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# Teaching Students with Down Syndrome: Mothers' Perspectives on the Most Appropriate Educational Environments for Their Children

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Teaching Students with Down Syndrome:  
Mothers' Perspectives on the Most Appropriate Educational Environments for Their Children

by

Stacey Mulrenin

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Education Specialist in School Psychology  
Department of Educational and Psychological Studies  
College of Education  
University of South Florida

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## ABSTRACT

This study examined the perspectives that mothers of children with Down syndrome (Ds) hold regarding the most appropriate educational environments for their children. Environments for students with Ds may be classified as inclusive (fully included within a general education classroom with complete access to the general curriculum and typical peers), integrated (self-contained within a general education school, with some interaction with typical peers), or segregated (separate school for students with intellectual disabilities, or InD). A qualitative research design using semi-structured interviews, journaling, and a follow-up focus group was used to gather thick, rich descriptions of mothers' perspectives of these different types of settings, including academic (e.g., reading, math) and non-academic (e.g., self-esteem, peer relationships) outcomes for their children. Mothers of children of different ages ( $N=6$ ) were recruited to allow for examination of how of mothers' perspectives may change over time or vary with the child's age. Findings yielded information that can be used to help parents and educators understand mothers' perspectives on the risks and benefits of different types of educational environments for youth with Ds.

## CHAPTER ONE

### INTRODUCTION

In recent years, including students with Down syndrome (Ds) into general education classrooms has become a mission for many parents of such children. The Least Restrictive Environment mandate of 1975's Public Law 94-142 has allowed for multiple interpretations as to what constitutes a restrictive placement for a child with any type of disability. As opposed to segregated environments (separate schools) or integrated settings (self-contained classes within a general education school), parents are yearning to have their child with Ds educated in an inclusive environment, with typical peers and full access to the general education curriculum. Numerous obstacles are frequently encountered when seeking an inclusive placement. However, parents, and in particular, mothers, often adopt an especially passionate stance in advocating for what they perceive to be the most appropriate educational environment for their child with Ds. The educational journeys mothers of children with Ds take with their children are complex and varied. This was the basis for the research of my study.

I was inspired to study this topic based on my personal experience as a former teacher of students with moderate to severe Intellectual Disabilities (InD), many of whom had Ds, at a segregated school from 1993-1998. During this part of my career, I was unaware of opportunities for students with InD and specifically those with Ds to be educated in general education classrooms. However, during the 1997-98 school year, a movement toward inclusion began to place students with InD who had higher cognitive functioning and presented no external

behaviors in self-contained classrooms in general education schools (integrated setting). I left the field of special education in 1998, right as this movement started, but returned to it in 2006, when I served as the Director for Resource Services for students with mild learning impairments in a general education private school.

Although it would seem that integrating students with disabilities into general education environments has many positive benefits associated with it, some of the drawbacks have become clearer over time. For example, during fall 2012, Jennifer Caballero, an 11-year-old girl with Ds, drowned in a retention pond adjacent to the general education middle school in Tampa she attended. Jennifer had been placed in an integrated setting. When she went to physical education, she and her classmates were taught as a group in the gym alongside other classes that were comprised of students in general education. On the day Jennifer died, she escaped from the gym unnoticed by the PE teacher nor any of the assistants assigned to her class. Her body was found in the pond later that day. Horrified, I wondered to myself if a more restricted environment had ever been considered for Jennifer. Would she have been safer in a segregated school? Was the integrated model in place at her school poorly structured?

While students with InD, specifically those with Ds, may not be provided with much opportunity for interacting in a setting that simulates “real life” when they are placed in a segregated school, certainly they are more closely monitored. I also began to think about the happiness of this population of students. In my experience teaching in segregated schools, it seemed the students felt not only secure, but also a deep sense of belonging and connection to their peers. Eating lunch daily together along with weekly recreational activities, monthly dances, an annual talent show, and a field day were moments where each student radiated

feelings of being smart and strong among one another. I wondered if these students would feel the same way in an integrated school.

It was not until spring 2013 when I was confronted with a concept regarding the education of students with InD with which I was completely unfamiliar. In my Resource Services Director duties, I was asked by the administration to oversee the full inclusion of a student with Ds into the general education 2<sup>nd</sup> grade classroom. I was completely unaware that the movement of integrative education had become one of inclusive education, where students with InD were taught within the same classroom as typically-developing, same-age peers. To me, it was shocking. The parents of this particular child were quite insistent on their son's placement in general education, however, and I became intrigued. What made the parents so convinced that this setting was superior to the segregated or even integrated setting?

The experience of this student provided him with many positive benefits, including modeling of appropriate behaviors by typical peers and perhaps more rigorous academic expectations. His classmates readily accepted and supported him whenever possible, and situations in which he was purposely socially excluded were not observed. The year was also filled with challenges, including training for the faculty and staff on how to best modify and adapt the curriculum and lessons and develop interventions to address external behaviors the student displayed. Differences of opinion between the administration and parents regarding the level of support the student required and the amount and type of communication between home and school created confusion. Most significantly, I questioned whether the child himself felt happy. His own awareness of his differences was apparent as he verbalized or demonstrated frustration when he could not keep pace or complete the same tasks as his peers.

When I began the School Psychology graduate program at USF, my major professor introduced me to the documentary “Educating Peter” (1992) and its sequel, “Graduating Peter” (2001). Both were highly intriguing to me. The first film follows Peter, a boy with Ds, during his third grade year, where he is fully included in a general education classroom after having been previously educated in a segregated environment. His parents, teacher, and peers are interviewed multiple times throughout the year, and while challenges are faced most notably with helping Peter diminish his external behaviors, it is evident that the overall experience is positive for everyone, especially Peter.

In “Graduating Peter” (2001), his educational journey post-elementary school is chronicled as he continues to be included in general education classrooms. The disparity in developmental trajectories between Peter and his peers is keenly apparent. Peter works on simple addition worksheets (using a calculator) during an Algebra class and traces his first name on a handwriting sheet during social studies. He is isolated at lunch and does not socialize with peers, with the exception of a group who matches students with and without disabilities and arranges for outings such as a trip to an amusement park. Peter is not asked by “friends” to attend football games or other school events. He is diagnosed with depression and withdraws. It is decided to balance his school day in the general education classroom with on-the-job training situations in the community and, eventually, functional/adaptive skills classes. With encouragement, Peter asks a fellow student from the independent living class to the prom, and ultimately walks across the stage to a standing ovation when he receives his diploma.

After viewing both films, I wondered about the outcome of this story regarding inclusion of a student with Ds. When I compared Peter’s journey with the high-school aged students I taught in a segregated school, I recalled how happy my students seemed. They were not aware

of their differences and seemed to enjoy their school days with zeal. Which was the better type of environment, both for the long-term and short-term development of a student with Ds? How did a mother come to believe which might be best for her child? Through my ruminations, the concept of my study was born.

### **Overview of Down Syndrome**

Ds is a chromosomal condition that results from an embryo developing with three copies of chromosome 21 instead of the usual two. Ds occurs in all genders, socioeconomic levels, and ethnicities and is the most common of all the genetic conditions associated with InD (Brown, 2006; Davis, 2008; Fidler & Nadel, 2007; Harris, 2006; Jacola, Hickey, Howe, Esbensen, & Shear, 2014; Pelatti, 2015). Approximately 7,000 babies are born with Ds each year and currently, more than 400,000 people with Ds live in the United States (National Down Syndrome Society, 2012).

Youth with Ds have a broad profile of physical, cognitive, and social/behavioral characteristics. Specific physical features including smaller midfacial area and flat facial profile; upturned, outward slanting eyes; a protruding tongue; small, low set ears; a broad neck with abundant neck skin; short, broad hands and fingers, with a single transverse palmer crease; low muscle tone; and shorter stature (Gupta & Kabra, 2014; Harris, 2006) make them easily recognized within society, and they are at increased risk for congenital heart defects, respiratory problems, vision and hearing impairments, gastrointestinal issues, and thyroid conditions (Harris, 2006; Leshin, 2002).

Cognitive strengths for a child with Ds typically include visual processing and implicit memory, whereas deficits tend to occur in verbal processing and explicit memory, including speech and language production; auditory short-term memory; verbal short-term memory; and

delayed recall (Davis, 2008; Fidler & Handel, 2007; Harris, 2006; Pueschel, 2002). Students with Ds tend to “plateau” around 2<sup>nd</sup>-4<sup>th</sup> grade reading levels (Olwein, 2002).

The social-emotional domain is a relative area of competence for people with Ds, although it is delayed in comparison to other children and subject to mental age. Despite this strength, as the demands and complexities of social situations increase in middle childhood and beyond, individuals with Ds may have difficulty with social adaptation and selecting appropriate social strategies (Fidler & Handel, 2007; Pelatti, 2015). Many children with Ds have high self-esteem and awareness of their condition does not appear to negatively impact their self-image (Cunningham & Glenn, 2004). Generally, individuals with Ds show a profile of stronger receptive language skills and weaker expressive language skills. They often understand much more language than they can produce (Davis, 2008; Fidler & Handel, 2007; Pelatti, 2015).

Cognitive functioning and expressive language skills are linked significantly with behavior for people with Ds (Patterson, 2002; Buckley, Bird, Sacks & Archer, 2006). Oppositional, stubborn, or aggressive behaviors may actually be a means to communicate frustration for not having the language to be understood. Still, people with Ds are generally placid, good tempered, and possess a strong propensity for imitation of others (Harris, 2006).

### **Educational Environments for Youth with Down Syndrome**

The impairments I’ve described often affect the placement of a child with Ds in the educational system. Federal legislation of Public Law 94-142 in 1975 and the Individuals with Disabilities Education Act (IDEA) in 1990, as well as its revision in 2004, stated the provision that all children with disabilities should be educated in the Least Restrictive Environment (LRE). Simply put, LRE means that the setting should be as close to general education as is feasible and still adequately meet the child’s needs. However, the LRE mandate contains language that is

open to interpretation depending on the resources a state, district and/or school have to offer a specific student with exceptional needs. Because of the ambiguity, there is much confusion about how to implement the provision in order to appropriately serve students with InD.

Inclusive education has been a slow process and at times even stagnant. Resistance among educators and researchers to include students with more complex and challenging InD in general education remains a huge obstacle for proponents of the movement. There are mostly encouraging results on the academic outcomes for students with Ds in inclusive classrooms (de Graaf, van Hove, & Haveman, 2013; Turner, Alborz, & Gayle, 2008), as opposed to integrated or segregated classrooms, about which very few studies are available. It is unclear, however, whether the better academic outcomes of students in inclusive classrooms are due to higher cognitive capabilities of the students enrolled in these settings (as compared to students in other settings) as well as more mature social and/or behavioral dispositions. The results for nonacademic outcomes were mixed when comparing inclusive, integrative, and segregated classrooms. Students with Ds made social gains in terms of maturity and expressive language (Alquraini & Gut, 2012; Fitch, 2003), but it was questioned whether true and lasting friendships were formed by these students and their typically developing peers within inclusive learning environments (Buckley, Bird, Sacks, & Archer, 2006; Peetma, Vergeer, Roeleveld, & Karsten, 2001).

### **Parental Attitudes Toward Inclusion for Youth with Down Syndrome**

There are several key studies regarding parental attitudes about inclusive educational environments for children with disabilities and specifically, Ds (Lalvani, 2013; Lightfoot & Bond, 2013). Some parents admit concerns about inclusion for their children with disabilities, including exclusion by peers and less attention and support from teachers and staff. (Cole, 2005;

Garrick Duhaney & Salend, 2000; Lalvani, 2013; Leyser & Kirk, 2004.) However, the majority of parents of children with disabilities express supportive attitudes about inclusion and indicate they believe an inclusive educational environment would provide greater academic and nonacademic benefits for their children (Bennett & Gallagher, 2013; Downing & Peckham-Hardin, 2007; Garrick Duhaney & Salend, 2000; Jones, Thorn, Chow, Thompson, & Wilde, 2002; Leyser & Kirk, 2004; Kasari, Freeman, Bauminger, & Alkin, 1999). Research also suggests that certain variables, such as educational background of parents, may have an influence on parents' opinions regarding inclusive education (Hanson, et. al., 2001; Kasari, Freeman, Bauminger, & Alkin, 1999; Leyser & Kirk, 2004). Additionally, as children age, parents often discover that inclusive environments are actually not conducive to meeting their children's needs (Hanson, et. al., 2001; Lightfoot & Bond, 2013).

### **Purpose of the Study**

My study researched the perspectives of mothers of children with Ds in regard to the educational environment they believe is best for their children. I used a qualitative methodology, consisting of semi-structured interviews and a focus group, in order to collect mothers' stories of the educational journeys their children with Ds have taken. In particular, I was interested in analyzing how mothers viewed the outcomes, both academic and non-academic, for their children with Ds in varying educational environments (inclusive, integrated, and segregated.) Additionally, I studied how the mothers' perspectives of the most appropriate educational environment shifted as their child aged.

### **Significance of the Study and Research Goals**

My goal for this story was to allow mothers of children with Ds to share their stories in order to enlighten teachers, administrators, leaders in the field of exceptional education, and

policymakers. Additionally, connecting mothers of children with Ds created a more unified and influential body of advocates. These goals were accomplished through the interviews I collected from the mothers who participated in my study. They were asked to describe their child's educational journey, as well as define the ideal educational environment for their children. Moreover, the mothers were asked to explain how they decided upon a placement for their children, what barriers or supports they encountered in their children's educational journey, and how their perspectives have changed as their children grew and aged. With my results, it is hoped that greater attention and consideration will be given to the placements of students with Ds in the school systems in our community.

### **Terminology**

- Mother is defined as the birth or adoptive mother of a child with Ds who lives with the child full time and has custodial rights to the child's educational planning
- Down syndrome is defined as a chromosomal abnormality in which a child carries three chromosomes on the 21<sup>st</sup> pair. (Variations—mosaic pattern? Will you include these kids?)
- A segregated educational environment is defined as a separate school for students with disabilities (Gordon, 2013).
- An integrated educational environment is defined as a setting for students with disabilities divided between the general education classroom and special education classroom (Gordon, 2013).
- An inclusive educational environment is defined as full inclusion for students with disabilities within the general education classroom (Gordon, 2013).

- Inclusion is defined as “a system of policy and practices that embraces diversity as a strength, creates a sense of belonging, equal membership, acceptance, being valued, and involves fundamental civil rights. Inclusive teaching and learning occurs in natural settings, with extensive and appropriate instructional supports, modifications, and accommodations, which are meaningful to students and teachers.” (Jones, White, Fauske, and Carr , 2011, p. 13.)

## **CHAPTER TWO**

### **LITERATURE REVIEW**

The following areas are addressed within this literature review: (a) the diagnosis of Ds and its prevalence in the population; (b) development among youth with Ds including physical, cognitive, and social-emotional characteristics as well co-morbid disorders; (c) history of Least Restrictive Environment (LRE) and how it shaped the call for educationally inclusive programs for students with disabilities; (d) current educational settings for students with InD and specifically Ds in public and private schools, including research on the outcomes of these settings and challenges in providing the most appropriate and least restrictive educational programs; and (e) research on parental beliefs and attitudes toward educational inclusion for children with Ds.

#### **Diagnosis and Prevalence of Down Syndrome**

Ds is the most common of the genetic disorders associated with InD (Brown, 2006; Davis, 2008; Fidler & Nadel, 2007; Harris, 2006; Jacola, Hickey, Howe, Esbensen, & Shear, 2014; Pelatti, 2015). Harris (2006) notes its significance as being “the first intellectual disability syndrome described...because of its frequency, the general public is most aware of Ds, and for many, it is the prototypical form of intellectual disability” (p. 194). Ds is a chromosomal disorder that creates a broad profile of physical, cognitive, and social/behavioral characteristics in people diagnosed with it. While the cause is unknown, it can be diagnosed prenatally or at birth through genetic testing.

There are three types of Ds. *Nondisjunction/Trisomy 21* is the most common type, found among 95% of those diagnosed with Ds. It results from an embryo developing with three copies of chromosome 21 instead of the usual two. Before or at conception, a pair of 21st chromosomes in either the sperm or the egg fails to separate. As the embryo develops, the extra chromosome is replicated in every cell of the body. *Mosaicism* occurs when nondisjunction of chromosome 21 takes place in one - but not all - of the initial cell divisions after fertilization. When this occurs, there is a mixture of two types of cells, some containing the usual 46 chromosomes and others containing 47, with the extra chromosome 21. One percent of people with Ds have this type. *Translocation* accounts for about 4% of all cases of Ds. In translocation, part of chromosome 21 breaks off during cell division and attaches to another chromosome, usually chromosome 14. While the total number of chromosomes in the cells remain 46, the presence of an extra part of chromosome 21 causes the characteristics of Ds (Davis, 2008; Leshin, 2002).

The National Down Syndrome Society (2012) states that there are more than 400,000 people living with Ds in the United States. This is one in 691 births, and according to Harris (2006), leads to approximately 7,000 total American infants born with the genetic condition each year. The World Health Organization (2015) estimates the incidence of worldwide births of children with Ds as between one in 1,000 to one in 1,100. The genetic condition occurs in all races and economic groups.

### **Development Among Youth with Down Syndrome**

The developmental process of a child with Ds leads to more pronounced end states of relative strengths and weaknesses than any other genetic disorder (Fidler & Handel, 2007). While the brain of a newborn baby with Ds does not significantly vary from that of a newborn without any impairments, differences in cognitive abilities start emerging in late infancy and

become increasingly apparent during the developmental period from childhood through adolescence as these youth fall further behind same-aged children who are not InD (Fidler & Handel, 2007; Harris, 2006). In this section, the development of a young person with Ds will be presented, including specific descriptions of the development in physical, cognitive, social/emotional, and behavioral domains, which are those most relevant to educating youth.

### *Physical Development*

There are distinct physical features of a child with Ds (Harris, 2006). These include a large posterior fontanel and a flat facial profile; a low hair line; upturned, outward slanting eyes; a wide, flat nasal bridge; a small mouth and protruding tongue; small, low set ears; a broad neck with abundant neck skin; short, broad hands and fingers, with a single transverse palmer crease; relatively short upper arms; a large cleft between the first and second toes (referred to as “sandal gap”) and shorter stature (Gupta & Kabra, 2014; Harris, 2006).

Low muscle tone (hypotonia) is a common physical trait of a person with Ds, which can not only lead to delayed gross motor development but also cause constipation and gastroesophageal reflux, since the smooth muscles of the intestinal tract are affected (Leshin, 2002). Approximately 40-60% of individuals with Ds have structural heart lesions of varying degrees (Harris, 2006; Leshin, 2002), which may be treated with surgery, medication, and/or regular monitoring. Vision problems are common among children with Ds, (Harris, 2006; Leshin, 2002) and they also have a greater risk for hypothyroidism, which can cause decreased growth rate, lethargy, dry skin, and weight gain (Leshin, 2002). As obesity is a problem among adolescents with Ds (Davis, 2008), hypothyroidism poses an even greater cause for concern.

Many of the problems faced by children with Ds are due to variations in the anatomy of the upper airway (Leshin, 2002). Because of their smaller midfacial areas, they tend to have

recurrent upper respiratory infections, croup, and may also experience sleep apnea. Hearing loss and impairment is a significant problem for children with Ds. (Harris, 2006; Davis, 2008; Leshin, 2008; Wisniewski, Mizejeski & Hill, 1988). This results from chronic fluid in the ears, dysfunction of the transfer of sound from the inner ear to the brain, or a mixture of both types (Leshin, 2002.) Hearing loss may lead to increased difficulty with receptive language for children with Ds (Wisniewski, Mizejeski & Hill, 1988).

The physical differences between a child with Ds and that of a typically developing child become even more pronounced during adolescence, which can increase the social stigma of Ds (Davis, 2008). To that end, the cognitive developmental domain is discussed next followed by the social/emotional domain and the behavioral domain.

### *Cognitive Development*

Although children with Ds usually display global intellectual deficits, there are variations in cognitive abilities between and among individuals with Ds. Thus, a “Ds profile” should not be assumed (Davis, 2008). Most commonly have moderate to severe InD (Harris, 2006). However, increasingly, individuals with average and, occasionally, above average intelligence are seen (Brown, 2006). The highest developmental scores are recorded during the early years of life, particularly infancy, with progression slowing during chronological development (Harris, 2006).

Despite the range of abilities, there are cognitive features that are typically found in children with Ds, many of which are biologically based within the brain. Altered development in the hippocampal system and prefrontal cortex has been linked to deficits in explicit memory skills (Fidler & Handel, 2007), and impairments in the development of the cerebellum affect a the higher order processing skills, including executive functioning, reading, sequencing, motor learning, and language (Davis, 2008). Cognitive strengths for a child with Ds include visual

processing and implicit memory, whereas deficits tend to occur in verbal processing and explicit memory, including speech and language production; auditory short-term memory; verbal short-term memory; and delayed recall (Davis, 2008; Fidler & Handel, 2007; Harris, 2006; Pueschel, 2002).

Students with Ds can perform as well as some of their nondisabled peers in some academic areas, especially reading, but generally struggle with arithmetic, which may be secondary to a deficiency in receptive language (Wisniewski, Mizejeski, & Hill, 1988). Oelwein (2002) reported studies of children with Ds who could read above their mental ages by up to 2.2 years, especially on word recognition tasks. However, Channell, Loveall and Connors (2013) found that students with InD performed more poorly than typically developing children of the same mental-age on word recognition tasks. Specifically, phonological decoding is a particularly challenging skill that the authors posited may block the acquisition of word recognition skills in students with InD. Research has also demonstrated that children with Ds can benefit from instruction in phonological awareness in regard to reading (Davis, 2008) They tend to “plateau” around 2<sup>nd</sup>-4<sup>th</sup> grade level with lower scores on reading comprehension (Olwein, 2002) and ultimately, most adolescents and young adults with Ds test at the emergent literacy or word identification (i.e., ability to recognize and name single words) stages (Pelatti, 2015). Most children with Ds have the ability to become literate mathematicians (Olwein, 2002, 435), but have learning differences that require specialized, systematic, and individualized instruction to reach this potential. The typical relative strengths in visual processing (Davis, 2008) and word identification (Pelatti, 2015) for a student with Ds should be considered when planning for his/her education.

### *Social/Emotional Development*

This section will address the domain of social/emotional development for a child with Ds. Included within this domain are expressive and receptive communication skills and behavioral traits, which include self-help/adaptive skills.

As with cognitive profile, a consistent personality type for a person with Ds has not been identified (Harris, 2006). Social and behavioral development is an area of strength for many children with Ds (Davis, 2008). Social relatedness skills include the ability to engage with a social partner in a triadic fashion in the forms of play acts, turn taking, invitations, and object shows. This domain is a relative area of competence, although it is delayed in comparison to other children and subject to mental age. Despite this strength, as the demands and complexities of social situations increase in middle childhood and beyond, individuals with Ds may have difficulty with social adaptation and selecting appropriate social strategies (Fidler & Handel, 2007; Pelatti, 2015).

Cunningham and Glenn (2004) found that awareness of their differences and social categorization in children with Ds were significantly associated with verbal mental age and closely approximated the typical social-cognitive developmental sequence. Only those with verbal mental ages at approximately 8 years were making relative social comparisons and beginning to form complex social categories of Ds and disability in general. Thirteen percent of their sample displayed a negative emotional reaction to Ds, and most of those were male. A similar percentage, mostly female and with higher verbal mental ages, discussed concerns and

limitations. Still, they all had high self-esteem and their awareness of Ds and disability did not appear to be a major issue for them.

On the other hand, people with InD tend to feel lonelier than those in the general population. Social relationships can be compromised by difficulties in areas such as communication, perspective-taking, social information processing, attention, and self-regulation, and the cognitive, physical, and mental health problems they may already be experiencing are likely to be compounded by feelings of chronic loneliness (Gilmore & Cuskelly, 2014).

### *Expressive and Receptive Communication*

Jacola, Hickey, Howe, Esbensen, and Shear (2014) found that people with Ds often possess disproportionately impaired verbal skills. Generally, individuals with Ds show a profile of stronger receptive language skills and weaker expressive language skills. They often understand much more language than they can produce (Davis, 2008; Fidler & Handel, 2007; Pelatti, 2015).

Developmental language is almost always delayed in a child with Ds, and expressive communication is more affected than receptive. Pragmatics of language, semantics, and comprehension serve as relative strengths, compared with grammatical skills such as syntax, morphology, and production. During later development, language in a child with Ds is characterized by word comprehension being more advanced than overall cognition, and deficits in syntax are more impactful than vocabulary limitations (Harris, 2006; Pelatti, 2015).

IQ appears to play a substantial role in determining the prognosis of language learning in children with Ds, with IQ of 50 or above being the critical range for likely growth in language skills if maturational factors allow for it (Fowler, 1988). Children with Ds start to show differences in their language development around 20 months of age, generally when the

“vocabulary surge” occurs in typically developing children. At this point, children with Ds tend to use the same “first words,” but are challenged to go beyond simple utterances, reflecting disproportionate difficulties in grammatical aspects of language and in production rather than comprehension (Nadel, 1988). A virtual halt in language development takes place during middle childhood years, as discovered in a study by Fowler (1988). These years in particular pose considerable difficulties for children with Ds in regard to expressive language and speech intelligibility, and they may experience increasing frustration in classroom contexts (Fidler & Handel, 2007).

### *Behavior*

People with Ds are generally placid, good tempered, and possess a strong propensity for imitation of others. They are sociable and do not usually present problem behaviors such as self-injury or aggression (Harris, 2006). However, 18-30% of children with Ds experience externalizing behavior problems, which is a higher incidence than that of typically developing peers of the same age (Jacola, Hickey, Howe, Esbensen, & Shear 2014). Some of these behaviors include decreased attention, hyperactivity, and impulsivity. (Vimercati, Galli, Stella, Caiazzo, Ancillao, & Albertini, 2015). Motivational orientation and task persistence are also challenges for children with Ds. They may abandon tasks such as puzzles and other nonsocial/nonverbal tasks sooner than other children at similar developmental levels and adopt strategies that divert attention away from the task (Fidler & Handel, 2007), a tactic at which they can be quite adept (Patterson, 2002). Typically, this behavior is displayed in order when a child with Ds wants to be removed from a frustrating situation. However, it is often interpreted as being oppositional or stubborn.

Cognitive functioning and expressive language skills are linked significantly with behavior for people with Ds (Patterson, 2002; Buckley, Bird, Sacks & Archer, 2006). Oppositional, stubborn, or aggressive behaviors may actually be a means to communicate frustration for not having the language to be understood. It is emphasized to gain a clear understanding of a person's language and cognitive development when evaluating for behavior problems and not to assume that stronger social adaptive skills mean an equal level of functioning for receptive and expressive language skills (Patterson, 2002).

Jacola, Hickey, Howe, Esbensen, and Shear (2014) found a relationship between behavior problems and adaptive skills in people with Ds. However, Harris (2006) reported that people with Ds actually have fewer adaptive behavior problems than individuals with other cognitive disabilities.

#### *Comorbidity with Other Conditions*

There is a marked increase in rates of mental health disorders among children and adolescents with an InD (Einfeld, Ellis, & Emerson, 2011). Dykens, et al. (2015) studied mental health conditions between children with Ds and those with other InD and found that the group with Ds had significantly higher rates of psychosis NOS or depression with psychotic features than the group with other InD. However, the group with Ds experienced lower rates of bipolar and impulse control disorders.

Attention problems are often reported in children with Ds (Patterson, 2002). However, challenges in processing verbal information as well as anxiety disorders, both of which can present inattentive and/or impulsive behaviors, may lead to a misdiagnosis of ADHD in some children with Ds. Additionally, children with Ds engage in compulsive behaviors more frequently and intensely than children without Ds.

Harris (2006) stated that the comorbidity rate for Ds and Autism is very rare, although Leshin (2002) noted that 7-10% of children with Ds may also fit the diagnosis of one of the Autism Spectrum Disorders.

### *Summary*

Children with Ds have specific physical features that make them easily recognized within society. In terms of cognitive functioning, most children with Ds have moderate to mild InD and tend to have much stronger visual processing skills than auditory skills. A significant impairment in expressive language is almost always present and can lead to frustration and sometimes oppositional behaviors. However, the typical child with Ds typically displays an affable and pleasant disposition.

### **History of The Least Restrictive Environment and the Origin of Inclusion as an Educational Practice**

The history of educating students with disabilities in the United States is long and complex. In this section, the legislation involved in mandating education for students with disabilities is outlined, with particular emphasis on the tenet of Least Restrictive Environment (LRE). Next, the concept of Inclusive Education/Inclusion is described, followed by a review of research that examines the contrasting opinions regarding inclusion as the most appropriate method for educating students with disabilities.

Beginning in the 1950s, the federal government responded to the increasing demand for public educational opportunities for such students by developing and validating practices that would evolve into “special education” (A 25 Year History of the IDEA, (2007) <http://www2.ed.gov/policy/speced/leg/idea/history.html>). However, the landmark Public Law 94-142, the Education for All Handicapped Children’s Act of 1975, ensured that “all

children with disabilities have available to them...a free appropriate public education which emphasizes special education and related services designed to meet their unique needs" (*Education for All Handicapped Children's Act of 1975*). This was followed by the Individuals with Disabilities Education Act (1990) and its revisions in 1997 and 2004. Within these legislative acts is the tenet of Least Restrictive Environment (LRE). Specifically, in order to receive funding from the federal government under Part B of IDEA, states must have in place procedures that assure,

"to the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and that special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

(Questions and Answers on Least Restrictive Environment (LRE) Requirements of the IDEA, 1994, <http://www.wrightslaw.com/info/lre.osers.memo.idea.htm>).

Therefore, the regular classroom in the school the student would attend if not disabled is the first placement option considered before a more restrictive placement is considered.

However, a thorough analysis of the individual educational needs of a student with a disability must be conducted to determine the possible range of supplementary aids and services that are needed to satisfactorily implement the student's Individualized Education Plan (IEP) in the general education classroom. Alquraini (2013) noted several considerations that should be undertaken by IEP teams when placing a student with a disability in the LRE. These include not only the financial implication of the student's placement but also whether the education of the

student can be successfully accomplished in a general education classroom with the addition of aids and services; the impact of the student's presence to the degree that the teacher can successfully teach all students and the students without disabilities can successfully learn to their fullest potential; and the non-academic benefits (such as social skills) for education in a general education classroom contrasted with those of a special classroom. After reviewing these points, the IEP may conclude that a more restrictive environment is appropriate for a given student.

While Kurth, Morningstar and Kozleski (2014) found that very few students move from more to less restrictive educational environments, it is reported that the majority of children with disabilities are now being educated in their neighborhood schools in regular classrooms with their non-disabled peers. (A 25 Year History of the IDEA, (2007) <http://www2.ed.gov/policy/speced/leg/idea/history.html>) However, Handler (2007) argued that while federal reports imply that segregated special education classrooms are no longer the dominant form of instructional delivery for students with disabilities in the United States, regular and widespread separation of students with disabilities from general education classrooms remains the typical educational practice.

Smith (2007) agreed and found specifically for the population of students with InD that approximately 90% still spend the majority of their time outside of general education classrooms. However, Williamson, McCleskey, Hoppey, and Rentz (2006) maintained that during the 1990s, the proportion of students classified as mentally retarded (MR, now referred to as Intellectually Disabled, InD) placed in general education classrooms for some or much of the school day increased from 27.3% to 44.7%, while placement in separate settings decreased from 72.7% to 55.3%, and the proportion of students with MR (InD) placed in separate facilities decreased by 46%. The disagreement in these findings is perplexing and serves to underscore the difference of

opinion within the field of education about how best to serve students with disabilities (separated from or included within general education.)

Similarly, the concept of *inclusion* often denotes different and sometimes ambiguous meanings throughout the literature. Because the term is not used in the language of IDEA, the U.S. Department of Education does not provide a definition. Ryndak, Jackson and Billingsley (2010) discovered seven themes researchers use when defining inclusion: placement in natural typical settings; all students together for instruction and learning; supports and modifications within general education to meet appropriate learner outcomes; belongingness, equal membership, acceptance and being valued; collaborative integrated services by education teams; systemic philosophy or belief system; and meshing general and special education into one unified system. Inclusion is viewed as an “educational orientation that embraces and values diversity” and as “a revolution, a social action, and a critical political movement” (Kluth, Straut & Biklen, 2003, p. 3). In 1994, the National Center on Educational Restructuring & Inclusion (NCERI) prepared the National Study of Inclusive Education report that revealed:

Inclusion is more than court decisions, pronouncements, and policy statements. It is more than a matter of physical placement. It is a recognition that the current design of a separate special education system does not provide the desired outcomes (academic, behavioral, social) for students; has failed to assure beneficial post-school outcomes; is not in keeping with the broad societal efforts of integration; and is excessively costly. Inclusion combines placement (LRE) with the appropriateness of the services provided, i.e., the law's requirement for the provision of a "free appropriate public education." Inclusion means: providing to all students, including those with severe disabilities, equitable opportunities to

receive effective educational services, with supplementary aids and support services as needed, in age-appropriate general education classes in their neighborhood schools, toward the outcome of preparing all students for productive lives as full members of the society (p. 14-15).

For the purposes of this study, inclusion will be defined using that of Jones, White, Fauske and Carr (2011): “a system of policy and practices that embraces diversity as a strength, creates a sense of belonging, equal membership, acceptance, being valued, and involves fundamental civil rights. Inclusive teaching and learning occurs in natural settings, with extensive and appropriate instructional supports, modifications, and accommodations, which are meaningful to students and teachers” (p. 13.)

Rogers (2013) stated that those impacted by and involved in the process of inclusive education include not only children with disabilities and their families, but also politicians, policymakers, professionals, and support workers. Still, the disagreement in the field regarding what level of inclusion is best for students with disabilities persists (Alquraini & Gut, 2012.) Some believe in partial or “responsible” inclusion for students with disabilities, while others argue that full inclusion, where students with disabilities are educated with their typically developing peers in the general education classroom, regardless of the degree or intensity of their disability, is best for meeting their needs. Embedded within the latter belief is a reform movement to overhaul traditional educational systems and join the separate systems of regular and special education so schools can more effectively meet the needs of all students (Lupart & Webber, 2012.) Sailor and McCart (2014) contend that a reauthorization of IDEA is needed. They propose that policy should shift focus from placements of students and toward the

structural elements of a system that ensures effective instruction and high-quality interventions for both typical students and those with disabilities.

Those opposed to full inclusion present compelling points of view. Cole (2005) voiced concern about students with disabilities risking bullying and isolation from peers if included within the general education school and classroom, while Gordon (2013) noted that the requirements and demands of lessons within the general education class may cause frustration for students with disabilities and impact their self-esteem. He suggests that “if one adopts the strategy of providing each student with the best available education according to the narrow sense, then one should abstain from inclusive education in order to guarantee that each student is best educated according to his or her particular needs and capabilities” (p. 765). Likewise, Mock and Kauffman (2004) argued it is impossible for teachers to educate typical students effectively while offering the intensive and relentless instructional methods required by students with disabilities. The authors’ resistance to full inclusion is further discussed:

...special education is by nature paradoxical, in that it is a way of achieving equal opportunities through treatment that is different (and therefore unequal). In attempting to provide students the same access and opportunity afforded to everyone, we treat students with disabilities differently and individually. It is impossible to offer such treatment to all students. This reality may prove difficult for some to accept, as they see equal treatment as the key to equal opportunity. Without different treatment, unfairness is assured (Mock & Kauffman, 2004, p. 123).

Finally, some researchers feel conflicted about what constitutes the most appropriate educational environment for students with disabilities. Norwich (2008) expressed that if included in general education, students with disabilities are less likely to have accessible facilities and

receive the necessary services, but if not included in general education, they are more likely to experience feelings of exclusion and not being accepted by peers. Most proponents of either side of the argument have a primary emphasis on the best interests of students with disabilities. As our society continues to advance, however, “the identification of students as ‘disabled’ shifts with the mores and tenors of the times...shifts (that) reflect not only changes in epistemology related to disabling disorders, but also shifts in perception and construction of disability by changing social norms” (Handler, 2007, p. 383). In time, there indeed may be a change in how students with disabilities are defined and classified. For the present, though, the argument resonates with elements of social justice and ethics in defining the most appropriate educational environment for any student with an InD (Rogers, 2013).

In sum, the Least Restrictive Environment mandate contains language that is open to interpretation depending on the resources a state, district and/or school have to offer a specific student with exceptional needs. Because of the ambiguity, there is much confusion about how to implement the provision in order to appropriately serve students with InD. The movement to full inclusion of students with disabilities gained popularity with the passage of IDEA in 1990. Inclusive education has been a slow process and at times even stagnant. The literature clearly articulates the positive benefits of inclusive education for students with disabilities. However, resistance among educators and researchers to include students with more complex and challenging InD in general education remains a huge obstacle for proponents of the movement.

### **Educational Environments for Youth with Down Syndrome**

Children with Ds account for approximately one third of students with InD served in special education (Harris, 2006). There are many types of classroom environments for students with InD, specifically those with Ds that have been studied. As Davis (2008) noted, the “purpose

of psychoeducational assessment for children with Ds is not to provide differential diagnosis for special education placement. Rather, the primary rationale of the assessment process should be to generate intervention strategies based upon the child's unique profile" (p. 273). With this in mind, research has been examined for academic (cognitive) and nonacademic (social-emotional, communication, behavioral and adaptive/self-help) outcomes for students with InD in these different types of settings. In this section, the "continuum of special education programs and services" is defined. Next, research on different types of educational settings for students with Ds is described. The most restrictive environment is described first, followed by successively less restrictive environments. Within each section, academic outcomes for the particular environment are described, followed by nonacademic outcomes.

The concept of a continuum of special education programs and services was established to define the educational environments that constitute more- to least-restrictive (Sailor & McCart, 2014). These range from segregated special education schools to placement in grade-level general education classrooms. Norwich (2008) lists the continuum in this order from most to least restrictive: full time residential special school; full time day special school; part time special – part time regular school; full time special unit or class in regular school; part time special unit/class – part time regular class; full time regular class with some withdrawal and some in-class support; full time in regular class with in-class support; and full time in regular class. In our present educational system, the primary methods for teaching students with disabilities can be condensed into the following categories: segregated (separate school), integrative (divided time between the general education classroom and special education classroom) and inclusive (full inclusion within the general education classroom) (Gordon, 2013).

For the purposes of this study, these three categories will be what is described as the educational environments available for students with InD and specifically, Ds.

### *Segregated Environments: Academic and Non-Academic Outcomes*

The model of segregated education typically provides for a wide range of special education schools, some of which offer programs for students from pre-Kindergarten through post-graduation and some which are designed for specific age ranges. Usually, the schools are focused on the needs of the students in question, accounting for the degree of severity of the physical, intellectual, and/or emotional/behavioral disability, within a homogenous learning environment. (Gordon, 2013). The use of the segregated classroom/school has remained the core of special education since its origin (Handler, 2007). Cole (2005) maintains that special education schools are an integral part of the education system; however, with increasingly strong community support for inclusive education, such schools should ensure they are providing a welcoming atmosphere that promotes dignity, responsibility, and friendship.

The literature is sparse regarding academic outcomes for special education schools, but most findings indicate smaller gains for students in segregated education as opposed to integrative or inclusive education (de Graaf, van Hove, & Haveman, 2013; Peetsma, Vergeer, Roeleveld, & Karsten, 2001; Tiegland, 2009; Turner, Alborz, & Gayle, 2008). However, for nonacademic outcomes, the research is mixed. Peetsma, Vergeer, Roeleveld and Karsten (2001) found that psychosocial development (specifically school motivation) seems to develop more positively in special education than in regular education. However, Heiman (2000) noted that students with InD in special education schools tended to have fewer friends than students with InD enrolled in general education schools. This study involved 575 Israeli students aged 12 to 15 from central Israel who were classified into three groups: 121 students with mild InD enrolled

in segregated schools, 189 students with mild InD enrolled in self-contained classes in general education schools (semi-integrative setting), and 265 students without disabilities in general education schools. The students with InD were individually interviewed by the author using the Friendship Quality Questionnaire, while those without InD completed the questionnaire independently. Additional findings from this study showed that students in special education schools indicated more passivity and expressed greater feelings of loneliness than students in integrative or inclusive educational environments.

#### *Integrative Environments: Academic and Non-Academic Outcomes*

Integrative education encompasses models of partial-inclusion, which may consist of some academic instruction in the general education classroom along with pull-out resource support as well as self-contained special education classes within a general education school. *Mainstreaming* is another interchangeable term for integrative education. Originally known as the Regular Education Initiative (initiated by Madeleine Will in the mid-1980s), the concept behind mainstreaming was that students would spend part of the day visiting the general education classroom and attending extra-curricular non-academic activities, such as lunch, recess, physical education, music, and art (Alquraini & Gut, 2012). This merger of special education and general education tends to successfully promote inclusive (integrative) education at the primary level (Gibb, Tunbridge, Chua, & Frederickson, 2005.) The major benefits of integrative education are that it allows students with disabilities to receive special education academic instruction and services in a self-contained classroom while participating with their typically developing peers in non-academic activities, allowing students with and without disabilities to learn from each other (Alquraini & Gut, 2012).

In analyzing the types of instructional models utilized in integrative education, Idol (2006) found that in addition to resource programs, cooperative teaching (team teaching with a special educator) was a viable option. Others include consulting teaching (using a special educator as consultant) and using instructional aides to form teacher assistance teams. In her research on integrating students with Ds in general education classes, Wolpert (2001) noted that team teaching between a general education teacher and a special education teacher occurred 25% of the time, while 51% used the consultative model. Peer tutors were also used almost 50% of the time to support the students with Ds. Fifty two percent received pull-out services, such as instruction and therapies in a resource room, compared to 48% whose services were provided as “push-in”, where the services and support were provided within the classroom. The general education teachers reported pull-out and push-in services as having an equal impact on the instructional process.

Reports of both academic and nonacademic outcomes for students in the integrative model are limited in the literature. Students with disabilities in general education classes have the opportunity for verbal and nonverbal interaction with the instructional aide and as well as any of 15 to 35 class peers. By contrast, special education classes for students with disabilities have a much smaller size: typically there is a teacher and an aide for six students. However, the teacher and aide will likely be frequently occupied in assisting the other students with disabilities with tasks, and as the other students in the class are themselves possibly unlikely to initiate communicative interactions, this classroom environment offers limited opportunities for spontaneous communication (Foreman, Arthur-Kelly, & Pascoe, 2004, p. 191).

### *Inclusive Environments: Academic and Non-Academic Outcomes*

Increasingly, many families of children with disabilities are demanding placement for their children in general education classrooms with the necessary supplementary aids and support services. Especially insistent are families of young children, having benefitted from inclusive preschool programs and wanting the same option for their children in public schools (NCERI, 1994). Interestingly, Doyle and Giangreco (2013) found that inclusive opportunities for high school students with InD in particular are scarce. It may be that although inclusion in general education is initially successful for students with InD, as the trajectories for cognitive growth between typical students and those with InD begin to diverge, the situation becomes less ideal. Still, as Jones, Thorn, Chow, Thompson, and Wilde (2002) stated, “inclusion of all special needs students into the regular classroom setting is rapidly becoming the dominant educational ideology” (p. 625). There is considerable support among professionals for the practice of inclusive education (Doyle & Giangreco, 2013; Idol, 2006; Turner, Alborz, & Gayle, 2008; Villa & Thousand, 2002).

In terms of *academic outcomes*, higher reading, writing, and numeracy skills was noted by Turner, Alborz, and Gayle (2008) for students with Ds who attended general education schools. Using the Academic Attainments Index (AAI), an instrument developed specifically for this study, the researchers analyzed data that had been collected from seventy-one young people with Ds who were of approximately the same age and living in the Greater Manchester Area of the United Kingdom. The AAI was administered to the families and/or teachers of the youth when they were of the mean age of 9 years, 14 years, and 21 years. Of the seventy-one youth, 13% attended mainstream (general education) schools throughout the time span of the study, while 24% attended a mainstream school at one or more times during the data collection period.

Although the severity of the InD that an individual student possessed tended to have the greatest impact on academic progress, those who attended a general education school as opposed to a segregated school had higher AAI scores. Similar results were found in a study conducted by de Graaf, van Hove, and Haveman (2013) in the Netherlands. Approximately 140 parents of children with Ds in primary education participated in the research by responding to questions including their child's school history, academic and nonacademic skills. Students with Ds were found to make more academic gains, particularly with reading skills, in an inclusive classroom. However, the authors cited other factors which may have also contributed to the difference in comparison to students with Ds in a segregated school, such as cognitive functioning level of the student and the extent to which parents provided supplemental support on academics. Buckley, Bird, Sacks, and Archer (2006) surveyed the parents of forty-six youth with Ds between the ages of 11 and 20 in the United Kingdom using a questionnaire designed by the authors, the Sacks & Buckley Questionnaire (SBQ), as well as the Vineland Adaptive Behavior Scale (VABS) and the Conners Rating Scale (CRS). 61% of the sample were enrolled in segregated schools for moderate or severe learning difficulties, while 39% attended inclusive schools. Results indicated that teenagers in mainstream (inclusive) school settings gained the equivalent of 5-6 years progress in spoken language and literacy when compared to the teenagers educated in special (segregated) classrooms.

While the literature was sparse regarding the non-academic outcomes of students specifically with Ds who receive their education in an inclusive environment, several studies evaluated the non-academic outcomes for students with general disabilities who attend inclusive schools. Cooney, Jahoda, Gumley, and Knott (2006) interviewed a sample of sixty Scottish students aged 15-17 who had been identified as having mild to moderate InD and attended either

a mainstream (inclusive general education) school or a segregated school. Students with autism spectrum disorder, serious physical or sensory impairments and/or specific language difficulties were excluded from the sample. Measures included the British Picture Vocabulary Scale – Revised (BPVS-R), Adapted Social Comparison Scale, Modified Life in School Checklist – Junior School Version, the Experience of Stigma Checklist and the Future Aspirations Checklist. The authors found that students from inclusive school settings had rated themselves higher for being treated in a stigmatized fashion at school, primarily by their nondisabled peers, than students who attended segregated schools. The work of Buckley, Bird, Sacks, and Archer (2006), described earlier, found that while teenage students in mainstream (inclusive) school settings showed more social maturity, including more age-appropriate social behavior and more social confidence, a disadvantage was suggested in terms of friendships. These students were less likely to have special friends, boyfriends, or girlfriends and an independent social life, perhaps because of having less contact with peers with similar InD and/or Ds in school. As Peetma, Vergeer, Roeleveld, and Karsten (2001) expressed, “special care for (students with disabilities)’ psychosocial development seems to be required after inclusion” (p. 133).

Conversely, the research of Fisher and Mayer (2002) found that inclusive education promotes strong development of the domains of social competence in students with disabilities. A sample of twenty American students with moderate to profound InD who were enrolled in general education (inclusive) education classrooms was matched with twenty American students enrolled in self-contained (segregated) classrooms by chronological age and initial scores on the Scales of Independent Behavior (SIB). After two years in their placements, the students were assessed again on the SIB and the Assessment of Social Competence (ASC). Results for the students in the inclusive setting were higher than those in the segregated group. Furthermore, the inclusive group

made greater gains on psychometrically valid measures in comparison to their matched peers in the segregated group. After interviewing eleven developmentally disabled students ages 9-12, seven of whom were enrolled in inclusive schools and four who were educated in a segregated classroom, Fitch (2003) discovered those in inclusive classrooms constructed a sense of themselves that was significantly more positive from those in segregated classrooms. In a literature review conducted by Alquraini and Gut (2012), the authors noted that students with disabilities improve their communication skills more in inclusive education classrooms when compared with students with the same disabilities in segregated classrooms. Finally, in regard to physical activity, Pan, Liu, Chung and Hsu (2015) studied forty Taiwanese adolescents with InD. Half of the sample were educated in segregated classrooms, and attended adapted physical education classes, while and the other twenty were placed in inclusive classrooms and attended general physical education classes. The participants wore an accelerometer during the school day (approximately 8 hours) for five days and their physical activity was assessed. Those students enrolled in segregated classrooms were less physically active than those in inclusive classrooms during inclusive recess time. However, the authors noted that this result could be due to the fact that the physical and social abilities of those in segregated classrooms may have been more limited.

Within an inclusive classroom, students with Ds respond to particular forms of instruction more than others. Wolpert (2001) surveyed 189 teachers ranging from Kindergarten through 12<sup>th</sup> grade who had included students with Ds in their general education classrooms. In the survey, the teachers were asked to rate the effectiveness of instructional materials and methods they used in their classrooms for students with Ds. Results showed teachers ranked "hands-on" or "real" materials as most effective for successful instruction of students with Ds; computer, paper-and pencil tasks, and textbooks as occasionally effective; and workbooks as

least effective. The most successful instructional methods reported were one-on-one and small-group instruction, followed by peer tutoring, computer instruction, and team teaching. Large group and whole-class lessons were described as ineffective for instructing students with Ds, while praise and small rewards had the largest positive impact on motivating students with Ds.

In conclusion, the literature revealed mostly encouraging results on the academic outcomes for students with Ds in inclusive classrooms as opposed to integrated or segregated classrooms, about which very few studies were found. It is unclear, however, whether the higher academic outcomes of students in inclusive classrooms are due to possibly higher cognitive capabilities of the students enrolled in these settings as well as more mature social and/or behavioral dispositions. The results for nonacademic outcomes were mixed when comparing inclusive, integrative, and segregated classrooms. Students with Ds made social gains in terms of maturity and expressive language, but it was questioned whether true and lasting friendships were formed by these students and their typically developing peers within inclusive learning environments.

### **Parental Attitudes Toward Inclusion for Youth with Down Syndrome**

Parents of children with disabilities have many beliefs regarding the most appropriate educational environment for their children. The literature contains several studies that detail parental attitudes and perspectives about segregated, integrated, and inclusive educational environments for students with disabilities, in particular, Ds. The hopes and fears these parents possess for the academic and non-academic outcomes of their children's education is described and discussed in this section.

Parents of children with disabilities generally express positive perspectives toward inclusive educational placements (Bennett & Gallagher, 2013; Downing & Peckham-Hardin,

2007; Garrick Duhaney & Salend, 2000; Jones, Thorn, Chow, Thompson, & Wilde, 2002; Leyser & Kirk, 2004; Kasari, Freeman, Bauminger, & Alkin, 1999). In an examination of seventeen research studies published since 1985 regarding parental perspectives of and experiences with inclusive education programs, Garrick Duhaney and Salend (2000) noted a majority of parents of children with disabilities support inclusion, believe that it promotes the acceptance of their children by peers who are not disabled, and believe that it helps their children develop socially, emotionally and academically. Moreover, the literature review revealed parents of children with disabilities perceive inclusive placements to be superior in enhancing their children's self-image; afford their children greater access to appropriate role models and friendships; make their children happier, more confident and more extroverted; and prepare their children for the real world (Garrick Duhaney & Salend, 2000).

Specifically regarding children with Ds, Lightfoot and Bond (2013) conducted a case study to examine the factors influencing the transition from primary to secondary school for two British students with Ds. Their research included semi-structured interviews with the mothers of each student. While this sample size is quite small, both mothers' responses suggested that the inclusion of their children with Ds in primary school had been successful, and "conveyed a shared ideology in terms of inclusion and believed in it as a concept" (Lightfoot & Bond, 2013, p. 172).

Lalvani (2013) interviewed nineteen mothers of children with Ds who ranged in age from six months to six years. Thirteen of the children were being formally educated in preschool or elementary school, with four in inclusive classrooms and nine in segregated classrooms or schools. Responses from the mothers indicated their overwhelming belief in inclusion and negative feelings regarding segregated education:

I think in a self-contained classroom with other kids, it's sort of like – the land of misfit toys. Where everybody is in it together. If you look at all the disabled kids together, it's sort of like, the land of misfit toys . . . It doesn't rise to the top as much. It doesn't become noticeable and you could write it off as a quirk. (p. 440).

On the contrary, research indicates that parents also possess concerns about inclusive placements for their children with disabilities. These include the lack of highly trained teachers and staff as well as diminished individualized services. Cole (2005) interviewed six special education teachers who were also mothers of children with disabilities whose ages ranged from three to nineteen, therefore presenting unique dual perspectives on inclusion. One of the main themes that emerged in the study was that children should be treated with dignity and care. However, as teachers, these mothers were keenly aware of the reality involved with including children with disabilities in general education and providing the level of care necessary in such a setting. The author, a special education teacher and mother of a child with disabilities herself, notes...

...it would seem reasonable to say that 'inclusion' in its present form is very much about 'risk'. The question surely is about who should be taking these risks and for what gain? There can be little doubt that in the system as it is at the moment, the ultimate risks lie with those who are already the most vulnerable, the children themselves, and often for very little gain. (p. 342)

Other concerns expressed by parents were mistreatment and/or isolation by their children's nondisabled peers as well as frustrations with school administration and personnel to convey support for inclusive education. (Cole, 2005; Garrick Duhaney & Salend, 2000; Lalvani, 2013; Leyser & Kirk, 2004.) Lalvani (2013) discovered that some mothers who were

considering an inclusive educational environment for their children with Ds were dissuaded by the team of professionals that made the placement. In these instances, the mothers remembered “they had ‘bought’ the idea because it was presented to them in an appealing manner, and that they had become ‘convinced’ that segregated classrooms were indeed the ‘best’ for their children” (p. 441-442). Many parents expressed the issue of membership extends beyond the classroom and school for their child.

It would be a very hard thing for me to do, to let him go into an inclusive setting. I don't want him to be laughed at. Or made fun of because he's different. My biggest concern about an inclusive setting down the road, as he gets older, is that I want him to have friends. . . . That is what really scares me about an inclusive setting. In the middle school years, in the high school years, socialization is a huge component of the child's school day. And I don't think he would be invited to all the teenage parties . . . I want him to feel accepted and part of the group. And it's a nice thought that it could happen, but in all honesty, I don't see it happening (Lalvani, 2013, p. 443).

While enthusiastic about the inclusive experience their children had enjoyed during primary school, the mothers in Lightfoot and Bond's (2013) were not as optimistic about inclusion as they transitioned to secondary school:

... and as the children grow up the gap's widening – and while she's wanting to play in the corner with a ball, or sing nursery rhymes, the other children are on their cell phones chatting about the boys that they met last night ...(p. 171).

A study by Hanson, et al. (2001) had similar findings in regard to shrinking options for students who were enrolled in inclusive settings in preschool years. The researchers followed a

sample of twenty five children with disabilities and their families (a subsample from a large national investigation of early childhood inclusion) over a five-year time period. The parents of the children were interviewed starting at the time when their children were in preschool and preparing to transition into formal Kindergarten. Interview questions included the services in place for their children; the process involved for choosing the desired educational environment for their children; the hopes and expectations for their children and for the future educational environment; and their satisfaction with their ability to be heard when voicing their preferences for the setting in which their child would be educated.

One hundred sixty seven interviews (approximately one per family per year) were conducted by the research team. In addition, the researchers were present for approximately 20 IEP meetings of students in the sample and had the opportunity to observe twelve of the sample students in their classroom environments during the course of the study. During preschool, all of the 25 children in the sample were enrolled in either full or partially inclusive educational environments. At the conclusion of second grade, only 15 remained in this setting. The other 10 students were moved into segregated classrooms and/or schools.

The parents in Hanson, et al.'s (2001) study were all in favor of an inclusive educational environment for their children based on the positive experience they had in preschool. However, barriers became evident in inclusive settings as the children moved into formal elementary grades. These barriers included the size of general education classes; availability of specialized therapies and services; their children's social acceptance by their peers; perspectives of teachers' attitudes toward their children's disability; and concerns over the extent teachers had been trained in serving students with exceptional needs.

Reverend D. C. Bakely (2002), whose daughter, Beth, has Ds, expressed much fear and confusion regarding her continued recommended placement in a general education classroom during her elementary school years:

What if some specific things were really beyond her grasp? What if her condition really does make it harder for her to grasp certain things? What if Down syndrome puts some things out of her reach? Is it specific and genetic – like math? Or is it general and generic? Does she see everything through a fog? Is she a ‘normal’ child with a slight hesitation in her comprehension, or is she abnormal enough that soon ‘normal’ classes could no longer work for her? Where do we push her – and where do we let her function at her own speed? Our problem was that we are just normal parents, and there were so many unanswered questions for us. If the experts didn’t know, how were we supposed to know? (p. 69.)

Preference for self-contained education was articulated by some parents, for reasons including the concept of belonging and group membership as well as safety and protection from feelings of rejection. Furthermore, they believed inclusive settings would be lacking in resources in professional expertise (Lalvani, 2013). In particular, they embraced “the idea that in self-contained classrooms, their children with Down syndrome would be educated by teachers who are not only trained ‘especially for special needs,’ but who also possess the dispositions deemed necessary for doing so...(they perceived) special education teachers as people who have qualities such as patience, understanding, and empathy in excess of general education teachers. General education teachers were perceived as lacking not only the training but also the willingness to teach children with disabilities” (p. 440-441.)

Leyser and Kirk (2004) surveyed 437 parents of students with disabilities residing in a midwestern state using a questionnaire entitled “Parent Opinion About Inclusion and Mainstreaming”, which solicited background information to include the type of disability of their child, severity level, level of schooling of mother and father, occupations, age of child with the disability, extent of inclusion/mainstreaming, and years child has been receiving special education. Additionally, the questionnaire incorporated a rating scale regarding attitudes toward inclusion as well as a section for respondents to express their level of satisfaction with their child’s placement. Results indicated that parents possessed both positive and negative opinions regarding inclusive education, but the most interesting findings regarded the parent respondents themselves, 343 of whom were mothers. Parents of children who were not in an inclusive setting expressed more support of inclusion than those of students who were enrolled in inclusive classrooms. Furthermore, parents who had higher levels of education stated stronger positive opinions in the benefits of inclusion, leading the authors to hypothesize that those parents were more likely to be exposed to information and have more awareness of the issues regarding inclusion.

In a similar study, but more specific to Ds, Kasari, Freeman, Bauminger, and Alkin (1999) examined parental perspectives of children with autism and children with Ds, two groups whose social skills are typically significantly different. The participant sample, comprised of 113 parents of children with autism and 149 parents of children with Ds, were presented surveys requesting background information on themselves and their children, a ratings scale for their child’s current educational placement, and a multiple choice section regarding the ideal educational setting they envisioned for their child. Results were analyzed both quantitatively and

qualitatively. Most notable in the findings was the fact that parents of the youngest children were the most supportive of inclusion. As Hanson, et al. (2001) notes,

Success with inclusion within this age period is eased by the social aspects of the early childhood curriculum (e.g., focus on play, making friends, and cooperation) and the similar developmental needs for both children with and without disabilities. By contrast, at the elementary level, the discrepancy in children's ability levels and school demands may become more marked (p. 79)

To summarize, the literature contained several key studies regarding parental attitudes about inclusive educational environments for children with Ds. Some parents admitted concerns about inclusion for their children with Ds, including exclusion by peers and less attention and support from teachers and staff. However, the majority of parents expressed supportive attitudes about inclusion and indicated that they believed an inclusive educational environment would provide greater academic and nonacademic benefits for their children with Ds. Research also revealed that certain variables, including age of the children and educational background of parents, may have been an influence on parents' opinions regarding inclusive education. In particular, inclusion appeared to be a far more permissive and viable option for children during their earliest formal educational experiences as opposed to intermediate or secondary school.

### **Summary of Research**

Ds is a genetic condition caused by an extra 21<sup>st</sup> chromosome which forms for unknown reasons in developing fetuses. Although all people with Ds are unique individuals, there are some common identifying physical features. Most have moderate to mild InD and expressive language impairments, which can cause frustration and some external behaviors. However, most people with Ds are friendly and engaging and capable of being productive members of society.

The Least Restrictive Environment mandate within the legislation for the education of students with disabilities (P.L. 94-142, IDEA and its revisions) requires that such students receive a public education in a setting that poses the greatest opportunity for access to the general education curriculum. Interpretation of what constitutes the least restrictive educational environment for an individual student may vary considerably between families, school staff, and districts and cause considerable debate. The movement for full inclusion of students with disabilities stipulates that the least restrictive environment be considered the general education classroom of a student's district school, with supplementary supports and aids as needed.

While the argument regarding the most appropriate educational environment for students with disabilities continues, settings that exist today to serve students with InD and specifically, Ds, include segregated (special schools), integrative (special classrooms within a general education school) and inclusive (fully included within a general education classroom in a general education school). While research is limited regarding academic and nonacademic outcomes for segregated and integrative settings, the literature indicates that inclusive settings seem to offer much greater opportunities in terms of academic gains but mixed results in terms of non-academic gains.

Parents of children with Ds seem to favor inclusive settings as opposed to integrative or segregated as the most appropriate educational environments. However, the literature did show that some parents have adopted cautious stances in regard to inclusion and are uncertain about what the best environment for their child is. Several studies indicated that parents of younger children maintained stronger beliefs that inclusive classrooms are the most appropriate educational setting, but that those opinions changed as their children grew older.

In my study, the perspectives mothers of children with Ds of varying ages hold regarding the most appropriate educational environment for their child were examined. Through a qualitative methodology, the perspectives were compared and contrasted, and variables that influenced the opinions the mothers possessed were studied. Non-academic outcomes for students with Ds in the three described educational environments (inclusive, integrated, and segregated) is an area that needs more research. Furthermore, the current literature is limited regarding how perspectives of mothers of children with Ds may change over time regarding the most appropriate educational environments. My study explored these issues as well as common highs and lows mothers of children with Ds experience on the educational journeys of their children.

## CHAPTER THREE

### RESEARCH METHODS

#### **Purpose**

My study focused on the perspectives mothers of children with Ds hold regarding the settings in which they have been educated. The children of the participants varied in age, from pre-school years through secondary. The study provided insight into (a) the factors mothers of children with Ds consider regarding the most appropriate educational setting for their child; (b) the barriers mothers encounter to placing their child with Ds in a desired educational setting; and (c) how and why mothers change their views of what constitutes the best educational placement for their child. My ultimate goal was to better understand the academic and non-academic factors mothers of children with Ds consider when deciding upon a school placement for their children.

According to Chase (2005), when a group of people is able to tell their story, it may have sociological ramifications as well as interest people culturally by accessing “issues that most members of our society would find familiar and (in some sense) important” (p. 82). The vision I held for this study was to awaken educational stakeholders to the stories of the mothers of children with Ds, with possibly new educational environments and methods of instruction created as a result. On a smaller scale, conversations occurred that highlight the need to examine and improve our present educational services for students with Ds. To achieve this goal, I collected interview data from mothers of children with Ds regarding the educational journeys of their children. The following research questions guided my study:

1. How do mothers of children with Ds describe their children's educational journeys?
2. What do mothers of children with Ds perceive as the ideal educational environment for their children?
3. How do mothers of children with Ds determine what educational environment is most appropriate for their children?
4. How do the age of the child with Ds and his/her previous educational experiences impact mothers' perspectives of what constitutes an ideal educational environment?
5. What barriers and facilitators do mothers of children with Ds describe in terms of accessing what they believe to be an ideal educational environment for their child?

### **Conceptual Frameworks**

I used two conceptual frameworks to guide the data collection, analysis, and interpretation of my study. The first of these frameworks was Algood, Harris, and Hong's (2013) theory of success for parents of children with disabilities. Using Bronfenbrenner's ecological model, the authors contend that parenting success is complex and dependent upon a variety of factors for parents who have children with disabilities. The supports in place at the micro-, meso- and macro-levels for each individual family must be considered. My study explored how a mother's perception of the best educational environment for their child with Ds may be predicted by influences in her micro-, meso- and macro-systems. In the micro-system, her own experiences and personal feelings may persuade her to choose one setting over another. The meso-system, including her spouse/partner, other children, parents, siblings, and close friends may also lead the mother toward a particular choice of educational environment, as might the macro-system, which would be the community and culture in which she lives.

The second framework guiding my study was the theory of Lloyd and Hastings (2008),

who found that mothers of children with InD who have higher levels of acceptance of their child's disability are better able to adjust to the parenting demands presented by a child with an InD. The authors' research indicates the more a mother accepts her child's InD, the less likely she is to experience anxiety, depression and stress. Conversely, mothers who display active avoidance coping behavior when facing their child's InD are more prone to psychological adjustment problems. The stories shared by the participants in my study revealed how a mother's perception of the best educational environment for her child with Ds tended to transform as her child aged. Her willingness or refusal to accept the educational environments available to her child and ability to adapt to educational needs of her child over time may be related to her perspectives and experiences. Although no judgments were made about each mother's own adaptation to having a child with Ds, using this theory to interpret my findings drew my attention to potential issues of struggle, resistance, disappointment, problem-solving, and resolution, which varied between mothers.

These conceptual frameworks informed my analysis of commonalities in mothers' perspectives of the most appropriate educational environments for their children with Ds, how those perspectives may be affected by a variety of sources, and how they may change over time during the course of their child's educational journey.

### **Research Design**

This was a qualitative, interview-based, interpretive inquiry of mothers who have children with Ds. I selected this research design because it provided an opportunity to develop an in-depth understanding of the experiences of mothers of children with Ds. Through the stories they shared, my goal was to discover the mothers' beliefs, perspectives, opinions, and attitudes

regarding the education of their children. The transcribed interviews were not changed in any way in order to enhance data.

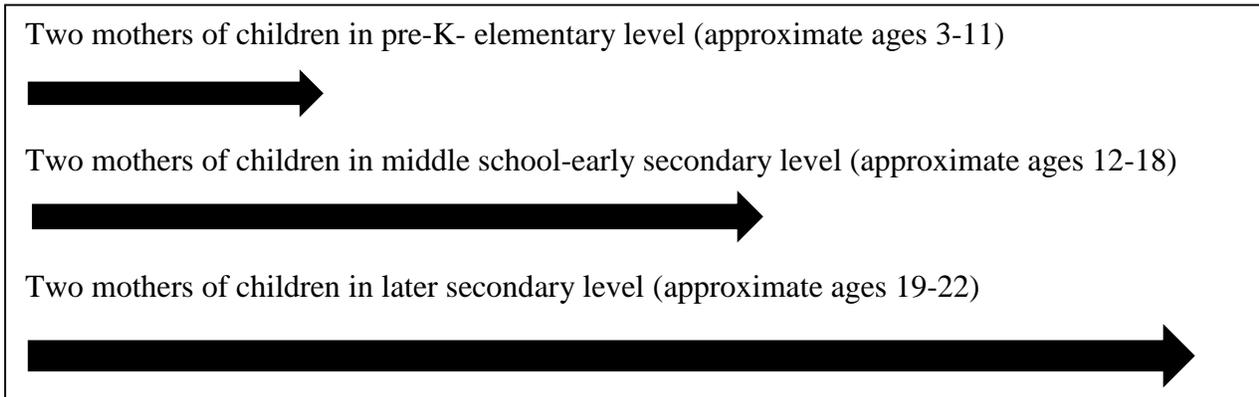
## **Participants**

I chose mothers as the participants in my study because my observations have led me to believe they are generally the primary decision-makers in regard to their children's education. Valle (2011) states that mothers "engage more frequently with school personnel than either father or sets of parents" (p. 184) and contends that "if we ask mothers to tell their stories, we learn about the consequences of our (educators) practices within their lives. They have much to teach us about the impact of disability on their identities as mothers and about the profound experience of parenting a child with a learning disability. And it is within those archetypal narratives of "the reluctant hero" that we find points of resistance that tell us what is not working within our system of practice" (p. 188.) For the purpose of this study, the term mother was defined as the birth or adoptive mother of a child with Ds. Each mother lived with the child full time and had custodial rights to the child's educational planning. In order for me to conduct the interviews in person, the mothers in my study were required to have lived in the Tampa Bay.

To participate, mothers must have had at least one child with Ds who was enrolled in a private or public school in the Tampa Bay area, and was therefore between the ages of 3 and 22 years of age. This age range was selected because IDEA allows for children with disabilities to receive a full-time, public education from their local education agency (LEA) from the time they are three until the time they turn 22. This age range was appropriate because mothers had at least considered the educational placement process for their child, initiated it, or had participated in it fully.

**Participant recruitment.** I purposefully selected the sample for my study through a non-random sampling technique. Because this study targeted a specific population and required a particular age range, random sampling was not a viable option. Instead, women who are mothers of children with Ds were recruited through contacts at a local charter school for students with InD; personal and professional contacts in the Diocese of St. Petersburg, Hillsborough and Pasco County School Systems; and a website for a community group for parents of children with Ds. Mothers of children with Ds from the charter school, public or Diocesan school systems, or community group were notified about the study by one of the contacts listed above through a descriptive letter, shown in Appendix A, explaining the purpose of my study. Mothers who were interested in participating were directed to contact me via email or telephone. When they contacted me, I included the following points in our conversation: (a) expressed my gratitude to them for contacting me; (b) ensured they understood the purpose of my study; (c) explained how many mothers I intended to interview; (d) ensured they understood their role as a participant and how long their participation would take; and (e) if they were still interested in participating, arranged a time and location for the interview.

From the group who contacted me, I selected six whose children met the specified age ranges. Two were mothers of children with Ds at approximate ages of 3-11 (pre-Kindergarten-elementary level); two were mothers of children with Ds at approximate ages of 12-18 (middle school level-high school/early secondary level); and two were mothers of children with Ds who are 19-22 (later secondary level). The purpose of this specificity was to allow for comparing and contrasting perspectives of participants across children's age groups. See Figure 1 for the model that displays this concept.



*Figure 1. Continuum of Participants' Children's Ages*

### **Instrumentation**

My research was guided by the invitation to each mother to share the story of her child's educational journey. Chase (2005) advises qualitative researchers to construct detailed interview guides when preparing to meet with participants. These guides serve to help the interviewer be ready to receive a variety of responses. However, the guide should be available for consulting but not strictly followed after posing the opening question, which should invite the life story the interviewer seeks to hear. Rather, questions evolve from listening closely to the stories of participants. Furthermore, Chase recommends the use of narrative principles to devise interview questions that focus on eliciting specific, concrete life stories. Hypothetical questions are avoided because they move narrator away from their actual experience. "Listening well to the person's particular story should be the main goal...many interview questions will be answered without even being asked" (Chase, 2005, p. 84).

I developed an interview guide, shown in Appendix B, to address the primary research questions and focus the participants toward specific aspects of their perspectives. The interviews were semi-structured and occurred at a location each participant chose. I asked the mothers to

bring pictures, artwork created by their child, psychological reports or evaluations, report cards, journals, and other visual/written aids that helped them recall their child's life to aid them in their story telling. Prior to starting the interview, which took between one to two hours, I obtained informed consent.

### **Data Collection**

At the conclusion of the interview, I collected demographic information from each participant using a document that I provided to them (Appendix C). The next day, I sent an email to the participant thanking them for their participation. .

I transcribed the interview within two weeks. After this, I sent a follow-up email to the participant with the transcribed interview attached. I requested that the participant reviewed the transcript and verify it reflected what she intended to communicate. Next, I asked her to inform me via telephone or email if she wished to add to her story or change any parts of it. I incorporated any additional information the participant provided with the interview data in my analysis.

After every participant was interviewed and confirmed their story, I invited all the participants, my major professor, and members of my major professor's research group to a focus group, which was held at my house. Due to schedules of the participants, the focus group occurred three months following the last interview. I emailed each participant with a request to send a picture of her child and answers to the following questions: (a) Where does your child attend school now? (b) What schools has your child attended in the past? and (c) Describe your child's personal strengths, interests and hobbies. From this data, I prepared a slide show with an individual slide of each child that I played at the focus group as I introduced the participants to one another.

The focus group session was audio recorded and transcribed. Three questions were asked of the participants in attendance: (a) As you have sought the most appropriate educational environment for your child, what have you learned along the way?; (b) What do you see as strengths and weaknesses of the educational systems for youth with Ds in this area?; (c) How has participating in this study impacted you? Responses to these questions were included in my analysis.

### **Data Analysis**

I conducted an initial auditory review of the data following the interview to ensure that the interview adequately addressed the research questions. If I believed that all questions were not addressed, I intended to revisit those areas in the follow up phone call to the participants, but this was not found within any of the interviews.

I transcribed and analyzed each interview and focus group response to construct a codebook of themes, which Lichtman (2013) defines as “central issues or concepts that a researcher identifies based on coding the original data”. I worked with my major professor to develop and clarify definitions of the thematic codes. The codebook includes definitions of each code, examples of statements from the narratives, and guidelines for when codes should be used.

In order to ensure the credibility of the data, member-checking, peer examination, and reflections will be utilized. Member-checking took place when the participants reviewed the transcript of their interview, which allowed them the opportunity to review the interview data, clarify points, and make additions. A peer colleague examined each transcription in order to verify the presence of themes within the data as well as identify problems that I did not recognize. Reflecting on the data collection process allowed me to analyze my relationships with the topic, the research questions, and the participants.

## **Ethical Considerations**

To protect the identity of study participants, pseudonyms were used; all real names of both mothers and children were replaced in each interview and in this final document. In order to participate in the study, participants were asked to sign a consent form which explained the reasoning, rationale, risks, and benefits of the study. With the participant's permission, each interview was recorded and transcribed. Recordings will be destroyed in compliance with IRB specifications to eliminate the possibility of voice recognition of subjects. Transcripts with pseudonyms will be retained to comply with IRB records requirements.

## CHAPTER FOUR

### RESULTS

This chapter will describe the results of my data analysis, where I will present the themes that emerged across the participants in my study. First, however, I will describe each of the participants and their children, including the types of setting each child has attended and the participant's overall perspective about her child's educational journey. Each participant and her child referred to by pseudonyms. All participants in my sample are married and all self-identified as Caucasian, with the exception of Dana, who reported her ethnicity as Asian. The median household incomes of the participants is \$80,000. Two of the participants possess high school diplomas, while the other four additionally hold college degrees at the Bachelor's level. The order in which I describe the participants is chronological based on the age of the child. Table 1 presents the demographics in terms of pseudonym of the participant; pseudonym, age, and gender of the child; and current educational environment for the child.

#### Participants

**Allison** is forty years old and works full time as an Area Business Manager for a Pharmaceutical Company. Andrew, who is 5, is Allison and her husband's oldest child; they also have a four year old daughter, who does not have a disability. For the first two years of his formal education, Andrew was enrolled in a Varying Exceptionalities Pre-Kindergarten classroom at the elementary school for which his family is zoned. When the district would not permit Andrew to attend an additional year in the class, Allison and her husband chose to move him to a private pre-

school for Voluntary Pre-Kindergarten (VPK). They are now exploring options for Andrew as he completes pre-kindergarten. While Allison expressed disappointment over the fact that Andrew could not remain for an additional year in the setting in which she believed had been so positive for him, she is optimistic regarding his educational journey and feels encouraged by the progress he has made. Allison believes Andrew has the potential to eventually attend college and keeps her expectations for him equal to what she has for her daughter.

**Anna**, 45, does not work outside the home. Currently, she is homeschooling her 9-year-old son, Adam, who began his formal education in an Early Exceptional Learning Program (EELP) class at the closest district elementary school that offered the program. After attending this school for two and a half years, he transitioned into a general education Kindergarten class at the elementary school where his only sibling, his sister who is now 12, attended a full-time gifted program. Adam also attended this school in a general education first grade class. He started in a second grade general education class, but Anna and her husband elected to withdraw him approximately six weeks into the semester and begin homeschooling. Anna's perspectives about Adam's journey thus far are that he achieved academic and social success in preschool and the first two years of elementary school, but was stymied by both the restrictiveness of Core Curriculum assessments as well as a district administrator who warned Anna that the inclusive setting was not going to continue. She believes, however, that her decision to homeschool Adam has been one of the best she has ever made and intends to continue with this arrangement

Forty-one year old **Carrie** works as a part-time pharmacist. Cameron is Carrie and her husband's oldest child; they also have two other sons and a daughter. Like Adam, Cameron's formal education started with EELP at the closest district elementary school that offered the program. He attended EELP for two years and Carrie intended him to transition to a Kindergarten

Exceptional Learning Program (KELP), but the plans for the program were dissolved by the district. Therefore, Carrie enrolled Cameron at a new charter school for students with exceptional needs. Cameron attended this school for Kindergarten and part of first grade, but the behaviors of the classmates were quite severe and Cameron began mimicking them. Dismayed, Carrie then turned to her district elementary school and requested Cameron be placed in a general education first grade classroom, to which they agreed. According to Carrie, Cameron thrived for the remainder of first grade, but was less successful in second and third grades when the work became more challenging and the teachers were less skilled at differentiating. Cameron was increasingly pulled out for resource support with other students who had IEP's, which resulted in little time in the general education setting. Carrie saw Cameron's regression as a signal that another change in setting was warranted, and enrolled him at a private school for students with exceptional needs for fourth and fifth grade. This school provided more challenging curriculum for Cameron; however, at this time, his younger siblings began attending their church's elementary school, and Cameron became depressed and withdrawn over the fact that he could not attend with them. Carrie elected to speak with the head of the church as well as the principal and after many meetings to discuss various options, was able to secure a special arrangement for Cameron's sixth and seventh grade years. Cameron is not officially enrolled as a student, but receives his core education from a private tutor in a room on the church's campus while also participating in the religion and specials' classes with his grade-level peers. Carrie's repeated disappointments in Cameron's educational journey color her perspective: she feels disgusted by the lack of willingness on the part of both the public and private school districts and believes it is representative of Florida's overall limited knowledge and implementation of inclusionary education for students with exceptional needs.

**Dana** is forty-five and married to the father of Deshan, their son, who is eighteen. In order to be on the same schedule as Deshan and her younger son, who is 10 and has been identified as gifted, Dana chose to leave her career as an accountant and now works as a paraprofessional and substitute teacher at the district public high school Deshan attends. Deshan is enrolled in a full-time special education class for students who are labeled as Intellectually Disabled. His elementary school years occurred mostly in New York, where he was enrolled in a partial-inclusion program before moving to Florida. Partial-inclusion is defined as attending core classes within a special education self-contained class, and special classes and lunch integrated with general education students. Deshan continued in partially-included settings in Florida for middle school, but then Dana and her family then relocated to Maryland, where Deshan finished middle school and began high school. The family moved back to Florida this past year, where Deshan attends his present high school. Deshan's journey as described by Dana has been moderately successful, but personally aggravating for her in that she always independently researches the available educational settings for Deshan in any district where he has been enrolled. Instead, she believes it would be beneficial to receive from the district a menu of choices that would be appropriate for Deshan.

**Belle**, 53, has been a homemaker since her children were born, but has spent a great deal of her time volunteering in and for her children's schools. She and her husband are parents to Bluto, 20, who is their younger child. Their daughter was enrolled in an International Baccalaureate program in high school and graduated from a prestigious university in the Midwest last year. In his educational journey, Bluto has attended four elementary schools, one middle school, and two high schools, all in the same public school district. Two of the elementary schools in which Bluto was enrolled were satisfactory to Belle, but the other two were grossly inadequate

in terms of teacher and/or administrator effectiveness. Belle found Bluto's middle school and the first high school he attended were equally substandard for the same reasons. However, the current school Bluto attends, a charter secondary school for students with exceptional needs, has been Belle's favorite because of the structure and emphasis on life skills.

Fifty-one year old **Barbara** is the mother of the only female child in the sample, Briana, who was 21 at the time of the interview and preparing to graduate from the public school system at the close of the school year. Barbara works full-time as the Parent Services Program Manager for the Florida Diagnostic and Learning Resource System (FDLRS) in the county where she lives and her children have attended school. Barbara and her husband also have two other children, a son who is older than Briana, and one who is younger. From Barbara's perspective, Briana's educational journey has been filled with many positives and yet the struggles have been tiring for Barbara. As with many of the participants' children, Briana first attended EELP at her district elementary school. She transitioned into a general education Kindergarten class at the same school, but received pull out special education services for 25% of the time. In first grade, Barbara felt the workload began to become too challenging for Briana, and elected to apply to a magnet elementary school for performing arts, where another child with Ds had found success. The school offered Briana a spot and she was enrolled into a general education class with supports for the remainder of her elementary school years. For middle school, Briana again attended a performing arts magnet school with the same arrangement, only this school was much farther from Briana's house and involved a lengthy bus ride. Briana's brothers also attended this school with her. When ninth grade arrived, Barbara decided to enroll Briana at the district high school in her neighborhood in a full-time self-contained ESE class. Briana spent all of her high school career there.

*Table 1. Demographic Features of Study Participants*

Participant name	Child's Name, Gender, and Age	Child's Current Educational Setting
1. Allison	Andrew, Male, 5	Private Preschool
2. Anna	Adam, Male, 9	Homeschooled
3. Carrie	Cameron, Male, 14	Tutored on Private School Campus
4. Dana	Deshan, Male, 18	Public High School, Self-Contained
5. Belle	Bluto, Male, 20	Charter Secondary ESE School
6. Barbara	Briana, Female, 21	Public High School, Self-Contained

The results of my data analysis revealed a total of six themes and one essence, all of which are named and defined in Table 2. In my descriptions of the themes, I will provide quotations from my participants to exemplify and clarify the meanings and nuances within them. I will end by describing the essence, which integrates all of the themes into an overall picture of the perspectives of the participants regarding the educational journeys of their children with Down syndrome (Ds).

*Table 2. Summary of Themes and Essence*

Theme name	Description of theme	Participants discussing theme
1. "She just got it"	Participants described the importance of having a teacher who connects with their child, wants him to be in her class and challenges him, and calls for administration and community to recognize his capabilities and potential.	All
2. "A very long battle"	The exhaustion and frustration participants experienced from persistent discussions with teachers and administrators as well as researching the available educational setting options for their child in the district left them feeling weary.	All

Table 2. (Continued)

Theme name	Description of theme	Participants discussing theme
3. "His comfort level was there"	Participants described the security they felt when finding the right fit in an educational setting for their child. Often this included the fact that siblings were also attending the same school.	Allison Anna Carrie Belle Barbara
4. "Let's give this a shot"	The willingness (or lack thereof) of administrators and teachers to allow the participant's child to enroll in a general education classroom in their school was an indicator of their acceptance for inclusion.	Anna Carrie Dana Belle Barbara
5. "You're the mom, so you know how he learns"	Participants described ways they became involved in the school their child attended through volunteering or paid work and established friendships with teachers and support personnel that were maintained after the child was no longer their student.	All
6. "Mayor of the school"	The child's interpersonal skills and affable nature led to a popularity within the school among students and staff. Inevitably, they believed they had learned valuable lessons from the child's presence.	Anna Carrie Dana Belle Barbara
Essence: Undeterred	Participants' stories evoked a tone of determination to acquire the most appropriate educational environment for their children with Down syndrome despite encountering multiple hurdles repeatedly.	All

### Theme One: She just got it.

I identified the first theme as "She just got it" after reviewing the transcripts and noting the frequency with which all six participants emphasized the importance of the teacher for their child. The theme was named by Carrie, who found that Cameron's first grade teacher was especially interested in teaching him.

The teacher made the difference because she wanted him in the classroom, which is the key. She spoke up and she said she wanted him exposed even though he wasn't up to speed at their level in reading and language arts. She wanted him in there to hear it. She got that he needed to hear it, but then he met with her one-on-one as well. So, I appreciated the fact that she understood that it wasn't going to do him any good to be pulled out during that time because he was so close to being there, but she didn't want to lose him one-on-one. So she just got it.

The teacher was a highly salient aspect of determining an appropriate educational environment for every participant. Allison stated early in her interview that when selecting a school in which to enroll her son, Andrew, "it always comes down to the teacher. It doesn't matter the school system, the school, the grade. It's all about that individual that can connect with my child." All of the participants, regardless of their child's gender or age, reported characteristics they believed made a quality teacher. Dana described Deshan's middle school teacher as exceptional because of the way she challenged him. Previous teachers for Deshan had left Dana questioning whether they had set lower expectations for her son. The issue of teachers recognizing the potential in their child was also expressed by Barbara, who stated that one of Briana's teachers was "just kind of a, I don't know how to describe them other than the 'oh, bless your soul people', you know. Like 'oh, dear, oh, well, yes, come here, come here', you know. She just kind of coddled her and then wasn't expecting her to be able to do anything."

Several participants described their perception of whether a teacher showed a desire to teach their child. Similar to Carrie's experience with Cameron's first grade teacher, Anna felt especially elated with Adam's first grade teacher, after she approached her while Adam was still

in Kindergarten. “She asked me if I would consider her to be his teacher for the following year. You know, you had me at hello, right. And she was wonderful.”

In contrast, Carrie recalled the frustration she felt upon realizing that Cameron’s second grade teacher did not want him in her general education class:

That was a tough year, because she really wanted him out of the classroom...although she was very loving, she didn’t feel like she had the extra time to put into modifying the curriculum. I asked for that several times. That was the start of Cameron’s decline academically. It was disappointing because we had such great success the year before. I think she just didn’t feel comfortable. She kept saying “I’m not qualified.” The first grade teacher and I both tried to give her some advice on how to handle Cameron. You know, treat him just like everyone else. You have to give him expectations and if he doesn’t meet them, then he loses things. I wasn’t looking for a handout. In fact, I wanted him to be held to the same standards as everyone else because when he isn’t, that’s when Cameron has problems and starts manipulating the situation. He’s smart enough to do that. She didn’t get it.

Barbara, however, believed that Briana never had a teacher who was opposed to having her as a student. As she explained, “some teachers are great and other teachers are just maybe not the right mix, but that’s part of life...you know sometimes you get a teacher that just doesn’t meet your personality.” Belle indicated that the ideal teacher possessed a combination of traits:

You find a teacher that thinks outside the box and still within the rules and who loves your child. Your kid connects with them and that’s all that counts. It’s because that teacher said, “let’s try this!”

An inclination to implement a variety of learning strategies to meet their child's needs, challenging him/her academically, and demonstrating enthusiasm for teaching him/her are the traits a successful teacher possesses, according to the participants. The theme of "She just got it" appeared more often than any other within the interview data.

### **Theme Two: A very long battle.**

The second theme identified from the interview data was "A very long battle." This theme was conveyed by all six of the participants in my study, who indicated that finding *and* keeping the most appropriate educational environment for their child involved frequent discussions, negotiations, and arguments with school officials, either with the administration or at the district level. "A very long battle" was named by Dana, who shared her experience of threatening legal action against the district for not responding to her requests for Deshan's environment.

My husband and I strongly believed in inclusion. We advocated for it. We wanted that for Deshan. Even if it wasn't all day, for part of the day, he needed to be included in whatever curricular the gen. ed. population was doing. We fought pretty hard for that and got it after a very long battle. We actually initiated a lawsuit because my husband and I said, "You've got to try. What's the next step if you don't try? What are our options?" They said, "Arbitration." And we said, "Yes, if that's what it takes. We are going to go there." So after we said we were willing to sue the district, they found another district that offered inclusion.

For some participants, broken promises regarding programs in which their child was participating or had been planning to enroll caused an added layer of anxiety in that new searches had to ensue and decisions made within a very short time period. Belle told the story where "the

principal kept saying, 'We're going to keep the EELP program. It's going to stay. It's going to stay.' And I'm not kidding you, the week before school got out, she pulled me to the side and said, 'We're going to drop the program.' And I kind of went, 'Now where do I go with him?' We scrambled to find an alternate school for the next school year." This experience mirrored Carrie's: "I was a little upset about the fact that we had really planned that next year around the fact that they were going to have KELP. That was where he was heading and we even discussed seeing how KELP went and then maybe putting him in regular Kindergarten the next year, then transition him on through. We felt like that was a good plan. So I started to see the true colors of the school district come out, when they just ripped that away, because then we were stuck since they would not put him in (general education) Kindergarten." Anna also recalled how involvement with district officials became contentious.

When I pushed to try to have assessments reworded for Adam, with the teacher's support, district said, "No. If you want him in gen. ed., he's going to take the gen.ed. assessments." The only accommodation they would make is making the questions bigger. They would put less (questions) per page and they would (let Adam use a) cover (for focusing), but they would not change the wording to make it more understandable. Every meeting after that had at least eight people, with always the principal and the vice-principal. It was always a lot of people, where other IEP meetings did not have that many people.

Dana felt frustrated by the fact that she was the one always initiating the research for Deshan's placement, which she expressed in both her personal interview and the focus group. She explained, "I never know what's out there. I find that every district doesn't open their books

and say, ‘Okay, Deshan has this disability and these restrictions, these are the things that we have that you can pick from.’ I always find that I have to do the research and I have to find the path.”

Gaining the attention of the district in terms of requests sometimes called for drastic measures, as was revealed in the example with Dana’s lawsuit initiation against the first school district that Deshan attended. Belle was aggravated by the amount of time it took for the district to enroll Bluto into EELP when her family relocated to the area. “We just happened to be at a town hall meeting and I said ‘Why does it take from November until the end of May to get him into a program?’ FDLRS kept telling me we had to do ChildFind (and I would say) ‘The child has been found, he doesn’t need help from FDLRS.’ A woman who was chairing that town hall meeting said ‘Call my office tomorrow.’ I got him in and he started in February. She was on the hook because the district had just settled a huge lawsuit against a child with Ds. So I think they were bowing to me at that point. He got in on a temporary IEP and off he went. But it was not a piece of cake.”

It was evident upon reviewing the interview data that a weariness set in for the participants whose children were older. As the child aged and transitioned, the battles between the mothers and school officials continued, but their desire to fight began to wane and a sense of defeat that could be interpreted as acceptance was revealed. This was especially apparent with Belle and Barbara, whose children were the oldest in the sample. Belle described Bluto’s initial high school experience at their district public school as “enough to just bring an elephant down,” while Barbara shared that her decision to enroll Briana at their district high school was due to the fact that she “was kind of tired of requesting things. She’s going to learn what she can learn.” The persistent arguments between the participants and school officials led to fatigue and even a

sense that they were settling for an environment that was far from what they considered to be the most appropriate for their child.

**Theme Three: His comfort level was there.**

The third theme I identified was “His comfort level was there.” Five participants discussed the sense of security they felt when the search for the most appropriate educational environment for their child resulted in the right placement. Allison named this theme when she expressed her feelings about finding a great fit for Andrew for his first formal educational experience.

Everyone knew us and knew Andrew. We knew the teachers there at all different levels and all the kids in the neighborhood go to that school, so Andrew knew everyone. His comfort level was there. There weren't just two sets of eyes on him; now there were hundreds...a whole community that could be the speaking voice, or the spokesperson for Andrew, because at that point he was still nonverbal. We just felt an overwhelming sense of security and safety. In our personal opinion, we like the community school, with its larger setting. I have researched smaller settings and I didn't get the warm and fuzzy for my son. I'm not saying it's not right for other people, it's just my opinion. I feel like Andrew needs more of “society” in his setting to be successful.

Belle echoed this sentiment when, after several unhappy elementary school experiences, she finally found a school she loved for Bluto.

It was a new school, so the numbers were not high. He stayed there until he graduated (from elementary school.) There was a phenomenal principal, AP,

teacher, and ESE specialist; a great staff. It just worked. And there were children with Down syndrome and autism so it was interesting. He thrived.

It is worth further noting that after leaving this particular elementary school, Bluto's middle school experience and the first two years of high school were unfavorable. However, after moving him to the charter secondary school for ESE students, Belle confessed "we're just so much more relieved. The tension is gone." The right educational environment for the participants' children provided both security and peace for the parents.

Bonding with peers was another aspect noted within the theme of "His comfort level was there." Barbara shared how Briana made girlfriends from Brownies and performing dance routines with her classmates in elementary school. While Briana continued taking dance as an elective into middle school, she also made a significant friend at this time.

Since there were kids with disabilities there, she developed a friendship with another little girl who had Down syndrome. That was kind of the first time that she had a friend that was more like her than not, so that in itself was a benefit.

They had sleepovers and did things on weekends, so that was different than what she had experienced before.

Several participants remarked that when their child could attend the same school as their other children, the comfort level was further enhanced. An example was provided by Anna about her daughter, who is four grade levels above Adam.

They'd never been at the same school before. With her going into middle school within a couple of years, we wanted to take advantage of that and see what would happen. I figured this would be the only chance in their lives that they'd be at the same school, because once she was in middle school, he would still be in

elementary. When she was in high school, he would be in middle school. They're very close, so we thought, "Wouldn't that be great if we could be together?"

Carrie shared that Cameron specifically asked to go to the same school as his younger brothers and sister. Barbara's two sons, one whom is older than Briana and one whom is younger, were unhappy with having to attend the same magnet school as Briana, as they preferred to attend the neighborhood middle school. Barbara believed keeping them together was important, though, and that the "family drama" was worth it. Bluto's older sister did not want him to attend high school with her, but according to Belle, this was out of concern and love for him.

My daughter graduated when he finished middle school. They never intertwined I'd been involved at that school as well on the IB board, and I remember her telling me, "Mom, for the love of God, I'm begging you. Please do not send him here."

A final iteration of "His comfort level was there" was expressed through participants' recollections of when the environment did not provide comfort. Anna shared the distress she felt when Adam began to complain about tests he was required to take.

During the second go-around with first grade, he started feeling for the first time like he was inadequate because of the way the assessments were. They were very verbose and he said, "Mommy, they're tricking me! Why are they tricking me?" Carrie felt similar pains over Cameron's fifth grade experience, at the conclusion of his elementary school years.

Yes, he was not a happy person. Academically, we were sliding down even further, like stuff he could do he wasn't doing. It was like he forgot how to do everything. He was so depressed. He hated going there.

The child's comfort had deep ramifications for the participant in terms of her selection of the educational environment for her child. This was conveyed in many instances by all but one participant.

**Theme Four: Let's give this a shot.**

The fourth theme I identified was "Let's give this a shot." This theme captured the idea that many of my participants encountered a willingness by administration and teachers to allow their child to enroll in a general education classroom in their school, which was an indicator to the participants as their acceptance of the inclusion model.

The theme was named by Anna, who relayed her story about Adam's transition into first grade.

From the beginning, our intention was for him to go into a gen. ed. classroom.

Although I don't believe the school had ever done a formal IQ test, Adam's intelligence was such that the school knew he was keeping up with the peer level and understanding of curriculum. His teachers backed me up and that obviously was a big factor. The school had never had anyone with a full IEP (in general education, but they welcomed us, openly, and said, "Let's give this a shot. We're happy to try!"

Barbara had a similar experience when she moved Briana from their neighborhood school into a magnet elementary school.

Before we actually got to that school, we had an IEP meeting with the principal, the ESE supervisor of the area at that time, and a brand new teacher fresh out of college. We were talking about what did we (Barbara and her husband) expect and how did we envision this to work. We said, "You know, we just kind of want her to participate in the regular classroom. We want somebody close by, but not

right sitting next to her. Just in case something goes wrong, (we want someone) that could maybe pull her aside or offer assistance or just be a back up to the teacher.” So, they agreed and started talking about one-on-one aides or classroom aides, and the principal asked the supervisor, “What’s the difference between one and the other?” The ESE supervisor explained, and then he (the principal) said, “Well, I think she needs a one-on-one. Let’s go for the top and we’ll go from there.” It was like, “Let’s pull out everything we possibly can to make this successful and be ready.” So, he got it approved, and so she had a one-on-one (aide). It showed an attitude of “She can do more than what she’s doing now” and (demonstrated) somebody being willing to give her a chance or an opportunity to do more.

Also acknowledged within this theme was the resistance many participants encountered from school officials when requesting to enroll their child in a general education classroom. As an example, in a discussion with Cameron’s school after he had completed EELP, Carrie recalled “I bugged them and told them I wanted him in (a general education) Kindergarten. They said, ‘You know, you’re setting him up for failure, blah, blah, blah.’ My issue was “Let’s just give him a chance.” Dana, too, felt frustrated by the opposition she found in Deshan’s initial venture into formal education.

I wanted to see where this (an inclusionary classroom) was possible. I didn’t know if it was possible and yet, I needed somebody to try it. They said, “No. We don’t, we can’t do it.” My husband and I said, “There’s got to be! We gotta go above that.” We wrote the district superintendent a letter, then the IEP specialist contacted us. We had a meeting and she said, “No,” and my husband said, “Yes,

there's gotta be a way! You've got to find a way, because you can't just tell me no. You've got to say, 'I'm going to try.'”

One participant, however, never vied for an inclusionary experience for her child. Belle believed that Bluto's education needed to be better suited for his needs, which she described in both her personal interview and the focus group.

When he was at Pizzo, the first year, I had the IEP changed to reduce the emphasis on the ABC's and 123's and had them focus more on social skills. The reason was he had behavior issues and was being distracted by so many other issues, making it difficult to learn. Also, I have always thought it was silly to place so much on Access Points or whatever was the testing du jour. He really doesn't need to know who the 16th president was and other useless facts. They could touch on it, but not spend so much emphasis on it. My child, with Down syndrome, isn't going to need any of that in his future after school. I am realistic in knowing that there is nothing out there for him after he is no longer in school that uses any of that. He needs to have been taught life skills from the beginning and not just in high school.

The theme of “Let's give this a shot” reflected the desires of most of the participants for their child to be included within general education and the appreciation they felt for schools who were willing to make the attempt at implementing such a plan.

**Theme Five: You're the mom, so you know how he learns.**

The fifth theme I identified was “You're the mom, so you know how he learns.” This theme was characterized by the ways every one of my participants described how they became involved in the school their child attended through volunteering or paid work and helped

educators better understand how to meet their child's needs, often forming friendships with teachers and support personnel that were maintained after the child was no longer their student. The theme was named by Carrie who was able to help Cameron's first grade teacher recognize how to adapt instruction in order for him to progress. As Carrie shared, "I often asked her if she had any experience (teaching students like Cameron before he was in her class) and she said she did not. She just said, 'I listened to you, because you're the mom, so you know how he learns.'" The situation that led to this remark years later involved the teacher taking Carrie's lead on helping Cameron practice spelling words at home.

She and I agreed. If they had ten spelling words, I said, "Let's just give him five."

I think he might have even started with three. Once he was successful, then we moved on and added words. So, you know, he was having success with three words and that motivated him to do more. Then it became a big deal to him.

Barbara had an almost identical experience:

First grade was kind of rough. They had no idea how to modify any assignments.

I would suggest, "You know, why don't you just black out six of the questions because everybody else has 12? Just give her half, or three spelling words instead of 12." To me it made common sense.

Interestingly, although Carrie and Barbara had no background in education, they taught the teachers how to become more effective in the profession and both felt satisfaction from the experience.

Another salient part of "You're the mom, you know how he learns" was participants who became involved through unpaid or paid work at the child's school. For example, both Anna and Belle chose to volunteer at their children's schools, as they believed it was an investment that

fostered connections with faculty and staff. Belle recalled how she “was the copy mom and would tutor some of the kids...never in his (Bluto’s) classroom.” Additionally, at every school Bluto attended she joined the PTA either as a board member or a volunteer. Being visible at the school often was important to her. Anna shared that volunteering was mutually advantageous for herself and Adam’s support team:

I went through district trainings to assist the literacy coach, so I worked one on one with other students that had nothing to do with my son. Most of the time that I volunteered within the school was not in my children’s classrooms. It was with their teachers or it was with other students. I made myself valuable to the school. I had the benefit of volunteering all the time, so it was very easy for them to say, “Hey, can you come over during my planning period?” or for me to say, “Will you have any time this week (for discussing an issue)?” The speech therapist would see me in the hallway and say, “Oh, guess what Adam got today?” and would fill me in on what they were working on, (including) where he was thriving and what we could do at home.

In contrast, Barbara expressed frustration over how her volunteer presence at Briana’s school did not necessarily equate to her requests for Briana being fulfilled. She said she explained to one teacher, “Do I need to volunteer 24 hours a day? Tell me what I need to do because this is not working, and she’s not getting what she needs, much less anything else.”

Two participants ended up working within the school system after determining the arrangement might be of benefit their children. As Dana recalled,

I have a public accounting background, but five years ago, when we moved to Maryland, I didn’t have anybody to take care of my kids after school. I took a job

in accounting and I found that they were having snow days, or early dismissal, and late starts. So I thought, “Well, why am I resisting this? I might as well join it.” I got a job in the school system. I was off when they were off, and in school when they were in school. I found, being in the (school) setting that everyone wants a common thing for children with disabilities. They want them to progress.

Barbara’s eventual job within Briana’s school district seemed to once have the opposite effect from Dana, however:

The special education teacher was supposed to have textbooks in the classroom. So she told me, “Oh, you need to go to the office and complain” and I was like, “Why aren’t you doing that?” So, I kind of backed off because I thought she was taking my position with the school district as one of authority, and that I could get something done. I didn’t want to cross lines, though. It didn’t seem appropriate for me to complain unless I thought that Briana wasn’t getting something that she needed, so it was kind of weird in that respect.

The trust that built between several of the participants and particular teachers that resulted in lasting connections and friendships was noted within this theme as well. Dana and Belle both referenced keeping in contact with teachers who really stood out in their sons’ educational journeys, and how the meaningful bond was triangulated between mother, child, and teacher. Anna explained “all of these people are friends. I know where they all are...the wonderful, fabulous teachers and speech therapist and OT. They aren’t his professional people anymore, so they can be my friends.” Likewise, Carrie relayed that she became really good friends with the teacher who had followed her suggestion for reducing Cameron’s spelling words.

Mothers are often respected as those who understand their child like no other person, and this was evidenced repeatedly throughout the theme of “You’re the mom, you know him best.” Teachers and schools that were willing to listen to the participants’ ideas and implement them for their child demonstrated this understanding. As Dana stated, “I’m the parent. I’m with him all the time. Not that the educator doesn’t know him, but I know him best and I am a team player.” Allison reiterated this concept when we came together at the focus group, sharing how important it is for her “to learn what the options are along the way and try to educate myself as much as I can to make sure I find the right fit for Andrew. We know our kids better than anyone else does and we know what environments they’re going to succeed in.”

#### **Theme Six: Mayor of the school.**

The sixth theme I identified was “Mayor of the school.” Five participants expressed how their child’s sociability and friendly disposition led to a likability by school staff and fellow students, many of whom indicated to the child how much he/she had taught them as a result of being their classmate. Both Carrie and Dana used the term Mayor of the School in their interviews when discussing their sons. Carrie expressed that at the school where Cameron attended EELP, he “became like the mayor of the school, but that’s his personality. They were very accepting of him.” Similarly, Dana shared that the staff gave Deshan the title “because he knew everyone and got an invitation to everything. He’s very sociable. He seemed to know what to ask of certain people, and the principal always said, “He’s the mayor!” She’d take him around the school and everybody knew Deshan.”

Other participants recalled experiences where faculty, staff and/or fellow students acknowledged their children’s presence as positively impactful. For example, Belle recalled that

during Bluto's middle school years "this teacher said, "Let's try him on the morning show. If he behaves all week, he can do it. It's closed circuit TV for the entire school, and he loves the weather, so he would go in front of the camera. His speech has always been fairly understandable, for the most part, to an unknown listener, and the regular ed. kids would come up to him at lunch, (and say), 'Oh, we saw you on the morning show!'" Barbara described a situation involving Briana's peers and teacher that was especially memorable.

That class embraced her so much (during the first time she was in third grade at the magnet school). At the end of the year, each kid created a page for a book, and wrote what Briana's presence in the classroom had meant to them. It was a tearjerker. Even the teacher wrote something, like, "I didn't know what I was getting into" and (how she) had a complete turnaround as far as what Briana taught her. So, it was really nice.

Interestingly, Anna saw two sides to Adam's popularity. While she stated that Adam's "positive impact that he had on every student in that school was a beautiful thing to see," she also revealed a festering concern:

Adam was always well-liked by his teachers and peers, but somewhere around age 7-ish, it seemed like he became the class mascot or project. He loved all of the doting, but as his parents, we really didn't like how that was going. Because the school didn't have a tremendous amount of experience with inclusion, no one knew how to address it. It's not an issue (anymore, because he is homeschooled), but I'm afraid it would have been if he was still there.

Knowing their child was accepted and well-received throughout the school he/she attended significantly affected whether the participant believed her child's educational environment was appropriate for him/her.

**Overall Essence: Undeterred.**

When I analyzed all of my themes cohesively, an overall essence that described the educational journeys of youth with Ds as viewed through the perspectives of their mothers, my participants, emerged. I called this essence Undeterred. I chose this term because, despite experiences that were filled with highs and lows, my participants remained determined to find and secure the most appropriate educational environment for every age and need he/she exhibited. I was especially moved by the passion displayed by each of my participants in the stories they shared about their child's journey. At the focus group, which Allison, Anna, Dana, Belle and Barbara (five of the six participants) attended, it was exciting for me to see the instant connections forged. Listening to their chatter before and after the formal discussion took place, I caught snatches of conversation about school placements, mutual friends, extra-curricular activity opportunities, and pediatricians who were considered remarkable. As mother of Andrew, the youngest child in the sample, Allison expressed her gratitude to all of the participants for "setting the path for younger children." She took fastidious notes about the ideas exchanged by the participants, and indicated she believed it is her responsibility as a parent to make sure she had equipped Andrew's teachers and administrators with those ideas. Her voice resonated with fortitude and exemplified an attitude that was unstoppable. Comparably, Barbara, whose daughter, Briana, is the oldest child in the sample, reflected the same spirit as she described how, as mothers, "we're always thinking of the end goal for our children and not a one year plan in IEP. The goals they write may take our kids 2-3 years to achieve. But the personnel involved

always say, 'Don't worry about it. That's far off.' If I don't worry about it, though, who will?" While Briana's educational journey is concluding, Barbara's words conveyed the foresight she maintained during the years her daughter was in school to ensure she received an education that prepared her for both short- and long-term outcomes.

The fact that my participants were and are undeterred in their mission to locate the most appropriate educational environment for their children with Ds speaks to the basic maternal instincts they possess to ensure their child was given every opportunity to fulfill his/her potential. However, upon reviewing the stories they shared, it was evident to me that this determination did not come without emotional costs. Tones of frustration, anger, and fatigue were all laced throughout their stories. I also sensed, to some degree, a feeling of grief for their children, who would never be given the chance to follow the educational journey of a typically developing child. They consistently faced uncertainty at the next transition they were either forced or chose to make. With each new age, teacher, and school, the journeys took unexpected twists, although sometimes they were filled with bright spots. People such as teachers, classroom aides, and administrators who willingly opened the doors to their classrooms and schools to my participants' children, and fellow students who recognized and celebrated their gifts gave each mother hope and further strengthened their resolve to continue the journey.

As they sought the most appropriate educational environment for their children with Ds, the mothers I interviewed for my study displayed commonalities in attitudes and opinions, which I have coded into themes. These included "She just got it," which expressed the feeling of elation mothers experienced when they discovered their children's teacher was excited by their presence, formed a strong connection with them, and used innovative instructional strategies to support their learning; "A very long battle," which indicated mothers' feelings of frustration and

fatigue when engaging in regular negotiations with school personnel regarding their children's placement and/or educational planning; "His comfort level was there," which conveyed the sense of security and peace felt by mothers when their children showed a strong affinity for a particular school, often one in which their sibling(s) were enrolled; "Let's give this a shot," where an open and willing approach (or lack thereof) by teachers and administration to enroll a child with Ds in a general education setting was evident to mothers; "You're the mom, you know how he learns," for which mothers recognized the value of their presence in their children's school, either through volunteering or paid work, and developed meaningful relationships and eventual friendships with school personnel who served their children; and "Mayor of the school," where the children's interpersonal skills were integral in forming a popularity within the student body of the school they attended, leading to lessons for both peers and staff regarding the importance of an affable disposition. An overall essence, "Undeterred" of the themes emerged when I examined them holistically. "Undeterred" implies that throughout the educational journeys of their children with Ds, the mothers in my study maintained a resolute yet optimistic outlook that they would find the most appropriate environment for their children. This spirit led them to discover the potential avenues of support for their children in various schools, and also work toward convincing and ultimately helping administrators, faculty, and staff learn how to include their children successfully within the fabric of their schools.

## CHAPTER FIVE

### DISCUSSION

The goal of this study was to learn from mothers of youth with Down syndrome (Ds) regarding the educational journeys of their children, particularly as they considered and/or experienced enrolling their child in a general education setting that reflected an inclusionary model. A qualitative approach was chosen to give participants the opportunity to describe their experiences in their own words. While Lalvani (2012) conducted a qualitative study regarding the perceptions mothers of youth with Ds held about their children's educational environments, my study examined perspectives of mothers whose children's ages spread across a spectrum from those who were just beginning their educational journey, to those in the middle of the journey, and finally those whose journeys were coming to an end. My objective was to examine common themes in the stories the mothers shared, as well as differences expressed by those whose children were younger from those who were older. With this information, I aimed to determine whether implications for families and schools might be revealed by the themes.

#### Major Findings

In my study, I discovered that mothers of youth with Ds consider an array of factors when searching for the most appropriate educational environment for their children. For example, as was revealed by the theme "*She just got it,*" it is very important to mothers that their child makes a connection with the classroom teacher, who is typically someone who displays warmth and sensitivity, tempered with keeping high expectations for their child. Teachers who

want the child in their general education classroom is a huge indicator for mothers that this is an educator who is open to trying new ideas and strategies. Furthermore, teachers who eagerly agreed to including a child with Ds showed mothers that they understood the how a student with Ds can offer valuable life lessons for the other classmates.

Knowing the potential positive experiences a child with Ds could have within a general education classroom or school led many of my participants to consider an inclusive or partially-inclusive educational environment to be the most appropriate. As the literature had indicated, the opportunity for social interactions with typical students was a primary factor mothers found desirable in such a setting. As Davis (2008) revealed, one of the characteristics of youth with Ds is that they tend to have strongly developed social skills, and several mothers indicated this was confirmed through reports they received about their child's affable disposition with peers, teachers, and administrators in the general education schools they attended, which was evoked in the theme "*Mayor of the school.*" Mothers such as Carrie explained that her child, Cameron, also attained greater academic success when he was included within a general education classroom, which was also noted in the work of Turner, Alborz, and Gayle (2008).

As children aged, though, mothers seemed to find that inclusive educational environments were not as beneficial for their child as a more segregated setting, which replicates the work of Leyser and Kirk (2004) and Lightfoot and Bond (2013), whose participants indicated similar feelings. The mothers in my study whose children were nearing the end of their educational journeys indicated segregated environments that provided more intensive instruction in job skills and independent living management were actually better suited for them. One mother in particular found that her child's behavior improved in a smaller, more structured school that exclusively served students with intellectual disabilities, as opposed to general

education schools and/or classrooms. Therefore, according to the participants of children who were more advanced in age, a non-inclusive educational environment became more appropriate for children with Ds as they matured. This may be in part due to the lack of a strong model for inclusive education at the secondary level in this area. However, this finding was key within my research, as it supported a theory I posited regarding whether a fully inclusive education is sustainable for the duration of the educational journey of a child with Ds in terms of both academic and non-academic outcomes.

Alquraini's (2013) research cited how general education schools and classrooms may consider their sites to be the LRE for a child with Ds, but participants still found it took a great deal of pleading and convincing of some general education schools to open their doors to their child, which was indicated by the theme "*A very long battle.*" This often led to frustrating struggles with personnel. Other participants met with schools that would not even consider enrolling a child with Ds, firmly stating they were not equipped to provide adequate support for him/her. However, many mothers shared that several schools, while uncertain about how to navigate including a child with Ds in a general education classroom, were willing to make the attempt and invited the child's mother to be an active participant in the educational planning process, a sentiment echoed in the theme "*Let's give this a shot.*" Ultimately, mothers felt satisfied with the environment based on their children's responses to the climate, including the administrators, staff, faculty, and peers, both within their classroom and throughout the school in general. Their contentment with a particular school was especially heightened when it was also the school their typically developing children attended, meaning their children with Ds would be taught within the same environment as their siblings and have possible opportunities for

interaction with one another during the school day. The sense of security mothers felt because of this arrangement was reflected in the theme “*His comfort level was there.*”

Mothers frequently decided the best way to support their children’s education within a given school was to consistently volunteer there, sometimes daily, and/or become employed within the school district itself. This resulted in mothers being allowed to work more intimately with the personnel chosen to teach and/or support their child, which fostered regular conversations between them and, therefore, a stronger connection between home and school. This situation was described by the theme “You’re the mom, you know how he learns.” Research has shown how a family’s involvement in the education of its children leads to greater outcomes for the students within the family (Zellman & Waterman, 1998), and this was confirmed for the mothers who chose to volunteer or work at their children’s schools. Furthermore, these situations tended to lead both mother and child to create enduring bonds with teachers and administrators that had a meaningful impact on all of them.

The overall essence of my study, “*Undeterred*”, conveyed the persistent attitudes the mothers in my study invoked in their searches, demonstrating the unconditional love they possessed for their children and their belief that his/her potential could be fulfilled within the right educational environment. While their children’s educational journeys were sometimes challenging to the point of exhaustion, these mothers remained steadfast in their commitment to seek such an environment, and learned along the way that what may have been appropriate when their children were younger evolved into a different setting as their child aged.

### **Implications for Mothers and Families**

My aim in interviewing mothers of youth with Ds regarding their perspectives of the most appropriate educational environment for their children was to expand the literature on the

topic of factors involved in selecting inclusive education for such youth. Working from the themes and the overall essence, “Undeterred”, that I generated from the stories my participants shared about their children’s educational journeys, below I describe the implications of my findings for mothers and families.

### *Become Active in the School*

First, mothers and all family members of a child with Ds should strive to nurture a positive relationship with their children’s school. This does not necessarily mean they must secure paid employment positions, or even volunteer during the school day, which is a luxury many mothers cannot afford. However, attending school meetings such as IEP’s and conferences, as well as activities and events, such as performances or special celebrations, indicates an investment in a child’s progress and success, and secures a place as a vital part of his/her team. Maintaining an open line of communication with teachers and school officials also signals a desire to be involved and offers insights into a child’s life outside of school that may impact his/her performance.

### *Advocate with an Optimistic Attitude*

Second, it is imperative that mothers and family members of a child with Ds speak up for their child’s needs when a different approach is warranted for his/her success. However, it is important to keep in mind that most schools have the same goal of successful outcomes for any student as the mother and family for their child. Often, schools simply do not know how to effectively plan for the academic and social/emotional development for a child with Ds, particularly if he/she is enrolled in an inclusive or partially-inclusive setting. It is therefore suggested that mothers and family members offer evidence-based ideas to teachers that may be adapted to the child’s educational plan and agree to follow up at home with reviewing academic

concepts and similar behavioral expectations. Educators may be more willing to attempt strategies that have been recommended by a mother or family member, especially when they are presented with an attitude that connotes empathy and appreciation. Valle (2012) contends that most “issues can be resolved if professionals commit to ‘playing nice’ with parents” (p. 180), but the reverse also holds true regarding the approach of mothers and families toward schools. It is also advisable to possibly seek the services of organizations such as The Florida Inclusion Network (FIN) and/or a private consultant who is familiar with educational law. These individuals understand the hurdles to be jumped in providing a successful inclusive educational experience for students with Ds and can work in conjunction with schools for developing realistic and meaningful plans for their successful growth in academic and social/emotional domains.

#### *Make Decisions Based on Your Child’s Needs*

Finally, mothers and family members of a child with Ds have an opportunity to learn from the experiences of other mothers and family members by making connections through support groups such as F.R.I.E.N.D.S., which stands for Families Raising Inspiring, Educating and Networking for Down Syndrome. Mothers may exchange information from doctors who have expertise with treating medical problems commonly found in people with Down syndrome to techniques for enhancing the expressive language skills of their child, to programs and activities tailored for children with Down syndrome and other disabilities. Arming themselves with knowledge allows mothers to be more confident when choosing routes to take on their child’s educational journey. However, it should also be understood that mothers must make decisions based on the individual needs of their child and family. Success for one child with Ds in a given situation or educational environment does not mean it will equate for another child

with Ds. Additionally, mothers must recognize that their own children's needs may change over time. An educational environment that previously provided a comfortable and stimulating atmosphere for a child with Ds in terms of both academic and non-academic outcomes may at some point become frustrating for the child in terms of peer relationships and academic expectations, which can lead to behavior problems. It is advisable for mothers to consider enrolling their child in a school with a different environment should this occur, although this may go against beliefs they have long held regarding the most appropriate type of educational environment for their child (i.e. segregated as opposed to inclusive or integrative.)

### **Implications for Schools and School Districts**

Findings of my study also have important implications for schools and school districts. These are described below.

#### *Consider the Mother an Expert About Her Child*

First, it is important for school personnel to understand the profound benefits of effective collaboration between families, especially mothers, and schools. This means to allow the mother's voice to be heard at meetings regarding her child's educational planning. When teachers and administrators are dismissive of a mother's suggestions and perceived demands, they may be losing one of the more valuable resources they have for supporting the success of a student with Ds. Mothers need to believe they are being not only heard, but respected in regard to their views. However, concurrent with Lalvani's (2013) findings, mothers who are uninformed about the educational laws in place or the limits a school has to serve a child with Ds must be guided with patience and sensitivity to services whose goal is to help them understand such.

### *Consent to Inclusive Educational Environments Whenever Possible*

Second, recognizing and seizing the beneficial opportunities of enrolling a child with Ds into a general education school and classroom is recommended. My study corroborated findings in numerous studies (Bennett & Gallagher, 2013; Downing & Peckham-Hardin, 2007; Leyser & Kirk, 2004) that indicated most mothers are champions of an inclusion model for their child with Ds. When given the chance to explore an inclusive or even a partially-inclusive classroom for the child's natural grade level at his/her district school, he/she is able to interact with peers from the neighborhood and create meaningfully reciprocal friendships. Furthermore, academic expectations are often higher for students enrolled in inclusive classrooms, which can lead to better post-educational outcomes for them. However, given the cognitive processing and communication challenges associated with the diagnosis of Ds, Tier 1 interventions are unlikely to be sufficient to meet the needs of students with Ds enrolled in an inclusive classroom. Such students will likely need to have a modified curriculum in place and receive Tier 2 or Tier 3 supports in order to make progress within a general education environment.

The mothers I interviewed indicated that schools seemed to be much more inclined to attempt including students with Ds in general education classrooms when they are younger, particularly in the pre-K and early elementary years. This sentiment is noted within the literature (Hanson et al., 2001), but does not need to be the status quo. From a systems level perspective, it is recommended that districts collaborate with consultants from agencies such as Florida Inclusion Network (FIN; <http://www.floridainclusionnetwork.com>) and seek their expertise regarding how to create successful inclusion models, especially at the later elementary school, middle school, and high school levels. Considerations for funding allocations and resources may need to be examined and FIN may be able to provide guidance within these domains. Following

Doyle and Giangreco's (2013) model of "Presuming Competence," school districts should seek to offer how they can increase their inclusive educational offerings for older students.

#### *Provide Professional Development and Support Regarding Inclusion*

The third highly salient finding of this study that has implications for schools is ensuring that teachers and support personnel who teach a student with Ds in an inclusive or partially-inclusive environment are given professional development opportunities to best understand how to meet the student's needs and effectively educate him/her. Abundant resources are available to educators who seek to learn more about increasing their knowledge about best practices for inclusion, and for those who are more hesitant or resistant, encouragement and incentives may need to be provided in order to show educators the benefits of inclusion for students with Ds. The mothers whom I interviewed were quite surprised by the lack of awareness and/or opposition many schools and districts demonstrated regarding enrolling a student with Ds into a general education classroom. Increased opportunities to learn about this progressive approach are essential for pre-service educators and current teaching staff.

#### **Limitations**

Several limitations of my study must be noted. First, my recruitment procedure resulted in securing mostly Caucasian mothers of youth with Ds, with the exception of one who identified as Asian. All of my participants were married. Furthermore, the minimum annual household income reported by my participants was \$60,000, leading to the presumption that my sample all belonged to the upper-middle class or upper-class. All of my participants had graduated high school, with four earning college degrees, so their education levels were mostly similar. This meant that the perspectives offered by the mothers were restricted from a cultural and socioeconomic standpoint.

Another limitation of my study is related to the exclusion of fathers and other family members, such as siblings, of children with Ds. I purposely chose to interview mothers about their perspectives, as typically they are the caregiver who is most involved within a child's education and serves as the primary decision-maker. However, several of my participants indicated their husbands (all mothers were married to the father of their children) would have been interested in offering their perspectives as well, which may have led to a richer story. Siblings were also frequently mentioned by participants, and including their stories about the educational journeys of their brother or sister, especially if they were close in age, and attended the same school, may have also enriched my research.

### **Directions for Future Research**

The results of my study have provided evidence of the importance mothers feel regarding finding the most appropriate educational environment for their child with Ds. From their stories, it is obvious that the trend of beginning the formal educational journey a child with Ds in an inclusive, general education classroom and/or school continues to gain traction. Future research should examine the perspectives offered by mothers from multiple ethnic and socioeconomic backgrounds to understand if sociocultural factors may be associated with different results regarding the most appropriate educational environment for youth with Ds. Stories shared by family members and/or siblings of youth with Ds would also be valuable to study. Other considerations include learning the perspectives of teachers who have successfully taught students with Ds in an inclusive, general education classroom at the secondary level. It would be helpful to discover how the inclusion model could be offered with more prevalence as students with Ds age. Finally, research that seeks the viewpoints of typical students who have students with Ds in their general education classrooms at all grade levels would be especially helpful.

This type of study may enhance the literature regarding variables that may influence friendships made between typically developing children and those with Ds and to what capacity those are perceived as meaningful and significant.

## **Conclusion**

My aim in this study was to understand how mothers decided what factors defined the most appropriate educational environment for their children with Ds, and discover commonalities they shared regarding the choices they make in determining such. After my own personal experiences as a teacher of students with Down syndrome in three different types of educational environments (segregated, integrative, and inclusive), and then viewing the documentary movies “Educating Peter” and “Graduating Peter”, I was especially interested in learning whether mothers’ choices encompassed both academic and non-academic outcomes and whether their views about what constituted the most appropriate educational environment changed as their children aged. Although the Florida Inclusion Network (FIN) provides a number of quality indicators, within domains of Leadership and Decision Making, Instruction and Student Achievement, and Communication and Collaboration, to describe the successful inclusive educational environment, this study relied on the definition provided by Jones, White, Fauske and Carr (2011), as outlined in chapter 2. I subsequently found that my participants’ interview responses also aligned with this definition, as the mothers overwhelmingly indicated their beliefs of an inclusive educational environment were found within a school “that embraces diversity as a strength, creates a sense of belonging, equal membership, acceptance, being valued, and involves fundamental civil rights. Inclusive teaching and learning occurs in natural settings, with extensive and appropriate instructional supports, modifications, and accommodations, which are meaningful to students and teachers” (p. 13.) “Natural settings”

equated to general education classrooms for my participants, and several themes emerged that indicated this type of environment was typically the one most sought by parents when their children were younger.

When asked to relay stories about their children's educational journeys in individual interviews, participants in my study described schools and teachers who were willing to include their children in general education classrooms and schools and provided a nurturing atmosphere that was academically challenging and allowed their children's social skills to shine. Mothers tended not to differentiate between academic and non-academic outcomes for their children, seeing them as one goal. Some mothers reported their children found made greater gains in terms of academic and emotional development within an integrative or inclusive environment, while others were prone to greater success in segregated environments. Mothers also recalled situations fraught with struggles, where schools were not open to providing the type of education for their children they believed was best suited for their needs. It was the undeterred spirit possessed by these mothers, who best knew their children's learning aptitudes, which allowed their children's development to flourish in the selected environment. The participants' descriptions of their children's educational journeys offer many insights into how mothers may approach and partner with their children's schools, and how schools and school districts may expand upon inclusive educational opportunities for youth with Ds.

An active participation within the child's school and advocating for him/her with a positive but assertive manner is the recommended approach for mothers to follow. Schools and school districts should acknowledge the mother's suggestions for her child's educational planning as valid and useful. In addition, they should attempt to create more inclusive educational classrooms at all grade levels and provide suitable professional development training

sessions for educators who teach students with Ds in general education settings. It should be the goal of both parents and schools to ensure youth with Ds are given the most appropriate educational experiences possible in order to augment their skills and participate as valuable and contributing members of society.

## REFERENCES

- Algood, C. L., Harris, C., & Hong, J. S. (2013) Parenting Success and Challenges for Families of Children with Disabilities: An Ecological Systems Analysis. *Journal of Human Behavior in the Social Environment*, 23(2), 126-136.
- Alquraini, T. (2013). An analysis of legal issues relating to the least restrictive environment standards. *Journal of Research in Special Educational Needs*, 13(2), 152-158.
- Alquraini, T., & Gut, D. (2012). Critical components of successful inclusion of students with severe disabilities: literature review. *International Journal of Special Education*, 27(1), 42-59.
- Bakely, D. C. (2002). *Down Syndrome: One Family's Journey*. Cambridge, MA: Brookline Books.
- Bennett, S. M., & Gallagher, T. L. (2013). High school students with intellectual disabilities in the school and workplace: multiple perspectives on inclusion. *Canadian Journal of Education*, 36(1), 96-124.
- Brown, R.I. (2006). Down Syndrome: The Changing Scene. *Journal of Developmental Disabilities* (12)1, xi-xvii.
- Buckley, S., Bird, G., Sacks, B., & Archer, T. (2006). A comparison of mainstream and special education for teenagers with Down syndrome: Implications for parents and teachers. *Down Syndrome Research and Practice*, 9(3), 54-67.

- Channell, M. M., Loveall, S. J., & Conners, F. A. (2013). Strengths and weaknesses in reading skills of youth with intellectual disabilities. *Research in Developmental Disabilities, 34*, 776-787.
- Chase, S. E. (2005). Learning to listen: narrative principles in a qualitative research methods course. In Josselson, R., Lieblich, A., McAdams, D. P. (Eds.) *Up close and personal: The teaching and learning of narrative research*. (pp. 79-99). Washington D.C.: American Psychological Association.
- Cole, B. A. (2005). 'Good faith and effort?' Perspectives on educational inclusion. *Disability & Society, 20*(3), 331-344.
- Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research, 50*(6), 432-444.
- Cunningham, C., & Glenn, S. (2004). Self-awareness in young adults with Down syndrome: I. Awareness of Down syndrome and disability. *International Journal of Disability, Development and Education, 51*(4), 335-361.
- Davis, A. S. (2008). Children with Down syndrome: implications for assessment and intervention in the school. *School Psychology Quarterly, 23*(2), 271-281.
- de Graaf, G., van Hove, G., & Haveman, M. (2013). More academics in regular schools? The effect of regular versus special school placement on academic skills in Dutch primary school students with Down syndrome. *Journal of Intellectual Disability Research, 57*(1), 21-38.

- Downing, J. E., & Peckham-Hardin, K. D. (2007). Inclusive education: what makes it a good education for students with moderate to severe disabilities? *Research & Practice for Persons with Severe Disabilities* (32)1, 16-30.
- Doyle, M.B., & Giangreco, M. (2013). Guiding principles for including high school students with intellectual disabilities in general education classes. *American Secondary Education*, 42(1), 57-72.
- Dykens, E. M., Shah, B., Davis, B., Baker, C., Fife, T., & Fitzpatrick, J. (2015). Psychiatric disorders in adolescents and young adults with Down syndrome and other intellectual disabilities. *Journal of Neurodevelopmental Disorders*, 7(9), 1-8.
- Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual & Developmental Disability*, 36(2), 137-143.
- Fidler, D. J., & Nadel, L. (2007). Education and children with Down syndrome: neuroscience, development and intervention. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 262-271.
- Fisher, M., & Meyer, L. H. (2002). Development and social competence after two years for students enrolled in inclusive and self-contained educational programs. *Research & Practice for Persons with Severe Disabilities*, 27(3), 165-174.
- Fitch, F. (2003). Inclusion, exclusion and ideology: special education students' changing sense of self. *The Urban Review*, 35(3), 233-252.
- Foreman, P., Arthur-Kelly, M., & Pascoe, S. (2004). Evaluating the educational experiences of students with profound and multiple disabilities in inclusive and segregated classroom

- settings: an Australian perspective. *Research & Practice for Persons with Severe Disabilities*, 29(3), 183-193.
- Fowler, A. E. (1988). Determinants or rate of language growth in children with Ds. In Nadel, L. Editor (Ed.) *The Psychobiology of Down Syndrome*. (pp. 216-245). Cambridge, MA: MIT Press.
- Garrick Duhaney, L. M. & Salend, S. J. (2000). Parental perspectives of inclusive educational placements. *Remedial and Special Education*, 21(2), 121-128.
- Gibb, K., Tunbridge, D., Chua, A., & Frederickson, N. (2007). Pathways to inclusion: moving from special school to mainstream. *Educational Psychology in Practice*, 23(2), 109-127.
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: an explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192-199.
- Gordon, J. (2013). Is inclusive education a human right? *Journal of Law, Medicine and Ethics*, 41(4), 754-767.
- Gupta, N. A., & Kabra, M. (2014). Diagnosis and management of Down syndrome. *Indian Journal of Pediatrics*, 81(6), 560-567.
- Handler, B. R. (2007). Who's in the classroom down the hall? An examination of demographic shifts within segregated special education classrooms, 1975-2005. *American Educational History Journal*, 34(2), 379-393.
- Hanson, M. J., Horn, E., Sandall, S., Beckman, P., Morgan, M., Marquart, J., Barnwell, D., Chou, H. (2001). After preschool inclusion: Children's educational pathways over the early school years. *Exceptional Children*, 68(1), 65-83.

- Harris, J. C. (2006). Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment. New York: Oxford University Press.
- Heiman, T. (2000). Friendship quality among children in three educational settings. *Journal of Intellectual & Developmental Disability*, 25(1), 1-12.
- Huck, S. Kemp, C., & Carter, M. (2010). Self-concept of children with intellectual disability in mainstream settings. *Journal of Intellectual & Developmental Disability*, 35(3), 141-154.
- Idol, L. (2006). Toward Inclusion of Special Education Students in General Education. *Remedial and Special Education*, 27(2), 77-94.
- Jacola, L.M., Hickey, F., Howe, S.R., Esbensen, A., & Shear, P.K. (2014). Behavior and adaptive functioning in adolescents with Down syndrome: specifying targets for intervention. *Journal of Mental Health Research in Intellectual Disabilities*, 7(4), 287-305.
- Jones, M. N., Thorn, C. R., Chow, P., Thompson, I. S., & Wilde, C. (2002). Equifinality: parents' and students' attitudes towards a student-centered approach to integration. *Education*, 122(3), 624-635.
- Jones, P. (ed). (2014). *Bringing Insider Perspectives into Inclusive Teacher Learning*. New York: Routledge.
- Jones, P., White, J. M., Fauske, J. R., & Carr, J. F. (2011). *Leading for Inclusion*. New York: Teachers College Press.
- Kasari, C. Freeman, S. F. N., Bauminger, N., & Alkin, M. (1999). Parental perspectives on inclusion: Effects of autism and Down syndrome. *Journal of Autism and Developmental Disorders*, 29, 297-305.

- Kluth, P., Biklen, D. P., & Straut, D. M. (2003). Access to academics for all students. In Kluth, P., Straut, D. M., & Biklen, D. P. Editor (Eds.) *Access to Academics for All Students*. (pp. 1-31). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Kurth, J. A., Morningstar, M. E., & Kozleski, E. B. (2014). The persistence of highly restrictive special education placements for students with low-incidence disabilities. *Research and Practice for Persons with Severe Disabilities*, 39(3), 227-239.
- Lalvani, P. (2013). Land of misfit toys: mothers' perspectives of educational environments for their children with Down syndrome. *International Journal of Inclusive Education*, 17(5), 435-448.
- Leshin, L. (2002). Pediatric health update on Down syndrome. In Cohen, W. I., Nadel, L. and Madnick, M. E. Editors (Eds.) *Down Syndrome: Visions for the 21<sup>st</sup> Century*. (pp. 187-201). New York, NY: Wiley-Liss, Inc.
- Leyser, Y., & Kirk, R. (2004.) Evaluating inclusion: an examination of parent views and factors influencing their perspectives. *International Journal of Disability, Development and Education*, 51(3), 271-285.
- Lichtman, M. (2013). *Qualitative Research in Education: A User's Guide* (3<sup>rd</sup> ed.). Los Angeles: Sage.
- Lightfoot, L., & Bond, C. (2013). An exploration of primary to secondary school transition planning for children with Down's syndrome. *Educational Psychology in Practice*, 29(2), 163-179.
- Lloyd, T., & Hastings, R. P. (2008). Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research*, 52(1), 37-48.

- Lupart, J., & Webber, C. (2012). Canadian Schools in Transition: Moving From Dual Education Systems to Inclusive Schools. *Exceptionality Education International*, 22(2), 8–37.
- Mock, D. R., & Kauffman, J. M. (2004). The Delusion of Full Inclusion. In Jacobson, J. W. Editor, Foxx, R. M. Editor & Mulick, J. A. Editor (Eds.) *Controversial therapies for developmental disabilities: Fad, fashion and science in professional practice*. (pp.113-128). New York, NY: Routledge.
- Nadel, L. (1988). Afterword: Down syndrome in psychobiological profile. In Nadel, L. Editor (Ed.) *The Psychobiology of Down Syndrome*. (pp. 369-374). Cambridge, MA: MIT Press.
- Norwich, B. (2008). What future for special schools and inclusion? Conceptual and professional perspectives. *British Journal of Special Education*, 35(3), 136-143.
- Oelwein, P. L. (2002). Liberation from traditional reading and math teaching methods and measurements. In Cohen, W. I., Nadel, L. and Madnick, M. E. Editors (Eds.) *Down Syndrome: Visions for the 21<sup>st</sup> Century*. (pp. 421-436). New York, NY: Wiley-Liss, Inc.
- Pan, C., Liu, C., Chung, C., & Hsu, P. (2015). Physical activity levels of adolescents with and without intellectual disabilities during physical education and recess. *Research in Developmental Disabilities*, 36, 579-586.
- Patterson, B. (2002). Behavioral concerns in persons with Down syndrome. In Cohen, W. I., Nadel, L. and Madnick, M. E. Editors (Eds.) *Down Syndrome: Visions for the 21<sup>st</sup> Century*. (pp. 215-219). New York, NY: Wiley-Liss, Inc.
- Peetsma, T., Vergeer, M., Roeleveld, J., & Karsten, S. (2001). Inclusion in education: comparing pupils' development in special and regular education. *Educational Review*, 53(2), 125-135.

- Pelatti, C. Y. (2015). Enhancing oral and written language for adolescents and young adults with Down syndrome. *Seminars in Speech and Language Development*, 36(1), 50-59.
- Pueschel, S. M. (2002). Visual and auditory processing in children with Down syndrome. In Nadel, L. Editor (Ed.) *The Psychobiology of Down Syndrome*. (pp. 199-216). Cambridge, MA: MIT Press.
- Rogers, C. (2013). Inclusive education and intellectual disability: a sociological engagement with Martha Nussbaum. *International Journal of Inclusive Education*, 17(9), 988-1002.
- Roulston, K. (2010). Considering quality in qualitative interviewing. *Qualitative Research*, 10(2), 199-228.
- Ryndak, D. L., Jackson, L., & Billingsley, F. (2010). Defining school inclusion for students with moderate to severe disabilities: what do experts say? *Exceptionality*, 8(2), 101-116.
- Sailor, W. S. & McCart, A.B. (2014). Stars in alignment. *Research and Practice for Persons with Severe Disabilities*, 39(1), 55-64.
- Smith, P. (2007). Have we made any progress? Including students with intellectual disabilities in regular education classrooms. *Intellectual and Developmental Disabilities*, 45(5), 297-309.
- Turner, S. Alborz, A., & Gayle, V. (2008). Predictors of academic attainments of young people with Down's syndrome. *Journal of Intellectual Disability Research*, 52(5), 380-392.
- Valle, J. W. (2011). Down the rabbit hole: A commentary about research on parents and special education. *Learning Disability Quarterly*, 34(3), 183-190.
- Villa, R. A., & Thousand, J. (2002). Inclusion: welcoming, valuing and supporting the diverse learning needs of all students in shared general education environments. In Cohen, W. I.,

- Nadel, L. and Madnick, M. E. Editors (Eds.) *Down Syndrome: Visions for the 21<sup>st</sup> Century*. (pp. 339-356). New York, NY: Wiley-Liss, Inc.
- Vimercati, S. L., Galli, M., Stella, G., Caiazzo, G., Ancillao, A., & Albertini, G. (2015). Clumsiness in fine motor tasks: evidence from the quantitative drawing evaluation of children with Down syndrome. *Journal of Intellectual Disability Research*, 59(3), 248-256.
- Williamson, P., McLeskey, J., Hoppey, D., & Rentz, T. (2006). Educating students with mental retardation in general education classrooms. *Exceptional Children*, 72(3), 347-361.
- Wisniewski, K. E., Mizejeski, C. M., & Hill, A. L. (1988). Neurological and psychological status of individuals with Down syndrome. In Nadel, L. Editor (Ed.) *The Psychobiology of Down Syndrome*. (pp. 315-343). Cambridge, MA: MIT Press.
- Wolpert, G. (2001). What general educators have to say about successfully including students with Down syndrome in their classes. *Journal of Research in Childhood Education*, 16(1), 28-38.
- Zellman, G. L. & Waterman, J. M. (1998). Understanding the impact of parent school involvement on children's educational outcomes. *The Journal of Educational Research*, 91(6), 370-380.
- “A 25 Year History of the IDEA.” (2007).  
<http://www2.ed.gov/policy/speced/leg/idea/history.html> Accessed 30.4.15.
- “Building the Legacy of IDEA 2004.” (2014).  
<http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CA%2C300%252E8%2C>  
 Accessed 24.1.15.
- “Down Syndrome Facts.” (2012). <http://www.ndss.org/Down-Syndrome/Down-Syndrome-Facts/>

Accessed 13.5.15.

“Questions and Answers on Least Restrictive Environment (LRE) Requirements of the IDEA.”

(1994). <http://www.wrightslaw.com/info/lre.osers.memo.idea.htm> Accessed 30.4.15.

“What is Down Syndrome?” (2012).

<http://www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome/> Accessed 21.4.15.

“Genes and Human Disease” (2015).

<http://www.who.int/genomics/public/geneticdiseases/en/index1.html> Accessed 13.5.15.

National Study of Inclusive Education, National Center on Educational Restructuring & Inclusion, The Graduate School and University Center, The City University of New York  
June 1994

Goodwin, T. C., Nevins, S. & Wurzburg, G. (Producers), & Wurzburg, G. (Director).

(1992). *Educating Peter* [Motion picture]. United States: Direct Cinema Limited.

Nevins, S. & Wurzburg, G. (Producers), & Wurzburg, G. (Director). (2001). *Graduating Peter* [Motion picture]. United States: Direct Cinema Limited.

**APPENDIX A**  
**IRB APPROVAL LETTER**



RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, IWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33613-1799  
(813) 974-3628 • FAX(813)974-4091

December 3, 2015

Stacey Mulrenin  
Educational and Psychological Studies  
Tampa, FL 33612

**RE: Expedited Approval for Initial Review**  
IRB#: Pro00022992  
Title: Teaching Students with Down Syndrome: Mothers' Perspectives on the Most Appropriate Educational Environments for Their Children

**Study Approval Period: 12/2/2015 to 12/2/2016**

Dear Ms. Mulrenin:

On 12/2/2015, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

**Approved Item(s):**

**Protocol Document(s):**

[Research Protocol Mulrenin.docx](#)

**Consent/Assent Document(s)\*:**

[CONSENT FORM USE Mulrenin 22992 Nov 24.docx.pdf](#)

\*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review

**APPENDIX B**  
**PARTICIPANT RECRUITMENT LETTER**

November 2015

Greetings!

I am a former ESE teacher who is now working toward an advanced degree in School Psychology at USF. My thesis will focus on the educational journeys of children with Down syndrome through their mothers' eyes. I plan to conduct individual interviews with mothers who agree to participate as well arrange for a focus group with all of the mothers (all who have children with Down syndrome of different ages and backgrounds). My goal is to learn about the positive and/or negative educational experiences of the children, through their mothers' perspectives, as well as the goals the mothers have for their children and how those could be accomplished.

I am looking for mothers of children with Down syndrome who are currently enrolled in school to participate. The questions I ask will include the setting(s) in which your child has been formally educated and what you believe has benefitted or hindered his/her cognitive, behavioral and social development. I will also ask you to provide me with personal information about your child, including his/her interests, strengths and challenges. The interview will be audiotaped and transcribed; however, in my written report, I will use pseudonyms for you and your child and de-identify any information you share with me. The interview process will take 1-2 hours. I will also ask you to write a response to a journal prompt I give you. Once I have interviewed all the participating mothers, I will hold a focus group for all of you to meet and share your stories with one another.

If you are interested in participating in my study, please email or call me. I certainly appreciate your time and consideration.

Sincerely,

Stacey Mulrenin

813-368-2159

[stacey.mulrenin@gmail.com](mailto:stacey.mulrenin@gmail.com)



## APPENDIX C

### INFORMED CONSENT

#### Informed Consent to Participate in Research Involving Minimal Risk

Pro # 22992

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You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher to discuss this consent form with you, and explain any words or information you do not clearly understand. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

The research study is called:

#### **Teaching Students with Down Syndrome: Mothers' Perspectives on the Most Appropriate Educational Environments for Their Children**

The person who is in charge of this research study is **Stacey Mulrenin**. This person is called the Principal Investigator (PI). However, other research staff may be involved and can act on behalf of the person in charge. The PI is being guided in this research by **Dr. Linda Raffaele Mendez**

The research will be conducted at sites to be determined – public places in the community or the home of the participants.

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#### **Purpose of the study**

The purpose of this interpretive, qualitative inquiry is to study the perspectives mothers of children with Down syndrome of different ages, from pre-school years through secondary, hold regarding the settings in which they have been educated. It will provide insight into (a) the factors mothers of children with Down syndrome consider regarding the most appropriate educational setting for their child; (b) the barriers mothers encounter to placing their child with Down syndrome in a desired educational setting; and (c) how and why mothers change their views of what constitutes the best educational placement for their child. The ultimate goal is to better understand the academic and non-academic factors mothers of

children with Down syndrome consider when deciding upon a school placement for their children.

## **Why are you being asked to take part?**

You are being asked to participate in this research study because you are the mother of a child with Down syndrome.

## **Study Procedures:**

If you agree to take part in this study, you will be asked to:

- Participate in one individual interview with the PI. You will be asked to share stories about your relationship with your child, his/her school experiences and your beliefs/opinions about the positive and negative outcomes from those experiences. The interview will be audio-recorded and transcribed by the PI. A peer colleague of the PI will examine the transcribed interview in order to verify the presence of themes.
- Participate in a follow up conversation with the PI where you will confirm your transcribed interview.
- Participate in a focus group with the other participants and the PI.
- The interview will take approximately one-two hours and will occur either at a public place that is mutually agreeable or at your home. The focus group will take approximately two hours at a location determined by the PI.
- The records of this study will be kept private. In any sort of report the PI makes public, information that will make it possible to identify you will not be included. Research records will be kept in a locked file; only the PI will have access to the records. Within 5 years after the Final Report is submitted to the IRB, the PI will destroy the audio recordings.

## **Total Number of Participants**

Six individual mothers will take part in this study at USF.

## **Alternatives / Voluntary Participation / Withdrawal**

You do not have to participate in this research study.

## **Benefits**

There are no known benefits from participating in this research study. However, it is hoped that you will benefit from:

- Having an opportunity to share your beliefs and opinions about your child's education and options available to him/her
- Connecting with other mothers of children with Down syndrome.

## **Risks or Discomfort**

The following risks may occur:

- Some of the questions about your child and beliefs may be of a sensitive nature.

## Compensation

You will receive no payment or other compensation for taking part in this study.

## Costs

It will not cost you anything to take part in the study.

## Privacy and Confidentiality

Your study records will be kept private and confidential. Certain people may need to see your study records. Anyone who looks at your records must keep them confidential. These individuals include:

- The research team, including the Principal Investigator, and Thesis committee members.
- Certain government and university people who need to know more about the study, and individuals who provide oversight to ensure that we are doing the study in the right way.
- Any agency of the federal, state, or local government that regulates this research. *Office for Human Research Protection (OHRP)*.
- The USF Institutional Review Board (IRB) and related staff who have oversight responsibilities for this study, including staff in USF Research Integrity and Compliance.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

## You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, call Stacey Mulrenin at 813-368-2159.

If you have questions about your rights as a participant in this study, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.

## Consent to Take Part in this Research Study

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

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Signature of Person Taking Part in Study

Date

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Printed Name of Person Taking Part in Study

## Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to

explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.

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Signature of Person obtaining Informed Consent

Date

---

Printed Name of Person Obtaining Informed Consent

## APPENDIX D

### INTERVIEW GUIDE

To open the dialogical conversation for interviews, I will begin by explaining to the participant the nature of my study and her purpose within it:

*Every parent goes on an educational journey with their child. What I'd like to discuss with you today is your child's educational journey and what you've learned along the way.*

Next, I will pose my first set of questions to the participant:

*Tell me about your child's first experience in a formal educational setting, such as a pre-Kindergarten class, EELP, or Kindergarten.*

- 1. What factors did you consider when choosing it?*
- 2. What worked well for your child and what did not work well for your child in that setting?*
- 3. When you looked at the work your child was completing, did you feel satisfied? Did it feel appropriate?*
- 4. When you shared with others about this school, what did you tell them? What made you happy? What saddened or worried you?*
- 5. What was the homework that your child completed? How was communication with the teacher(s)? What were your child's peer relationships like?*

After the initial educational journey of the child is fully explored, I will transition:

*Is your child still at that school or did he/she change to another school?*

6. *What was your takeaway from the first school and what factors dictated your choice for the next setting?*

I will then ask the same questions I posed for the child's first educational experience for each school the child has attended. After this, I will move into the mother's vision for the ideal educational environment for her child.

*Let's now discuss what your vision for what would make the best learning environment for your child.*

7. *If you could design a school that would be the ideal learning environment for your child, describe for me what it would look like.*
8. *What would the student population look like in this ideal school? What about the curriculum and resources?*
9. *To what degree have you been able to find this ideal school in our community? What would need to be added or deleted to your child's current learning environment to make it ideal?*

Finally, I will wrap up with an opportunity for the participant to summarize the story of her child's educational journey:

*All parents experience joys and triumphs on their child's educational journey – these are what we would consider the highs. We also face disappointments and frustrations and think of these as the “lows”*

10. *Tell me about the highs and lows you've experienced as you've taken this journey with your child.*

*11. What have you learned through your child's educational journey that you would want to share with a mother of a young child with Down syndrome?*

## APPENDIX E

### PARTICIPANT DEMOGRAPHIC INFORMATION FORM

Please complete the following questions so I may describe the demographic characteristics of the mothers in my sample.

1. Pseudonym you prefer \_\_\_\_\_
2. Pseudonym for your Child with Ds \_\_\_\_\_
3. What is your age? \_\_\_\_\_
4. What is the age of your child with Ds? \_\_\_\_\_
5. What is the highest level of education you completed? \_\_\_\_\_
6. Do you currently work outside your home?      Yes      No
7. If you answered yes to #6, how many hours per week do you work? \_\_\_\_\_
8. What is your current profession? \_\_\_\_\_
9. What is your marital status? \_\_\_\_\_
10. If you are comfortable sharing this information, please note your annual household gross income \_\_\_\_\_
11. How would you describe your ethnicity? \_\_\_\_\_
12. How many other children live in your home? \_\_\_\_\_
13. What are the ages of the other children living in your home? \_\_\_\_\_
14. Do any of your other children have special needs? \_\_\_\_\_
15. If you answered “yes” to #14, please describe your child(rens’) special needs  
\_\_\_\_\_