

Experience with Down syndrome. With regard to Down syndrome specifically, the majority of the 259 participants who responded (87%; *n* = 226) reported 10% or less of their current caseloads were comprised of individuals with Down syndrome, while 28 participants (11%) reported the diagnosis for up to a quarter of their caseloads, and five participants (2%)

reported the diagnosis for up to half of their caseloads. No participants reported more than half of their caseloads were comprised of individuals with Down syndrome.

Participants were then questioned as to the number of individuals with Down syndrome whom they had treated within the last five years. Over half of the participants (68%; *n* = 176) reported they provided treatment to one to five clients with Down syndrome. Approximately a fifth of participants (20%; *n* = 51) reported providing treatment to six to 10 clients with Down syndrome, and the smallest group (12%; *n* = 30) reported providing treatment to more than 10 clients with Down syndrome. Nonetheless, two participants (0.7%) reported never having provided treatment to an individual with Down syndrome within the past five years. These individuals were still included in the study because they had previously indicated they possessed experience with either treatment or evaluation of an individual with Down syndrome in the past five years. Thus, it was assumed their experience was characterized by evaluation only, indicating they met the inclusion criteria.

As having a family member with Down syndrome has the potential to increase one's knowledge on the disorder, participants were asked to report any familial connections. While the vast majority (92%; *n* = 238) reported they did not have a family member with Down syndrome, 4% (*n* = 10) reported having a cousin with Down syndrome, 2% (*n* = 5) reported having a child with Down syndrome, and 1% (*n* = 3) reported having a sibling with Down syndrome. The remaining (2%; *n* = 4) reported an unspecified familial connection.

Training

Because training often extends beyond simple instruction, personnel preparation involves a variety of factors and occurs across many contexts. As such, elements of participants' academic, clinical, and post-graduate training were queried.

Academic training. Participants were asked the extent to which they were trained to treat and evaluate individuals with Down syndrome in their undergraduate and graduate programs. With regard to time spent discussing Down syndrome, the majority of participants reported Down syndrome was discussed during one class period or less. Specifically, 36% (n = 94) reported it was discussed during one class period, 28% (n = 74) reported it was discussed during less than one class period, and 2% (n = 6) reported it was never discussed. The remaining participants reported Down syndrome was discussed for more than one class period, with 18% (n = 48) reporting it was discussed for one week, 7% (n = 17) reporting it was discussed for one month, and 8% (n = 21) reporting it was discussed for more than one month.

In addition to providing the total time their class spent discussing Down syndrome, participants were also questioned with regard to the number of courses in which various topics related to Down syndrome were discussed in their undergraduate and graduate programs. It was revealed that among all the topics covered, the communicative characteristics of Down syndrome and associated physical symptoms were the most likely to have been discussed in at least one class, while family-centered practice and research methods for the population were the least likely to have been discussed in at least one class. For an overview of all of the topics queried, see Table 3.

Clinical training. Participants were asked to provide information on their experiences providing treatment to individuals with Down syndrome throughout their undergraduate and/or graduate training experiences. Slightly over a quarter of the participants (28%; n = 75) reported never providing treatment to an individual with Down syndrome throughout their training experiences. On the other hand, over half (58%; n = 153) reported providing treatment to one to

three clients with Down syndrome. The smallest number of participants (13%; *n* = 32) reported providing treatment to four or more clients with the diagnosis.

When queried as to the type of support provided by their clinical supervisors during their treatment experiences with clients with Down syndrome and asked to select all that apply, the responses fell across multiple domains. While slightly over half of the 168 participants who responded reported receiving information about Down syndrome from their supervisor (55%; *n* = 92) and believing their superior was knowledgeable on the disorder (65%; *n* = 109), only about a

Table 3

Coursework on Down Syndrome

Category	*0 Courses* *n* (%)	*1-2 Courses* *n* (%)	*3+ Courses* *n* (%)
Genetic Cause (N = 251)	15 (6%)	218 (87%)	18 (7%)
Incidence/Prevalence (N = 250)	17 (7%)	220 (88%)	13 (5%)
Physical Symptoms (N = 245)	11 (5%)	209 (85%)	25 (10%)
Behavioral Phenotype (N = 246)	64 (26%)	171 (70%)	11 (4%)
Cognitive Phenotype (N = 248)	48 (19%)	178 (72%)	22 (9%)
Associated Medical Conditions (N = 247)	44 (18%)	185 (75%)	18 (7%)
Communicative Characteristics (N = 248)	9 (4%)	186 (75%)	53 (21%)
Published Literature Base (N = 242)	118 (49%)	118 (49%)	6 (2%)
Research-Based Treatment Methods (N = 246)	127 (52%)	106 (43%)	13 (5%)
Family-Centered Practice for Down Syndrome (N = 247)	155 (63%)	85 (34%)	7 (3%)

Note. N = number of total respondents; *n* = number of respondents per choice; % = percentage of total respondents

third (35%; *n* = 59) were encouraged to include the family in their treatment of individuals with Down syndrome. When questioned about evidence-based practice for the population, 40% *(n* = 68) reported their supervisors encouraged them to review the literature on Down syndrome, while only 16% (*n* = 27) received research articles on the topic.

Post-graduate training. Because training is no longer monitored by the faculty of graduate training programs upon graduation, the responsibility falls upon the individual to obtain

information on various topics. Thus, participants were questioned about the extent to which they had attended continuing education courses related to Down syndrome and/or intellectual disabilities throughout their careers. Approximately one third (30%; *n* = 78) reported they had never attended such a course. The breakdown of those who had attended a course are as follows: 41% (*n* = 106) of participants reported they had attended one to two courses, 14% (*n* = 37) of participants reported they had attended three to four courses, and 15% (*n* = 39) of participants reported they had attended more than five courses.

When provided the opportunity to share information that was not queried throughout the survey, 34 participants opted to provide open-ended responses. Among these responses, three themes emerged in which at least one-third of the responses provided information related to one, two, or three of the following areas: individual research (33%; *n* = 11), on-the-job training (42%; *n* = 14), and an unpreparedness to treat individuals with Down syndrome upon entering the field (48%; *n* = 16). It should be noted that some responses provided information related to more than one theme. As such, the *n* exceeds 34 (i.e., the number of participants who responded with open-ended answers).

With regard to the first theme, participants shared that they felt much of their knowledge came from the conduction of their own research on the topic. For instance, one participant stated, "most of what [she] knows [she] researched for herself," while another shared that she did research to "brush up on the syndrome and look for the most effective therapies." Through consideration of participants' individual research also came consideration of the on-the-job-training that often occurs, which led to the second theme.

The second theme illustrated the ways in which training occurs at the work-site. This included direct experience or information obtained from co-workers in speech-language

pathology or other fields. For instance, one participant explained that "experience taught more than class." Another participant stated her knowledge came from "trial by fire" and that she "relied heavily on co-treats with PT/OT to learn some strategies so [her] individual treatments were more successful."

With regard to the third theme, participants provided statements related to their initial preparedness to treat the population. As such, one participant explained, "[he] was unprepared to work with the DS population" and that "more material should have been covered in grad school." In addition, another participant shared, "[she] felt like [she] just learned about cognitively average students when that is a very small percentage of [her] caseload." Even further, one participant believed she was taught with a bias, exclaiming, "[she] was instructed that children with Downs [would] be some of her most stubborn patients," which "clouded her judgement initially." These themes work together to provide a broad understanding of the current atmosphere of training for Down syndrome.

Knowledge of Down Syndrome

Upon answering questions in relation to their training, participants were also asked to determine the extent of their knowledge on different elements of Down syndrome. Overall knowledge of Down syndrome, knowledge of the communicative characteristics associated with Down syndrome, and ideals from the literature base were assessed.

Overall knowledge of the disorder. With relation to their knowledge of the basic elements of Down syndrome, participants were asked a series of questions. When queried as to an alternative name commonly used to refer to Down syndrome, 257 participants responded. Approximately 97% (n = 250) chose the correct answer, "Trisomy 21." Of the participants who chose an incorrect answer, 2% (n = 5) chose "Mental DS," 0.4% (n = 1) chose "Genetic

Dysplasia," and 0.4% (*n* = 1) chose "SQ Down." In addition, participants were asked a sequence of true/false questions. Almost all respondents (≥ 98%) answered questions about Down syndrome's association with speech/language difficulties, medical conditions, and time of development correctly. A smaller majority (≤58%) answered questions correctly with relation to the propensity for individuals with Down syndrome to participate in routine and/or compulsive behaviors and the extent to which it is passed through families. When asked whether most children with Down syndrome are born to mothers who are 35 years of age or older, over half of the participants (64%; *n* = 166) answered incorrectly (see Table 4). When the data for this section was aggregated, it was found that 98% (n = 252) of the 256 participants who answered all seven queries selected correct answers on at least four of the questions.

Table 4

General Knowledge of Down Syndrome

Concept Queried	Correct *n* (%)	Incorrect *n* (%)
• *A name commonly used to refer to Down syndrome is "Trisomy 21"	250 (98)	7 (3)
• The majority of children with Down syndrome are born to mothers who are 35 years of age or older	94 (36)	166 (64)
• Some individuals with Down syndrome develop the disorder shortly after birth	256 (98)	4 (2)
• *Individuals with Down syndrome have a propensity to participate in routine and/or compulsive behaviors	151 (58)	108 (42)
• *Down syndrome is commonly associated with speech and language difficulties	258 (99)	2 (0.7)
• *Down syndrome is often associated with other medical conditions	253 (98)	6 (2)
• *Down syndrome is not usually passed through families	141 (54)	119 (46)

Note. * = true statement; *n* = number of respondents; % = percentage of total respondents

Knowledge of communicative characteristics. Participants were then asked about the communicative characteristics associated with Down syndrome. Of the seven questions, one was

answered correctly by greater than 90%. This question assessed participants' awareness of the association between Down syndrome and cognitive impairment. The incorrect answer choices depicted connections to "kidney disease," "muscle spasticity," or "another genetic syndrome." A similar yet smaller margin reported correctly that the prevalence of Down syndrome is less than the prevalence of autism spectrum disorder in the United States; however, approximately 12% (*n* =31) answered the question incorrectly. The third question answered correctly by over half of the sample (62%) asked participants to choose a specific weakness often found in the population. While the correct answer was "verbal memory," the "perceptual memory" answer choice was chosen by approximately a fifth of the respondents (see Table 5).

Table 5

Knowledge of Communicative Characteristics

Concept Queried	Correct *n* (%)	Incorrect *n* (%)
• *Individuals with Down syndrome have a significant weakness in verbal memory	154 (62)	96 (38)
• *Individuals with Down syndrome have a significant strength in visuospatial memory	115 (46)	135 (54)
• *It is common for individuals with Down syndrome to experience cognitive impairment	244 (95)	14 (5)
• *In the United States, the prevalence of Down syndrome is less than the prevalence of autism spectrum disorder	228 (88)	31 (12)
• Childhood verbal apraxia is not likely a cause of intelligibility issues due to associated anatomical and physiological differences	115 (45)	143 (55)
• Individuals with Down syndrome generally show more affection and have more personable personalities than their typically developing peers	69 (27)	190 (73)
• *Individuals with Down syndrome generally exhibit a lower signal-to-noise ratio than their typically developing peers	98 (40)	148 (60)

Note. * = true statement; *n* = number of respondents; % = percentage of total respondents

Alternatively, four of the seven questions were answered correctly by less than half of the respondents. They queried the following topics: strength in visuospatial memory, vocal qualities, the potential for developmental apraxia in the population, and perceptions of common personality characteristics. When asked about a strength present in individuals with Down syndrome, slightly less than half of the participants correctly chose, "visuospatial memory," while 32% (n = 79) chose "long-term memory," 12% (n = 31) chose "perceptual memory," and 10% (n = 25) chose "verbal memory." With regard to the voices of individuals with Down syndrome, approximately 40% (n = 98) chose the correct answer, "lower signal-to-noise ratio." However, a similar number of participants chose an answer that defied physiology; approximately 42% (n = 104) indicated individuals with Down syndrome exhibit breathy vocal qualities due to their larynxes sitting "higher in the neck." When asked about the potential for individuals in the population to have childhood verbal apraxia, slightly less than half provided the correct answer. Lastly, 27% (n = 69) of participants correctly disagreed with the notion that individuals with Down syndrome show more affection and have more personable personalities than typically developing individuals (see Table 5).

Upon analyzation of responses to individual questions, participants' total number of correct responses to questions in this section was considered. It was found that of the 229 participants who answered all seven questions, 65% (n=148) answered at least four questions correctly. Only two participants (0.009%) provided correct answers to all seven questions.

Evidence-based intervention practices specific to Down syndrome. After answering the questions related to general knowledge of Down syndrome and its associated communicative characteristics, participants were asked about their knowledge of evidence-based intervention practices for the population. While slightly less than half (45%; n = 114) reported they never

review the literature published on communicative interventions for the Down syndrome population, slightly under a third (30%; *n* = 75) reported reviewing the literature annually, and slightly under a fourth (21%; *n* = 54) reported reviewing it biannually. Further, 4% (*n* = 9) reported reviewing the literature monthly, and 1% (*n* = 2) reported reviewing it weekly. Next, participants were queried about the truth of various statements related to the published evidence-base on Down syndrome. The majority answered each question correctly; however, the specific percentages varied. For instance, while 98% (*n* = 256) correctly reported that it is helpful to use visual aids when treating individuals with Down syndrome, only 68% (*n* = 164) correctly reported the efficacy of speech recasts. Similarly, while 86% (*n* = 222) correctly denied a false statement related to the influence of gestures on verbal development, a smaller group (77%; *n* = 190) correctly identified the positive potential of grouping AAC symbols by color (see Table 6).

The additional questions included in this section were also designed to determine the extent to which participants understood the element of visual memory present in the Down syndrome literature. When asked about the reasons by which electropalatography has been suggested, 80% (*n* = 203) correctly identified its potential to "cultivate visual memory," while 10% (*n* = 25) reported its potential to "cultivate linguistic abilities," 5% *(n* = 14) reported its potential to "cultivate faster mental processing speeds," and 4% (*n* = 11) reported its potential to "cultivate verbal memory." Next, participants were provided a list of techniques used to aid in verbal comprehension of short passages and asked to choose the one which was shown to be most appropriate for individuals with Down syndrome. Over half (59%; *n* = 149) correctly chose visualization strategies, while about a fourth (22%; *n* = 56) indicated verbal cues would be most helpful, 13% (*n* = 33) indicated discussion of the outline would be most helpful, and 5% (*n* = 13) indicated reading each story an additional time would be most helpful (see Table 6). Finally, the

total number of correct answers provided to questions in this section was considered. It was found that 87% (n = 199; N = 230) selected correct answers to at least four of the six questions, and an additional 10% (n = 25) answered at least three questions correctly.

Table 6

Knowledge of Evidence

Concept Queried	Correct *n* (%)	Incorrect *n* (%)
• *Speech recasts have been shown to increase intelligibility in the Down syndrome population	164 (68)	77 (32)
• *It is helpful to use visual aids when treating individuals with Down syndrome	256 (98)	4 (2)
• Encouraging the use of gestures with verbal utterances will slow verbal development in the Down syndrome population	222 (86)	35 (14)
• *Individuals with Down syndrome have been shown to exhibit more accurate and quicker locating abilities when the symbols included within AAC devices are grouped by color	190 (77)	56 (23)
• *The use of electropalatography has been suggested for use with individuals with Down syndrome because it may cultivate visual memory	203 (80)	50 (20)
• *Teaching visualization strategies has been shown to improve verbal comprehension of short passages in the Down syndrome population	149 (59)	102 (41)

Note. * = true statement; n = number of respondents; % = percentage of total respondents

Confidence in Treatment

To determine levels of confidence at different times in participants' careers, respondents were questioned about the level of confidence they felt while treating their first client with Down syndrome (with no supervision) and the level of confidence they would have felt while treating a client with Down syndrome at the time the survey was completed. With regard to the first client with Down syndrome, most participants (91%; n = 237) reported either feeling "moderately confident," "moderately unconfident," or "neither confident nor unconfident." The distribution

fell fairly even amongst the three groups, however it leaned slightly more toward the side denoting confidence than the side denoting a lack of confidence. Alternatively, when queried as to their level of confidence in their current abilities to treat the population, most participants (95%; $n = 243$) reported either feeling "extremely confident," "moderately confident," or "neither confident nor unconfident," with 55% ($n = 141$) reporting moderate confidence and 28% ($n = 73$) reporting extreme confidence (see Figure 1).

Relationship between confidence, experience, and knowledge. Pearson correlation coefficients were calculated to determine the extent to which relationships exist between reported confidence and experience with Down syndrome in the past five years, total experience in the field, and knowledge of various aspects of Down syndrome (determined by a total score of correct responses to these questions in the survey). Using the Bonferroni approach to control for Type 1 error across the 3 correlations, a p value of less than .016 (.05/3 = .016) was required for significance. Based on the results of the correlation analysis, small, significant relationships were found between participants' clinical confidence and five-year experience with Down syndrome ($r = .256$, $p = .000$) and clinical confidence and total experience in the field ($r = .298$, $p = .000$); however, no significance was found between participants' clinical confidence and knowledge of Down syndrome ($r = -.054$, $p = .428$).

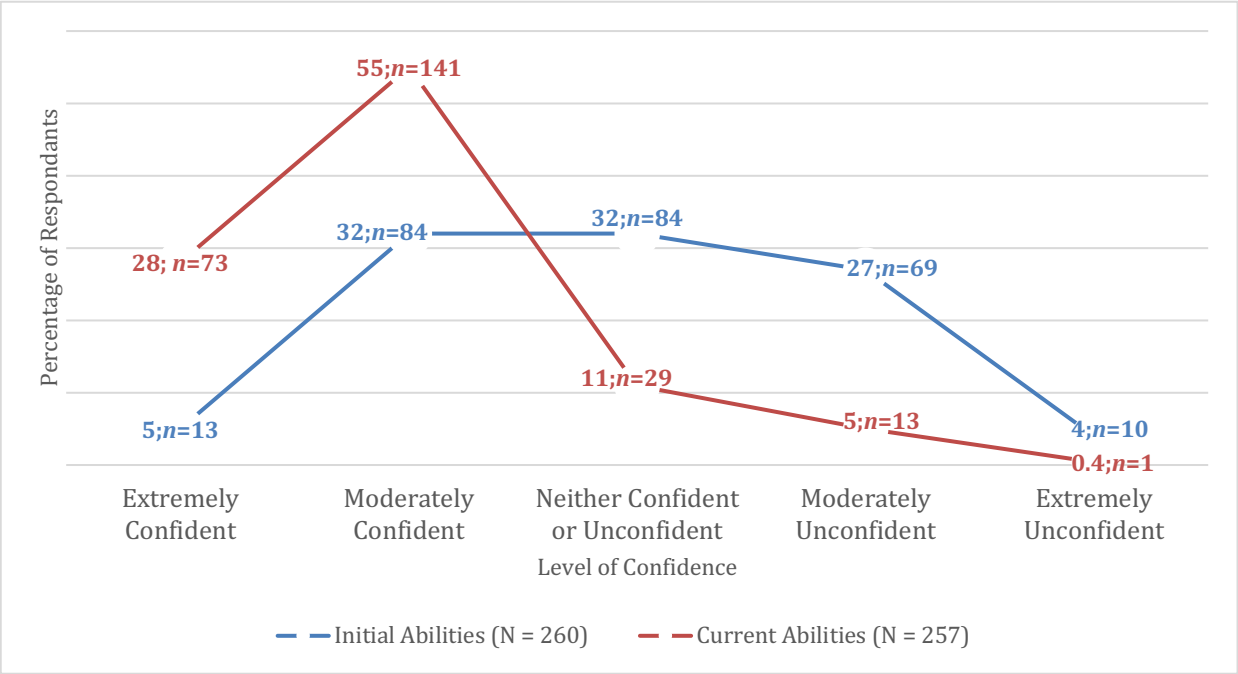

Figure 1. Confidence in initial and current abilities to treat individuals with Down syndrome

Familial Inclusion in Treatment

The last section of the survey was comprised of questions designed to acquire information on the extent to which participants include families in their treatments of individuals with Down syndrome. Participants were instructed to select all that applied. Of the 257 participants who responded, the areas characterized by the most responses involved reviewing treatment objectives with the family before beginning treatment and providing the family with progress reports at least quarterly. Alternatively, the areas with the least responses were characterized by the inclusion of parents and siblings (if applicable) in treatment sessions/homework assignments and visiting the family's home outside of therapy sessions. For an overview of each area queried, see Figure 2.

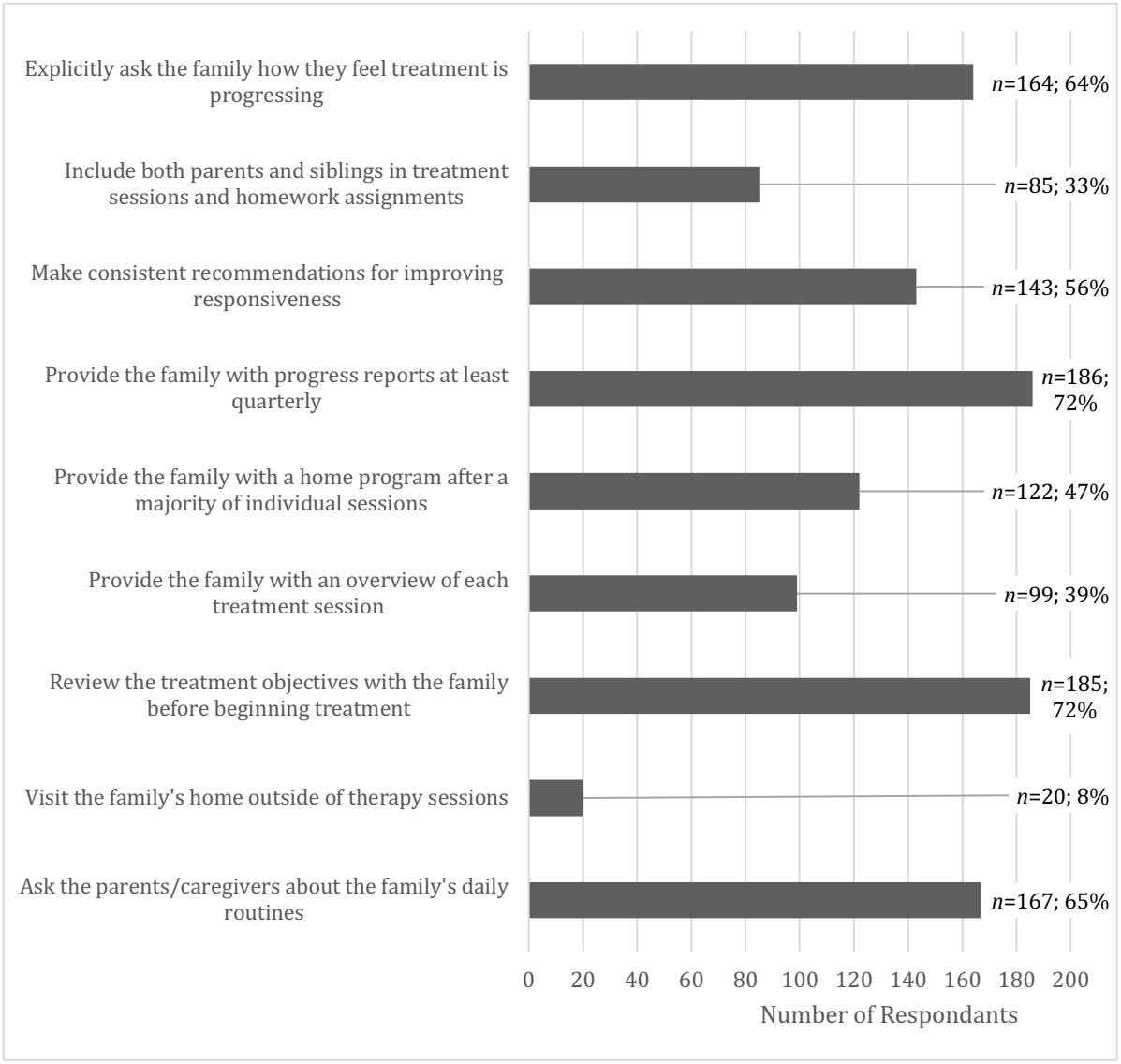

Figure 2. Familial involvement in treatment

Upon answering questions about their current inclusion of the family, participants were asked about their beliefs on familial inclusion and their comfort in doing so. With regard to their beliefs, 67% (*n* = 174; N = 257) of participants believed speech-language pathologists should select intervention targets based foremost on the client's evaluation results, with the family's ability to implement these targets considered second. In addition, half of the participants (51%; *n* = 132; N = 258) reported the belief that speech-language pathologists should place greater consideration on the family when the child with Down syndrome is three years of age or younger

than when he or she is school-aged. When queried as to their level of comfort in communicating with and including the family in treatment, 79% reported feeling either extremely comfortable (40%; *n* = 104) or moderately comfortable (39%; *n* = 102). Within the smaller groups, 13% (*n* = 35) reported feeling neither comfortable or uncomfortable, 7% (*n* = 18) reported feeling moderately uncomfortable, and 0.4% (*n* = 1) reported feeling extremely uncomfortable.

Chapter 6

Discussion

Training

With regard to the extent of training received by speech-language pathologists to prepare them for working with the Down syndrome population, it was hypothesized participants would report a combination of instruction during school and experiences after graduation (e.g., continuing education, reviews of the literature). Although research has supported communicative treatment for the Down syndrome population (Knight et al., 2015; Sepúlveda et al., 2012; Te Kaat- van den Os et al., 2015; Van Bysterveldt et al., 2010; Wright et al., 2013), speech-language pathologists have been shown to report a lack of preparedness to treat individuals in special populations (Brisk et al., 1997; Compton et al., 2009; Hux et al., 1996). In keeping with this literature, it was reported that much of the participants' training occurred after graduation, through continuing education courses as well as on-the-job training. It stands to suggest that the underlying need for greater experiences with Down syndrome during undergraduate/graduate schooling may have motivated clinicians to partake in additional training after graduation, subsequently supporting the idea that clinicians feel unprepared to treat special populations mentioned previously in the literature (Brisk et al., 1997; Compton et al., 2009; Hux et al., 1996). This idea is further supported by the consideration of the limited undergraduate/graduate academic experiences presented by the participants in this study. It is possible the limited clinical and academic exposure to Down syndrome during school led to the subsequent feeling of being unprepared to treat the population upon graduation and motivated clinicians to acquire additional instruction once working as licensed professionals.

Knowledge

Overall knowledge of the disorder. Because Down syndrome is the most common chromosomal condition in the United States (March of Dimes, 2016), it was hypothesized that the majority of the participants would provide correct answers to at least four of the seven questions that addressed general elements of Down syndrome. The results of this study indicated that approximately 98% of the sample met the criteria set forth by the hypothesis, indicating a wide understanding of basic information related to Down syndrome. Specifically, the areas in which almost all participants provided correct answers included alternative names for the disorder (i.e., Trisomy 21), ages in which the disorder manifests (i.e., before birth), and Down syndrome's association with medical and speech/language difficulties. These results highlight knowledge outside of the cognitive and behavioral phenotypes presented throughout the literature (Couzens et al., 2012; Fidler, 2005; Silverman, 2007).

The areas in which less than or approximately half of the sample provided correct answers involved the influence of hereditary and maternal age, as well as the disorder's association with routine and compulsive behaviors. While the research states that 80% of babies with Down syndrome are born to mothers younger than 35 years of age (NADS, 2016), this study showed that just over a third of the participants possessed this knowledge. It is possible that the participants in the study confused this statistic with the increasing risk of Down syndrome associated with increasing maternal age (March of Dimes, 2016). In addition, the results also highlighted the notion that almost half of the participants in the study did not accurately report a connection between Down syndrome and routine and compulsive behaviors, which is included in the behavioral phenotype presented in the literature (Feeley & Jones, 2006; Fidler, 2005; Povee et al., 2006). As the provision of speech-language pathology services often

involves direct and consistent interaction with the individuals with Down syndrome, knowledge of such behaviors widely exhibited by the population should be in the least considered and prepared for during evaluation and treatment. This way, clinicians may design their services with a greater level of appropriateness and research-based support.

Knowledge of communicative characteristics. Upon attaining a general level of knowledge on Down syndrome, clinicians should also possess knowledge of the communicative characteristics associated with Down syndrome, as speech-language pathologists are the professionals by which individuals with Down syndrome and their families receive treatment to enhance communicative functions. Although the importance of such knowledge is clear, it was hypothesized that less than half of the sample would provide correct answers to at least four of the seven questions. The results of the study showed that 65% provided at least four correct answers, illustrating a more extensive knowledge than was expected, however accompanied by the presence of areas in which knowledge of communicative characteristics could be improved. Such areas were characterized by knowledge of the processing abilities present in the Down syndrome literature, the likelihood of verbal apraxia, and the vocal qualities present in the Down syndrome population. Among the research published on Down syndrome interventions, it has been shown that individuals in the population exhibit a strength in visual memory over verbal memory. As such, many interventions have been published on the basis of cultivating the element of visual processing (Cleland et al., 2009; Hancock & Kaiser, 2006; Te Kaat-Van Den Os et al., 2015; Knight et al., 2015; Wood et al., 2009; Van Bysterveldt et al., 2010). Although a strong theme exists in the literature about the relationship between verbal processing and visual processing in individuals with Down syndrome, only 46% of the participants in the study correctly identified the strength in visual memory, and 62% correctly identified the weakness in

verbal memory. Knowledge of this information would guide treatment in ways that would cultivate the individual with Down syndrome's greatest ability to process new concepts. As professionals who work with clients with Down syndrome, this knowledge should be more common than it appears to be, as depicted in the results of this study. Nonetheless, these results align with other knowledge-based studies completed on autism spectrum disorder, in which participants possessed beliefs that were not supported by the research (Heidgerken, Geffken, Modi, & Frakey, 2005; Stone, 1987; Schwartz & Drager, 2008). While this study focused on Down syndrome, it stands to suggest speech-language pathologists may hold beliefs that contradict the literature-base on a variety of disorders.

Similarly, when participants were queried about the vocal qualities present in individuals with Down syndrome, 42% chose an answer choice that defied physiology. The incorrect choice stated that "individuals with Down syndrome are more likely to exhibit breathy vocal qualities than their typically developing peers due to their larynx sitting higher in the neck." However, a higher sitting larynx would not directly relate to breathy vocal qualities, regardless of a diagnosis of Down syndrome (Casper & Leonard, 2006; Pentz & Moran, 1988). These results can be described in two ways: either many speech-language pathologists could benefit from greater education on physiology, or they exhibit a likelihood to defy typical physiology when a more extensive medical diagnosis is present. Either way, the sheer volume of respondents who chose the physiologically incorrect answer choice raises means for concern for those with Down syndrome and the general population, as knowledge of anatomy and physiology forms the foundation of the field of speech-language pathology.

Down syndrome stereotype. In addition to various voice and processing characteristics, it has been suggested that clinicians should possess an awareness of the stereotype of Down

syndrome (Wishart, 2001). Research has shown that some professionals hold a belief that individuals with Down syndrome are more adaptable, loving, and joyous than their typically developing peers, which subsequently impedes their likelihood to align their sessions and treatment objectives with the notions presented by the behavioral phenotype (McDaniel & Yoder, 2016; Faught et al., 2016). However, only about a third of the participants in this study reported the affectionate and personable stereotype, illustrating a key awareness of the differences present in the population. It can be concluded that the importance of looking past disorder-based stereotypes, presented by Wishart (2001), is growing in the field of speech-language pathology, particularly with regard to Down syndrome.

Knowledge of evidence-based practices specific to Down syndrome. Another element of knowledge important to consider is the participants' understanding of the published evidence. While it was hypothesized less than half of the sample would provide correct answers to at least four of the six questions in the section, the results depicted 87% answered at least four questions correctly. Although many of the questions included in this section were based upon specific articles or areas within the Down syndrome literature base, it was suggested participants could arrive at the correct answer based upon knowledge of the theme of visual processing present across the literature as a whole, even if they had never read the specific articles. As such, questions inquired about visual aids, gesture use, electropalatography, and a visual method to improve verbal comprehension (Cleland et al., 2009; Gibbon et al., 2003; Te Kaat-Van Den Os et al., 2015; Lecas et al., 2011; Wood et al., 2009; Wright et al., 2013). Interestingly, while almost all of the participants agreed visual aids could be helpful in treatment for the population, only about three-fourths reported the connection between electropalatography and visual memory, and an even lower three-fifths reported the importance of teaching visualization

strategies to improve verbal comprehension. These results further align with the idea that clinicians hold beliefs about Down syndrome that do not align with the literature, similar to the research published on autism spectrum disorder (Heidgerken, Geffken, Modi, & Frakey, 2005; Stone, 1987; Schwartz & Drager, 2008). While the participants in the study may have possessed a general awareness of the potential for positive impacts made by the inclusion of visual components in treatment, the thought became less engrained when applied to other areas. With a strong knowledge of the research base as a whole, the idea of visual processing would have been more widely reported across the sample.

Connections between training, research, and practice. Throughout the study, the majority of participants exhibited relative knowledge on the published evidence for the Down syndrome population, represented by 87% providing correct answers to at least four of the six literature-based questions. However, approximately half of the participants reported never having discussed evidence-based practice for individuals with Down syndrome during their undergraduate and/or graduate experiences. The subsequent gap that exists between these two areas was likely bridged through training experiences once in the field. Past literature has supported the notion that challenges exist in training speech-language pathologists to possess the necessary skillsets for working in a variety of settings with a variety of populations (Whitmire & Eger, 2004), thereby presenting a possible explanation for why the discussion of Down syndrome evidence was not included in 50% of participants' training experiences. After all, it is a relatively small population in comparison that of autism spectrum disorder or specific language impairment (kogan et al., 2018; May, Brignell, Hawi, Brereton, Tonge, Bellgrove, & Rinehart, 2018). However, if the gap between limited discussion of Down syndrome evidence and subsequent knowledge in the area was bridged through post-graduation training experiences, it

stands to suggest that speech-language pathologists are generalizing other forms of training from graduate school to ensure they acquire appropriate knowledge in necessary areas.

It has been suggested in the past that a gap may also exist between research-based ideals and methods used in practice during the provision of various services for the Down syndrome population (McDaniel & Yoder, 2016). While the extent to which the participants in this study were knowledgeable on ideals from the literature does not suggest a gap between research and practice, as the logical progression of knowledge would be implementation in practice, this study was not designed to obtain information on the extent to which the participants actually implemented their knowledge. It is possible that speech-language pathologists are acquiring knowledge on the evidence for Down syndrome to feel more prepared (as exhibited in this study) yet experiencing difficulty transitioning their knowledge to the treatment room, as exhibited by McDaniel and Yoder (2016). Research efforts may be better placed on ways to bridge the gap between research and practice that goes beyond arming clinicians with knowledge of the evidence in the future.

Confidence

The provision of treatment to individuals with Down syndrome requires speech-language pathologists to possess knowledge of the disorder and supported treatment techniques, as well as confidence in their clinical abilities and chosen methods. Although all of the participants in the study were required to possess experience with Down syndrome within the last five years in order to meet the inclusion criteria, it was hypothesized that participants' confidence in their ability to treat individuals with Down syndrome would be varied. It was shown that only about one third reported extreme confidence, and about half reported moderate confidence. Because 87% of the participants reported that 10% or less of their caseloads were comprised of

individuals with Down syndrome, the possibility exists that when there is less opportunity to work with individuals with Down Syndrome, speech-language pathologists will be less likely to develop the upper levels of confidence. Nonetheless, these results align with a recent study of confidence in school-based speech-language pathologists, in which about half of the participants reported moderate to high confidence in their abilities to perform various duties related to practicing in the school setting (Davis & Murza, 2018). However, the results of this study do not align with published research on speech-language pathologists' confidence in their treatment of individuals with traumatic brain injuries, in which confidence was shown to be lower (Riedman & Turkstra, 2018). These mismatches illustrate how various areas of the field can elicit different levels of self-efficacy for clinicians.

Considerations for increasing confidence. As it has been previously presented that many clinicians do not feel adequately prepared to treat a variety of disorders (Brisk et al., 1997; Compton et al., 2009; Hux et al., 1996), clinicians' confidence in their abilities may be interlaced within their perceived preparedness. Fundamentally, if one does not feel he or she has been adequately exposed or prepared to work with a population of individuals, it would be a natural response to feel less confident. The methods by which one could increase his or her confidence were thought to be characterized by either increasing one's experience with Down syndrome or knowledge of different elements of the disorder. Once the components were isolated and the extent of the relationship with confidence was determined, it was shown that one component prevailed: experience. Significant relationships, albeit small correlations, existed between confidence and total experience in the field ($r = .298$) and confidence and experience with Down syndrome in the past five years ($r = .256$); however, a significant relationship was not found between confidence and the extent of one's knowledge on Down syndrome. Past research has

highlighted challenges in personnel preparation in the field of speech-language pathology (Whitmire & Eger, 2004), but the results of this study illustrate ways to better produce confident clinicians in graduate school (or arm them with the resources to gain targeted confidence themselves once in the field). Further, it can be concluded that to improve clinical confidence in working with the Down syndrome population, speech-language pathologists should increase their experience, either horizontally through increasing the number of individuals with Down syndrome on their current caseloads, or vertically through maintaining their current caseload and simply continuing to work in the field.

Familial Inclusion

Just as training and subsequent possession of knowledge are important for speech-language pathologists to acquire in order to provide effective treatment to the Down syndrome population, inclusion of the family in treatment is an area by which the literature base is growing (Bernheimer & Weisner, 2007; Van Hooste & Maes, 2013; Van Riper, 1999; Viana Pereira & Parlato Oliveira, 2015). As the research question asked the extent to which speech-language pathologists include families in their treatment of individuals with Down syndrome, it was hypothesized a dichotomy would exist in the results; although the majority of participants would report including the family in most treatment activities for the Down syndrome population, only a small percentage would report considering the client in the context of his or her family before treatment begins. While three-fourths of the respondents reported reviewing their clients' treatment objectives with families before beginning therapy, only a third reported including both the parents and/or siblings in therapy or homework assignments throughout the time they provided treatment. These results fall in line with the beliefs presented by McBride and colleagues (1993), characterized by the potential for a disconnect between family-centered

attitudes and authentic family-centered practice. Essentially, while many participants reported including the family before treatment, illustrating a family-centered attitude, the numbers decreased when asked about actual inclusion of the family within treatment, illustrating a lack of family-centered practice. Nonetheless, it could certainly be proposed that discussing treatment objectives with clients' families before beginning treatment would be considered family-centered practice, not simply a family-centered attitude. However, because those behaviors are not continued into treatment, the conclusion can be drawn that clinicians realize the importance of family-centered care and value families' opinions yet revert back to more individualized service-delivery models upon providing treatment.

In addition to including the family in treatment, the literature has also highlighted the importance of asking parents/caregivers about a typical day with their child in an attempt to understand the child's communicative abilities and needs within the context of his or her family (Bernheimer & Weisner, 2007). The majority, approximately 65%, of the participants in this study reported doing so, illustrating a positive indicator for family-centered practice within the sample population; however, the question stands as to the extent to which the participants refined their treatment based upon the knowledge they attained from the acquisition of such information. It is possible an additional gap exists between family-centered ideals and genuine practice, as illustrated by McBride and colleagues (1993), in this realm as well. Nonetheless, asking parents/caregivers about their typical day and acquiring information about each member of the family likely acts to foster a deeper therapeutic bond. It has been shown that when caregivers perceive a family-centered relationship, they are more likely to exhibit satisfaction with their care and even seek additional services (Van Riper, 1999). Thus, even if speech-language

pathologists do not generate true family-centered practice, such behaviors can work to build an effective family-centered relationship and generate client satisfaction.

Comfort with family-centered practice. If clinicians feel uncomfortable interacting with the families of their clients with Down syndrome, a barrier to the provision of family-centered practice may be created. While 40% of the participants in this research study reported feeling extreme comfort when communicating with and including families of Down syndrome in treatment, a similar percentage (39%) expressed moderate comfort, leaving a fifth to range from a neutral feeling to an extreme discomfort. In therapeutic instances in which clinicians are required to teach parents ways to improve their interactions with their children, as has been supported in the literature (Mahoney et al., 1990; Marchal et al., 2016; Vilaseca & Del Rio, 2004), any lack of comfort may interfere with the provision of such family-centered practice. These results further illustrate reasons by which clinicians have been shown to opt to adhere to more individualized service-delivery models yet maintain their family-centered attitudes (McBride et al., 1993). If uncomfortable with interaction, the likelihood one would actively include or even recommend communicative behaviors to families would naturally decrease. Through this, it can be shown that family-centered practice is a multi-faceted action that involves a variety of knowledge and skills to implement. While it appears family-centered attitudes are widely prevalent among speech-language pathologists, the extent to which clinicians include families in treatment is not as prevalent, further aligning with previous research on the topic (McBride et al., 1993). As more studies are completed in the subject area, a greater emphasis on family-centered practice may be exhibited across the profession.

Limitations and Future Directions

Although this research study illustrated meaningful results, the limitations of the study should be considered. Approximately 63% of the participants reported residing and practicing in the southern region of the United States. Thus, the results may not generalize to other geographic areas. In addition, the survey was self-initiated. Participants with limited interest and/or knowledge of Down syndrome may have been more likely to avoid taking the survey or exiting before it was completed than those with such an interest. It is possible the results could have depicted inflated levels of knowledge, confidence, and /or training due to the interest and/or experiences that led participants to initiate the survey in the first place. In addition, answers to the knowledge-based questions likely depended upon participants' specific experiences with Down syndrome. While the research provides a broad overview of Down syndrome, each individual with the disorder is different. Participants may have answered questions in ways that aligned with their individual experiences rather than the published research on the population. For example, while research shows that individuals with Down syndrome are likely to exhibit routine and compulsive behaviors in adolescence (Povee et al., 2012), each participant may not have personally experienced such behaviors and subsequently chosen a different answer.

Furthermore, with an un-monitored survey comes the opportunity for participants to find relevant information online or in textbooks before answering the questions. This presented a wide barrier to attaining useful and accurate information, as the results may have been skewed through participants' utilization of outside resources. With regard to interaction with and inclusion of families in treatment sessions, the setting in which each participant worked may have impacted the likelihood of such actions. For instance, while accessing the family may have been relatively simple for speech-language pathologists in early intervention or private practice

settings, speech-language pathologists may have experienced greater challenges with the same endeavor in school settings, as families are typically not as readily accessible. Although this study provided a broad overview of ideals related to family-centered practice, conclusions should be considered with caution due to the potential impact of the work setting.

Because Down syndrome is the most common chromosomal condition in the United States, research on various aspects of the disorder across a variety of fields is certainly warranted (March of Dimes, 2016). While this research provides a summary of speech-language pathologists' knowledge of and interaction with varying elements of Down syndrome, more research is needed in the areas of personnel preparation and the ways in which speech-language pathologists are taught to approach Down syndrome and individuals in special populations. More specifically, research on the ways in which clinicians approach members of the Down syndrome population who possess cultural backgrounds different from their own may create a more comprehensive understanding of areas to consider in training as well as in current practice. This research could also be furthered by determining speech-language pathologists' beliefs about their clients with Down syndrome, their abilities, and the elements that affect their prognosis and subsequent treatment decisions. Through this, the narrative on Down syndrome within the field of speech-language pathology may be expanded and refined in ways that will influence both evaluation and treatment of the population.

Conclusion and Clinical Implications

Upon the termination of this research study, it was concluded speech-language pathologists possess a foundational level of knowledge on Down syndrome and feel better prepared to treat the population after acquiring experience. However, gaps were highlighted in the areas of knowledge of the communicative characteristics associated with the disorder and the

provision of family-centered practice in varying areas of treatment. It appeared that much of the training (e.g., experience, specific instruction, etc.) with regard to the Down syndrome population was completed after graduation, and clinical confidence increased with experience (r = .256).

With this information, it became clear that training to treat the population should emphasize experiences with individuals with Down syndrome and their family members. As Whitmire and Eger (2004) highlighted the challenges present in truly preparing clinicians to enter the field, the ways in which clinicians are currently being prepared to approach all special populations, not only Down syndrome, should be considered to a greater extent. In relation to the knowledge component of the study, it stands to suggest speech-language pathologists should place a greater emphasis on learning the communicative characteristics associated with Down syndrome, as they are the only professionals who work specifically in this area. Without this knowledge, it is unlikely professionals in other fields will act to bridge the gap if needed.

The results of this research study also shed light on the disconnect highlighted by McBride and colleagues (1993) between family-centered attitudes and genuine family-centered practice. Although the participants in this study certainly demonstrated an understanding of the importance of family-centered practice and made attempts at familial inclusion, it was evident a greater emphasis could be made to bridge the gap and increase the depth of the family's inclusion. Overall, while there are areas related to Down syndrome in which clinicians could improve upon, the foundation of treatment for the population appeared to be present. With appropriate resources, knowledge, and experience, professionals in the field of speech-language pathology are likely to grow their abilities and provision of effective treatment to the Down syndrome population and beyond.

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Appendix 1. Survey

Section I: Demographics

1. Do all three of the following statements apply to you?
   – I have obtained a master's degree or higher.
   – I am a fully-licensed, practicing speech-language pathologist in the United States with a Certificate of Clinical Competence (CCC).
   – I have evaluated or treated a client with Down syndrome within the past five years
      - Yes
      - No

2. We appreciate your participation. How did you hear about the survey?
      - ASHA Special Interest Group
      - ASHA community discussion board
      - Social media (e.g., post on Facebook)
      - E-mail
      - Other (please specify):

        _____

3. Gender:
      - Male
      - Female
      - X

4. What is your race? Select all that apply.
      - White
      - Black or African American
      - American Indian or Alaskan Native
      - Asian
      - Native Hawaiian or Other Pacific Islander
      - Other _____

5. Are you of Hispanic, Latino, or Spanish origin?
      - No, not of Hispanic, Latino, or Spanish origin
      - Yes, Mexican, Mexican-American, or Chicano
      - Yes, Puerto Rican
      - Yes, Cuban
      - Yes, another Hispanic, Latino, or Spanish origin

        _____

6. In what age range do you fall?
    - 19-29 years
    - 30-39 years
    - 40-49 years
    - 50-59 years
    - 60-69 years
    - 70-79 years
    - Other

7. In what year did you receive your highest degree?
    - Prior to 1980
    - 1980-1989
    - 1990-1999
    - 2000-2009
    - 2010 or after

8. How long have you practiced speech-language pathology, beginning with your clinical fellowship?
    - 0-5 years
    - 6-10 years
    - 11-15 years
    - 16-20 years
    - 21+ years

9. In what geographic region of the United States are you currently practicing and professionally licensed?
    - West (Washington, Oregon, California, Montana, Idaho, Wyoming, Nevada, Utah, Colorado, Arizona, New Mexico, Hawaii, Alaska)
    - South (Texas, Arkansas, Louisiana, Oklahoma, Mississippi, Alabama, Georgia, Kentucky, Tennessee, South Carolina, Florida, North Carolina, Virginia, West Virginia, Maryland, Delaware)
    - Northeast (Pennsylvania, New York, New Jersey, Massachusetts, Connecticut, Rhode Island, Vermont, New Hampshire, Maine)
    - Midwest (North Dakota, South Dakota, Nebraska, Kansas, Missouri, Iowa, Minnesota, Wisconsin, Illinois, Indiana, Ohio, Michigan)

10. What do you consider your primary employment setting?
    - Private practice
    - Early intervention program
    - Hospital
    - Skilled nursing facility
    - School
    - Rehab facility
    - Home health
    - University clinic
    - Other (please list) _____

11. What is the age range of individuals with whom you currently work? Select all that apply.
    - ☐ Birth-3:0
    - ☐ 3:1-10:0
    - ☐ 10:1-20:0
    - ☐ 20:0 or older

12. What percentage of your current caseload has a diagnosis of Down syndrome?
    - o 0-10%
    - o 11-25%
    - o 26-50%
    - o Greater than 50%

13. Within the last five years, how many clients with Down syndrome have you provided treatment?
    - o 0 clients
    - o 1-5 clients
    - o 6-10 clients
    - o 10+ clients

14. Do you have a family member with Down syndrome?
    - o Yes
    - o No

15. What is your relation to the family member with Down syndrome?
    - o My child has Down syndrome
    - o My sibling has Down syndrome
    - o My cousin has Down syndrome
    - o My aunt or uncle has Down syndrome
    - o Other _____

Section II: Training

16. When treating your FIRST client with Down syndrome with no supervision, how confident did you feel?
    - o Extremely confident
    - o Moderately confident
    - o Neither confident nor unconfident
    - o Moderately unconfident
    - o Extremely unconfident

17. How confident do you currently feel in your ability to treat clients with Down syndrome?
    - o Extremely confident
    - o Moderately confident
    - o Neither confident nor unconfident
    - o Moderately unconfident
    - o Extremely unconfident

18. How many continuing education courses have you attended related to Down syndrome and/or intellectual disabilities?
    - o 0 courses
    - o 1-2 courses
    - o 3-4 courses
    - o 5+ courses

19. Approximately how much time was spent discussing Down syndrome in your undergraduate and/or graduate program?
    - o No time
    - o Less than one class period
    - o 1 class period
    - o 1 week
    - o 1 month
    - o More than 1 month

20. In how many courses were the following topics discussed in relation to Down syndrome throughout your undergraduate and graduate training experiences?

	0 courses	1-2 courses	3+ courses
Genetic cause	o	o	o
Incidence/prevalence	o	o	o
Physical symptoms	o	o	o
Behavioral phenotype	o	o	o
Cognitive phenotype	o	o	o
Associated medical conditions	o	o	o
Communicative characteristics	o	o	o
Published literature base	o	o	o
Research-based treatment methods	o	o	o
Family-centered practice (for Down syndrome)	o	o	o

21. How many clients with Down syndrome did you provide treatment throughout your undergraduate and/or graduate training experience?
    - o 0 clients
    - o 1-3 clients
    - o 4-6 clients
    - o 7+ clients

22. During your undergraduate and graduate experiences, how did your clinical supervisor(s) support your knowledge and subsequent treatment of the Down syndrome population? Select all that apply.
    - □ My supervisor encouraged me to review the literature on Down syndrome
    - □ My supervisor provided related research articles
    - □ My supervisor provided information about Down syndrome
    - □ My supervisor appeared knowledgeable on the Down syndrome population
    - □ My supervisor encouraged me to include the family in my treatment of the Down syndrome population

23. Please provide any additional information you would like to add with regard to your training and/or treatment of clients with Down syndrome. _____

Section III: Knowledge of Down syndrome

24. What is another name commonly used to refer to Down syndrome?
    - o Genetic Dysplasia
    - o Mental DS
    - o Trisomy 21
    - o SQ Down

25. Select and answer which most appropriately represents your thoughts on the accuracy of the following statements.

	Agree	Disagree
The majority of children with Down syndrome are born to mothers who are 35 years of age or older.	○	○
Some individuals with Down syndrome develop the disorder shortly after birth.	○	○
Individuals with Down syndrome have a propensity to participate in routine and/or compulsive behaviors.	○	○
Down syndrome is commonly associated with speech and language difficulties.	○	○
Down syndrome is often associated with other medical conditions.	○	○
Down syndrome is not usually passed through families.	○	○

Section IV: Knowledge of Communicative Characteristics of Down Syndrome

26. Individuals with Down syndrome have a significant weakness in:
    - Verbal memory
    - Visuospatial memory
    - Long-term memory
    - Perceptual memory

27. It is common for individuals with Down syndrome to experience:
    - o Cognitive impairment
    - o Another genetic syndrome
    - o Kidney disease
    - o Muscle spasticity

28. Individuals with Down syndrome have a significant strength in:
    - o Verbal memory
    - o Visuospatial memory
    - o Long-term memory
    - o Perceptual memory

29. In the United States, the prevalence of Down syndrome is:
    - o Greater than the prevalence of autism spectrum disorder
    - o Less than the prevalence of autism spectrum disorder

30. Select the answer which most appropriately represents your thoughts on the accuracy of the following statements.

	Agree	Disagree
Childhood verbal apraxia is not likely a cause of intelligibility issues in individuals with Down syndrome because of associated anatomical and physiological differences that affect intelligibility.	o	o
Individuals with Down syndrome generally show more affection and have more personable personalities than typically developing individuals.	o	o

31. Which of the following is true in regard to the voices of individuals with Down syndrome?
    - Individuals with Down syndrome have been shown to exhibit a lower signal-to-noise ratio than their typically developing peers
    - There is generally no difference in the voice qualities of individuals with Down syndrome and their typically developing peers
    - Individuals with Down syndrome are more likely to experience a paralyzed vocal fold than their typically developing peers
    - Individuals with Down syndrome are more likely to exhibit breathy voice qualities because their larynxes sit higher in the neck

Section V: Intervention Practices

32. How often do you review the literature published on communicative interventions for the Down syndrome population?
    - Not at all
    - Daily
    - Weekly
    - Monthly
    - Biannually
    - Annually

33. Select the answer which most appropriately represents the accuracy of the following statements.

	Agree	Disagree
Speech recasts have been shown to increase intelligibility in the Down syndrome population.	○	○
It is helpful to use visual aids when treating individuals with Down syndrome.	○	○
Encouraging the use of gestures with verbal utterances will slow verbal development in the Down syndrome population.	○	○
In regard to AAC users, individuals with Down syndrome have been shown to exhibit more accurate and quicker locating abilities when the symbols are grouped by color.	○	○

34. Why has the use of electropalatography (illustrates tongue placement during speech) been suggested for use with individuals with Down syndrome?
    - o It cultivates faster mental processing speeds
    - o It cultivates visual memory
    - o It cultivates explicit linguistic abilities
    - o It cultivates verbal memory

35. Which of the following has been shown to improve the Down syndrome population's verbal comprehension of short passages?
    - o Reading each story an additional time
    - o Teaching visualization strategies
    - o Providing verbal cues throughout the story
    - o Discussing the outline of the story before it is read

36. On average, to what extent do you target cognitive processes with your client(s) with Down syndrome?
    - o Never
    - o Sometimes
    - o About half of the time
    - o Most of the time
    - o Always

37. Select the ways in which you include the families of your clients with Down syndrome throughout treatment. Select all that apply.
    - ☐ I explicitly ask the parents/caregivers about the family's daily routines
    - ☐ I visit the family's home outside of the therapy session
    - ☐ I review the treatment objectives with the family before beginning treatment
    - ☐ I provide each family with an overview of each treatment session
    - ☐ I provide the family with a home program after The majority of individual sessions
    - ☐ I provide the family with progress reports at least quarterly
    - ☐ I make consistent recommendations for improving responsiveness
    - ☐ I include both the parents and the siblings (if applicable) in treatment sessions and homework assignments
    - ☐ I explicitly ask the family how they feel treatment is progressing

38. Select the answer which most appropriately represents your thoughts on the accuracy of the following statements.

	Agree	Disagree
Speech-language pathologists should select intervention targets based foremost on the client's evaluation results with the family's ability to implement these targets considered secondarily.	○	○
Speech-language pathologists should place greater consideration on the family when the child with Down syndrome is three years of age or younger than when he or she is school-age.	○	○

39. How comfortable do you feel communicating with and including the family in treatment for the Down syndrome population?
    - Extremely comfortable
    - Moderately comfortable
    - Neither comfortable nor uncomfortable
    - Moderately uncomfortable
    - Extremely uncomfortable

Appendix 2. Information Letter (embedded within survey)

INFORMATION LETTER

for a Research Study entitled

"Knowledge and Treatment of Down Syndrome in Speech-Language Pathology: A National Survey"

You are invited to participate in a research study to explore the scope of knowledge on Down syndrome in the field of speech-language pathology and the extent to which such professionals feel prepared to treat individuals in the population. The study is being conducted by Morgan Fritz, Master's student in Communication Disorders, under the direction of Dr. Allison Plumb, Associate Professor in the Auburn University Department of Communication Disorders. You are invited to participate because you are a practicing speech-language pathologist and are age 19 or older.

What will be involved if you participate? Your participation is completely voluntary. If you decide to participate in this research study, you will be asked to complete an online survey form that includes 40 questions. Your total time commitment will be approximately 10 minutes.

Are there any risks or discomforts? The risks associated with participating in this study are related to the potential for breaches of confidential survey responses. To minimize these risks, we will keep all responses anonymous by collecting no identifying information and using all reasonable and customary security measures. The data will be stored behind the secure firewalls

of the Qualtrics system, and all security updates will be applied in a timely fashion. While the majority of the exported data will be held on Auburn University firewall-protected computers, any data held on the personal investigator's password-protected computer will be numerical only and not linked to any IP addresses.

Are there any benefits to yourself or others? If you participate in this study, you can expect to gain exposure to various characteristics of Down syndrome and family-centered practice for the population. We cannot promise you that you will receive any or all of the benefits described. Benefits to others may include an increased awareness of Down syndrome.

Will you receive compensation for participating? No compensation will be provided; however, your participation will be greatly appreciated.

Are there any costs? The only cost will be related to the time commitment necessary to complete the survey.

If you change your mind about participating, you can withdraw at any time by closing your browser window. Since all data will be collected anonymously, your answers to the survey questions cannot be withdrawn once the survey has been initiated. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University or the Department of Communication Disorders.

Any data obtained in connection with this study will remain anonymous. We will protect your privacy and the data you provide by storing the information behind the secure firewalls of

the Qualtrics system and Auburn University computers. In addition, numerical data will be stored on the principal investigator's password-protected computer. Information collected through your participation may be published in a professional journal and/or presented at a professional meeting.

If you have questions about this study, please contact Dr. Allison Plumb at amp0016@auburn.edu or Morgan Fritz at mnf0014@auburn.edu.

If you have questions about your rights as a research participant, you may contact the Auburn University Office of Research Compliance or the Institutional Review Board by phone (334)-844-5966 or e-mail at IRBadmin@auburn.edu.

HAVING READ THE INFORMATION PROVIDED, YOU MUST DECIDE WHETHER OR NOT YOU WANT TO PARTICIPATE IN THIS RESEARCH PROJECT. IF YOU DECIDE TO PARTICIPATE, PLEASE SELECT "YES, I WISH TO PARTICIPATE IN THE STUDY" BELOW. YOU MAY PRINT A COPY OF THIS LETTER TO KEEP.

Morgan N. Fritz, B.S.E. August 1, 2018

Investigator Date

Allison M. Plumb, Ph.D., CCC-SLP August 1, 2018

Faculty Advisor Date

The Auburn University Institutional Review Board has approved this document for use beginning August 31, 2018. Protocol #18-321 EX 1808

- YES, I wish to participate in the study.
- NO, I do not wish to participate in the study.