The Educational Experiences of Students with Smith-Magenis Syndrome:

Parental Perceptions

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ABSTRACT

Smith-Magenis Syndrome (SMS) is a rare genetic disorder that effects 1 in 25,000 people. Characteristics include cognitive impairments, vision and hearing impairments, severe behavioral problems, maladaptive behaviors, impulsivity, aggression, self-injury, and sleep deprivation. A qualitative approach was employed to study the educational experiences of students with SMS in K-5 school settings in the United States. Eight parents were interviewed during this study. At the conclusion of the study, results indicated that students with SMS had distinct experiences within the school setting. These experiences include behavioral challenges, sleep deprivation, positive impacts within their community, a dichotomized social portrait, challenges and successes within the academic environment, and misunderstandings related to their syndrome and needs.

*Key words*: Smith-Magenis Syndrome, Person-environment interaction, Four-fronts approach, parental perceptions, qualitative, disability, school, education
DEDICATION

For my son Gavin, you are an inspiration to us all. Your remarkable beauty is undeniable. You are a true gift to us. Thank you for being who you are, and for giving me the strength to tell this story. You’ve made us all better.

For my wife Erin, you are the love of my life. Thank you for your patience and guidance throughout this process. I could not have done this without you.

For my son Eli and daughter Paige, two of the most beautiful people I will ever know. Thanks for surrounding me with your love each and every day. You inspire me to do my best.

For families everywhere who face the unknowns of rare syndromes, disorders, and diseases, continue to tell your stories so that others may experience the magnificence of your loved ones. They help all of us become better people.
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Chapter One: Introduction

Problem of Practice

Smith-Magenis Syndrome (SMS) is a rare genetic disorder that affects approximately 1 in 25,000 people (Greenberg et al., 1991; Finacune et al., 2001). The syndrome is caused by a micro-deletion on chromosome seventeen (17p11.2) which can cause a variety of distinct physical, behavioral, and developmental characteristics (Martin et al., 2006). These characteristics include cognitive impairments, vision and hearing impairments, severe behavioral problems, maladaptive behaviors, impulsivity, aggression, self-injury, and sleep deprivation due to an inverted circadian rhythm of melatonin (Dykens and Smith, 1998; Finacune et al., 2001; De Leersnyder et al., 2001). Both families and professionals report that the behaviors of people with SMS are “extraordinarily disruptive and hard to manage” (Dykens & Smith, 1998). SMS is most likely under diagnosed due to the overlap in symptoms related to other disorders (Smith & Gropman, 2001), with an estimated 600 cases reported worldwide.

Due to the under diagnoses of SMS, coupled with the fact that it is a rare genetic disorder, scholarly work supporting the needs of students with SMS is virtually non-existent. Upon an extensive review of literature, no published articles on the school experiences of students with SMS surfaced. Upon further review only two articles that address the educational needs of students with SMS surfaced, neither being published in a scholarly journal (Haas-Givler, 1994; Haas-Givler and Finucane, 1995). When the articles were written, Barbara Haas-Givler (1994) stated that she was “discouraged to find that there was not even one article that specifically discussed the educational needs of this unique group of children”, and hoped that her information would “serve as the basis for future research into the educational needs of children
and adults with SMS” (Haas-Givler, 1994, p. 1). Even more discouraging may be that fact that more than twenty years after her second article, there are still no published research articles that specifically discuss the school experiences of students with SMS.

Students with SMS face significant educational challenges very different than those of their peers, and require both an understanding of their unique needs and appropriate educational programming to support them. A lack of educational literature focused on the needs of students with SMS is clearly problematic and the need for specific research targeting their educational experiences is necessary.

**Significance of the Problem**

Since SMS was first identified in 1982 (Smith et al., 1982), not a single scholar has published a research article that specifically addresses the needs of people with SMS in a school or educational setting. Students with SMS face challenges that are sometimes similar, but often very different from their peers. Students with SMS have significantly higher levels of maladaptive behaviors, are extraordinarily disruptive and hard to manage, and are more demanding of attention than their counterparts with similar disabilities (Dykens & Smith, 1998). Additionally, children with SMS exhibit significant behavioral problems, “including temper tantrums, self-injurious behaviors, and physical aggression toward others” (Martin et al., 2006, p. 542). Evidence also suggests that the behavior problems associated with children with SMS are often more severe than populations with similar genetic syndromes, including externalizing behaviors (Martin et al., 2006).

This problem is significant because without conducting proper research to understand the educational experiences of students with SMS, schools, teachers, and parents are left without the
information needed to provide the most appropriate educational services for children with SMS. Without sufficient research, families of and students with SMS may continue to be underserved by an educational system that does not fully understand the unique needs of these students.

In an era where The Educational for All Handicapped Children Act of 1974, and the reauthorized Individuals with Disabilities Education Act (IDEA) of 2004 have been authored to ensure educational equity, students with SMS may not be receiving an optimal educational experience because so little is known about them. IDEA requires that all students who are found to be eligible under both the federal and state eligibility/disability standards to be provided an Individualized Education Program. In particular, IDEA requires that the IEP meets the child's needs that result from the child's disability to enable the child to be involved in and make progress in the general education curriculum, and the IEP must meet each of the child's other educational needs that result from the child's disability (U.S Department of Education, 2006). Without appropriate research that specifically addresses the needs of students with SMS, school experiences designed for students with SMS may not be developed to their full potential in serving this unique population.

**Practical and Intellectual Goals**

This research accomplishes a variety of practical and intellectual goals. As a father of a child with SMS, these goals are personally relevant. The research presented within specifically addresses two goals. (1) To develop further understanding of the educational experiences of children with Smith-Magenis Syndrome in K-5 settings. (2) To establish an intellectual understanding of the role that the environment plays in supporting the educational experiences of those affected by Smith-Magenis Syndrome.
To accomplish these goals, the research explores the following research questions. (1) How do parents of children with Smith-Magenis Syndrome perceive their child’s interactions with the educational environment? (2) What aspects of the educational experience are parents of children with Smith-Magenis Syndrome most and least satisfied with in the K-5 setting? (3) What can we learn from parents of children with SMS that can be applied in the classroom? (4) How can the educational experiences of those with Smith-Magenis Syndrome be improved in the K-5 setting?

**Theoretical Framework**

The theoretical understandings that provide the framework for this research are heavily influenced by Person-Environment Interaction theory (PEI) (Lewin, 1935), as well as Wright and Lopez’s (2002) accompanying Four-front approach to the PEI framework. Additionally, the Social Model of Disability theory, a deficit model, plays a minor but complementary role in this research, supporting the four-front approach to the PEI framework through understandings of disability as social pathology. For the purpose of this research, the four-front approach and Person-environment interaction will be used as the primary theoretical framework, grounding the research in an environmental context, with the social model of disability theory providing accompanying supports linking the framework to existing thinking on disability studies. Person-Environment Interaction Theory contends that environmental factors play a part in how individuals interrelate with their surroundings, and that their behaviors can be altered through environmental influences (Lewin, 1935). The four-front approach analyzes the behavior of individuals in an environmental context, allowing for a multi-directional analysis from the perspective of both the individual’s strengths and weaknesses, as well as that of the immediate environment (Wright & Lopez, 2002). The Four-front approach and Person-Environment
Interaction theories are used as the primary theoretical framework, grounding the research in an environmental context. The two theories provide a context that helps to traverse existing understandings of disability and the environment. Francescutti et al. (2011) describe the PEI framework as important in understanding disability as a systemic process, complimentary of the social model of disability, and involving more than just the individual:

Defining disability as the result of an interaction between a person and the environment directly implies that disability is a systemic attribute. This connection is the foundation of the so-called “social model” of disability insofar as the scenario that defines disability regards more actors than the individual, including the relationship with the social context. (Francescutti, 2011, p.2)

To understand the experiences of students with Smith-Magenis Syndrome in public school settings, the research presented within relies on a the Four-fronts approach, a PEI framework first introduced by Wright and Lopez (2002). This framework has allowed the study to analyze the student experience as one that includes the strengths and virtues of children with SMS, rather than focusing entirely on the deficits that exist. The social model of disability is important, as it presents the notion that disabilities are socially produced and that social barriers often limit or constrain the lives of those with disabilities (Marks, 1999, Siebers, 2008, Barnes, et al. 2002, Corker et al. 1999, Herndl, 2005, Carrier, 1983) While understanding deficits are an important understanding, focusing equally on the strengths of these students has allowed for a greater understanding of the student holistically, and has provided avenues for building greater capacity (Wright & Lopez, 2002).
**Person-Environment Interaction.** Person-Environment Interaction theory can be defined through multiple frameworks; however, its roots have been developed through a long existing analysis on the effects the environment has on the individual. The essential understanding is that environmental factors play a role in how an individual interacts with his/her surroundings, and through environmental manipulations or understandings, the behaviors of individuals can be altered (Lewin, 1935). This theoretical understanding is important, because while research related to students with SMS in educational settings cannot alter the genetic and biological differences these students present in comparison to their peers, it can support an understanding of environmental implications on these students and offer solutions to support greater levels of learning and understanding on the part of students with Smith-Magenis Syndrome.

Lewin (1935) addressed the importance of the environment on the behavior and development of children, specifically stating, “all aspects of the child’s behavior…are codetermined by the existing environment” (Lewin, p.66, 1935). Lewin further elaborated on his understandings, developing the Lewinian formula, $B = f(P, E)$, which stressed behavior as a function of the person and the environment (Lewin, 1935; Fraser, 1983; Hunt, 1975). The formula was developed to highlight the need to further research in which behavior functions with relation to the person and his/her environment (Fraser, 1983).

The development of the Person-Environment Interaction theory and the understandings that individual behaviors can be a function of both the person and the environment was addressed in large part in the book, *Learning and Individual Differences*, in which a variety of authors addressed individuality within the context of learning. Cronbach (1963) attends to the topic of learners and how instructional approaches can be adapted through altering instruction, or
matching goals to the individual. Cronbach notes that while tactics by schools are often used to minimize the difficulties of individual differences, when teachers do adapt instruction to meet individual differences, advantages often exist (Gagne, 1963). These adaptations are essential in altering the environment in ways that function to change behavior.

James V. Mitchell (1969) suggests that the “determinants of behavior” should be “sought more often” within the confines of the environment, and with relation to the interactions of the characteristics of the individual (p.696). Mitchell contends that the “search for individual characteristics in vacuum can lead only to partial understanding or no understanding at all” (p. 696). He argues that this type of interaction should not be difficult to accept in understanding human behavior, and that in some cases the environmental context may play a larger role in how an individual behaves than the individual traits themselves (Mitchell, 1969). This argument is supported by research conducted by Bass and Speak (2005) regarding the modifications made to address self-injurious behaviors presented by a woman with Smith-Magenis Syndrome. The authors treated the woman through a variety of interventions that included the differential reinforcement of other behaviors, self-monitoring and social reinforcement, and extinction. The results of this research showed a reduced frequency of self-injurious behavior, as well as reduced aggression toward others when behavioral interventions were introduced (Bass & Speak, 2005). The authors concluded that “the results of this study suggest environmental factors may play a significant role in maintaining some self-injurious behavior shown by people with Smith-Magenis Syndrome” (Bass and Speak, 2005. P.361).

Mitchell (1969) continues in his analysis of Person-Environment Interaction, contending that true understandings of this type of interaction would require multivariate terms, responding to “multi-trait individuals” and “multi-characteristic environments” (p. 698). This assumption
supports the Four-front approach presented by Wright and Lopez (2002), which analyzes the Person-Environment Interaction from multiple perspectives regarding both the individual and his/her environmental context. Jensen (1968) states that “perhaps our greatest hope of achieving equality of educational opportunity lies in the possibility of finding significant patterns of individual differences in the development of abilities and in taking advantage of these differences” to create optimal instruction to pupil interactions (p. 23). This type of thinking has been strengthened through recent national and local movements that support differentiated instruction, Positive Behavior Intervention Support, Universal Design for Learning and the process of Response to Intervention in schools.

Person-Environment Interaction is further developed through the B-P-E paradigm suggested by Hunt (1975), which proposes four characteristics in understanding the interaction between an individual and the environment. Hunt (1975) proposed that the B-P-E paradigm: (1) be interactive in coordinating PEI, as well as differential behavioral effects, (2) view the person developmentally, (3) consider PEI reciprocally, in terms of the effect the environment has on the individual, as well as the effect the individual has on the environment, and (4) consider the practicality of the interactions, so that the understandings can be made applicable. Hunt argues that this approach requires a change in how one thinks or asks about an individual. For example, instead of asking, “which instructional approach is better?”, one should instead ask “for whom?” and “for what purpose?” (Hunt, 1975, p. 218). Thinking about these situations in a differential context will allow educators to meet the needs of diverse learners as individuals who respond differently to the environment than their peers. A differential approach will enable an understanding, in particular for students with SMS, of how the environment (instruction, grouping, classroom arrangement) can be utilized to support learners and enable positive learning.
outcomes. Hunt (1975) views the B-P-E paradigm as a coordination of earlier assessments of Person-Environment Interaction, defining the formula as learning (B), as a function of the type of student (P), and the way of teaching (E).

An important aspect of understanding the PEI framework, is understanding not only the environmental effects on an individual, but also understanding the individual as a product of both his/her own genetics as well as a product of the environment. Understanding the person and his/her behaviors as “error” would provide us with no value in understanding the context in which the behaviors were developed (Vale, 1969, p. 1095). Hunt (1975) presents this case in his interpretation of Vale (1969), and helps propel Vale’s understandings of both the individual and the environment, setting up an important foundation in which research on PEI and student’s with genetic disorders, like SMS, can exist. According to Hunt (1975), Vale (1969) observed that:

The way in which we regard individual differences may thus depend upon the way we consider them to have come about. If we think of them as error, their information value is nonexistent. On the other hand, if we understand their genetic as well as their environmental base and understand them to be integrated to the evolution that all behavior can be assumed to have undergone, individual differences become highly important in the search for behavioral determinants (Hunt, 1975, p. 222).

The observations made by Vale (1969) and supported by Hunt (1975) create an avenue in which to evaluate individual and environmental factors, without viewing behavior as an isolated element related to human error. This is an incredibly significant concept when considering the behaviors of students with Smith-Magenis Syndrome. Students with SMS present a number of extremely challenging behaviors; however these behaviors in many cases can be attributed to the
genetic individuality of the student, making them not “error”, but as unique human behaviors associated with their individual genetic makeup.

Wang and Mauritz-Lindvall (1984) argue in favor of designing learning environments that “enable students to achieve desired outcomes” (p. 161). The authors support prior thinking by others familiar with the PEI framework, and contend that “learning is a function of the learner's response to the environment” and that “instruction is the intentional manipulation of the learning environment to facilitate appropriate responses” (Wang & Mauritz-Lindvall, 1984, p. 161). If so, these manipulations can and should support students with SMS, if understood correctly. These manipulations would be an important step in creating learning environments that support students with SMS, in an otherwise void area of research and understanding.

Most recently, the work of Thompson et al. (2010) focuses on the PEI framework with relation to students with disabilities and the implications these understandings would have on students, schools, and teachers. The authors argue that the PEI model, as well as other models relating to this framework, would have the potential to enhance the educational opportunities of students with disabilities. At the same time, the use of these models to understand and support student with disabilities, would contrast existing deficit models that focus heavily on deficiencies and “fixing the student” (Thompson et al., 2010, p. 168). The American Association on Intellectual and Developmental Disabilities (AAIDD) first promoted the idea of utilizing the PEI framework to address the needs of those with intellectual disabilities in 1992, and uses the World Health Organizations functional definition of disability where disability is defined “not as a defect…but as a poor fit between the person’s capacities and the context in which a person functions” (Thompson et al., 2010, p. 169).
Thompson et al. (2010) contend that there are three significant reasons as to why educators focusing on special needs students should adopt the PEI framework. First, it focuses its energy on the strengths of students as well as the environmental contexts in which they exist. Whereas other deficit models focus primarily on weaknesses, the PEI framework “focuses on the gap between a person’s capacities and the environment” as well as the implications it has for teachers to close this gap (p. 170). Secondly, the PEI approach supports already existing initiatives, including PBIS and UDL that work to implement interventions specifically designed to effect behavior. Not only do these types of interventions support students with disabilities, but they also are best practice approaches that support the academic achievement of all students. Finally, utilizing this approach allows students with disabilities to take control of their environments. By involving students in addressing their own needs, students begin to learn how to understand and navigate the gaps that exist between their own levels of ability and the environmental demands in which they exist (Thompson et al., 2010).

Thompson et al. (2010) argue that the move toward a PEI framework in understanding students with disabilities, allows educators to focus on “providing supplementary aids and supports that result in enhanced opportunities to learn across multiple activities and settings in addition to designing and implementing interventions that enhance student capacity” (p.171). The authors also make clear, that in no way are they suggesting that students with disabilities are without limitations if environmental constraints are addressed, however they do argue that while skills may be limited due to individual characteristics, additional constraints may be placed on students with disabilities due to environmental forces (Thompson et al., 2010).
**Four-Front Approach.** The Four-front approach looks explicitly at four areas of understanding that include both the strengths and weaknesses of the individual, as well as the resources and stressors relating to the environment (Neufeld et al, 2006). The Four-front approach aligns well within PEI framework, and presents a unique opportunity to examine the strengths of these individuals in understanding their environmental context. PEI focuses on the interactions that occur between a person and his/her environment, which helps to situate the disability “in the environment, not in the body” (Siebers, 2008, p.73). For example, students with SMS are often seen as loving, caring, eager to please, and humorous (Udwin, 2003), so one would hope that these students would be situated in environmental context that support these positive traits, rather than in a setting that may hinder their positive social attributes. Proponents of the social model of disability often understand the difficulties that present themselves due to physical, or mental impairment, however they contend that environmental forces often shape the experience to be more hindering than it presently should, and sometimes limit those with disabilities (Marks, 1999, Siebers, 2008, Barnes, et al. 2002, Corker et al. 1999, Herndl, 2005, Carrier, 1983).

Wright and Lopez (2002) assert that professionals should give “serious attention” to four distinct variables when assessing individuals. 1) Deficiencies and undermining characteristics of the person. 2) Strengths and assets of the person. 3) Lacks and destructive factors in the environment. 4) Resources and opportunities in the environment (Wright & Lopez, 2002). They present their framework as one that not only analyzes the individual and the environment, but also one that can support and lead to practical advancements in developing greater human capacity within those individuals. Wright and Lopez (2002) state that:
“Highlighting positives as well as negatives in both the person and the environment serves vital purposes…it affects the significance of the negatives and enlarges remediation possibilities. It also encourages the discovery of assets and resources that can be developed in serving human potential” (p. 81).

A critical component of this framework is the practical application it attempts to accomplish. Wright and Lopez (2002) ask the researcher to go beyond analysis of the individual, and to analyze the entire context in order to “ensure support” of the individual by providing practical solutions to existing environmental factors (p. 81). To accomplish this level of analysis, Wright and Lopez (2002) contend that information from the four fronts can be obtained through multiple assessments, including questionnaires, observations, and other collateral sources of information (Wright and Lopez, 2002).

The Four-front approach works as a complimentary framework in understanding the individual from a Person-Environment Interaction perspective. This approach balances the assessment of the individual, by examining both individual and environmental characteristics, and is useful as an entry point into understanding the interactions individuals have with their environments (Neufeld, et al, 2006). The approach allows for a critical analysis of the role the environment plays in the lives of students with Smith-Magenis Syndrome by examining the strengths and deficiencies of individual students, as well as the resources and barriers the environment presents. Additionally, this approach allows for practical and applicable solutions to surface, creating an opportunity to not only analyze the Person-Environment Interactions that exist, but to suggest interventions within those environments that would support students with SMS.
By utilizing the theoretical framework from the perspective of PEI and the Four-front approach, this research draws attention to the actual processes that are occurring in schools and classrooms where students with SMS are enrolled. The framework has allowed for the investigation of a variety of environmental facets, from instructional approaches and curricular decisions, to classroom arrangements and social groupings. Because this framework utilizes a multivariate approach, attention is not drawn to one particular function or process, but instead to a number of considerations, all of which play some role in the educational experience of students with SMS. As previously stated, the goal of this research has been to come to some understanding of the experiences of students with SMS in the school setting. To accurately determine these experiences, it was important to utilize an approach that takes into account the holistic nature of the experiences of students diagnosed with SMS.

**Chapter Two: Literature Review**

In examining the literature related to both students with SMS, as well as the environmental constructs related to the schooling process, this review focused on two distinct questions that correlated well with the Four-front approach theoretical framework. (1) What characteristics, both strengths and deficiencies, typically describe individuals with Smith-Magenis Syndrome? (2) How has the environment both supported, and hindered, the educational experiences of those with intellectual disabilities similar to those with SMS? The literature review looks specifically at these two themes of literature, creating a foundational understanding both students with SMS, and the role the environment plays with regard to students with special needs. The first body of literature focuses specifically on the characteristics of students with SMS with a particular focus on two distinct strands of understanding: Behavioral/developmental,
and educational characteristics of those with SMS. The second section focuses on the experiences of those with intellectual disabilities through the lens of parental perceptions, perceived experiences, and the environmental context. It should be noted that the literature regarding individuals with SMS is extremely limited due to its recent identification in 1982, its rare occurrence (approximately 1 in 25,000 births), and the identification of roughly only 600 cases worldwide (Greenberg et al., 1991; Finacune et al., 2001).

Behavioral characteristics of individuals with SMS. Smith-Magenis syndrome is a complex genetic disorder that is characterized by a variety of distinct developmental disabilities, along with number of behavioral phenotypes unique to SMS. These characteristics include intellectual disabilities, sleep disturbance, skeletal anomalies, vision and hearing impairments, impulsivity and hyperactivity, and both self-injurious and attention-seeking behaviors (Elsea & Girirajan, 2008; Dykens & Smith, 1998; Finacune et al., 2001; De Leersnyder et al., 2001; Smith et al., 1986). Behaviors in individuals with SMS can be extremely disruptive and are incredibly hard to manage (Dykens & Smith, 1998).

Self-injury is a common occurrence for those with SMS. In a comparative analysis of self-injurious behavior with similar groups of people with genetic syndromes, those with SMS showed the highest percentage of self-injury, constituting over 90% of those studied with the syndrome. The prevalence of self-injury in people with SMS was 6.32 times more likely to occur than the comparison group (Arron et al., 2011). In addition, individuals with SMS also showed a greater range of topographies of self-injury than their peers, exhibiting a range of self-injurious behaviors that include hitting one’s self with body, hitting self against object, hitting self with object, biting one’s self, pulling one’s self, rubbing/scratching one’s self, and inserting objects into body orifices (Arron et al., 2011). Arron (2011) also found high rates of physical
aggression in people with SMS. As was self-injury, physical aggression was found to be the highest among individuals with SMS in comparison to their peer groups. Over 73% of people studied by Arron with SMS were found to show some signs of physical aggression (Arron et. al., 2011).

These self-injurious behaviors, while prevalent at high rates in individuals with SMS, may also be related in some manner to environmental factors. Finucane et al. (2001) suggest that the result of self-injurious behavior may first be a result of gene expression due to sensations felt in the fingers and toes and often “reinforced by social consequences” (Bass & Speak, 2005). Finucane suggest that a behavioral approach might be successful in the treatment of self-injury in people with SMS (Finucane, 2001). Bass and Speak (2005) conducted research to test this hypothesis and found that in their study of a woman with SMS, behavioral interventions that included extinction, differential reinforcement, self-monitoring and social reinforcement were found effective in reducing the frequency and occurrence of self-injury. Additionally, the results also showed that through behavioral interventions, aggressive behavior towards others was also reduced (Bass & Speak, 2005). This study is important, because it offers promise that self-injury in people with SMS can potentially be reduced through targeted interventions and environmental changes.

The behaviors presented by individuals with SMS can be quite challenging. Sloneem et al. (2011) found that over 80% of those studied exhibited aggressive behaviors, with 100% of those under the age of 19 exhibiting some form of hitting. These aggressive behaviors were found to be related to a number of sub-scales, including attention, escape, self-stimulation, pain and discomfort, and access to tangible items. Those studies with SMS showed some form of physical aggression, verbal aggression, self-injury, and destruction in each sub-scale category,
with the highest forms of both physical and verbal aggression stemming from attention needs and escape, and the highest form of self-injury stemming from self-stimulation (Sloneem et al., 2011). The study had some important findings, specifically describing the “increased prevalence of challenging behaviors and impulsivity in SMS and a relationship between challenging behaviors and environmental events”, and found that impulsive behaviors can be correlated to challenging behaviors (Sloneem et al., 2011, p. 145-146). The authors also found that the etiology of aggression in individuals with SMS is likely related to operant factors, with physical and verbal aggression most related to positive reinforcement through attention seeking behaviors. In addition, the same may not be true for self-injury, with the authors finding that the prevalence of self-injury was most related to self-stimulation, and hence may not be as reliant on operant factors. This is not to suggest that operant factors do not play a role, Bass and Speak (2005) found in their study that they could, but it suggests that other more physiological factors may play a more critical role in the self-injury of those with SMS.

These behaviors, along with others, contribute to a level of maladaptive behavior that is significantly higher than other peer groups (Dykens & Smith, 1998). Consistent behaviors associated with those who have SMS include impulsivity, aggression, tantrums, attention seeking, hyperactivity, sleep-disturbance, and self-injury (Finucane et al.; 1994, Dykens and Smith, 1998). These behaviors make it increasingly difficult for parents and caregivers to manage, and stress levels for these caregivers have been found to be higher in those who care and parent individuals with SMS (Hodapp et al., 1998). Dykens and Smith (1998) conducted a study to identify specific behaviors related to SMS, and found that between 94%-100% of those studied exhibited disobedience, stereotypies, hyperactivity, tantrums, attention seeking, and sleep disturbance. In addition, other behaviors seen in more than 50% of individuals studied, and as
high as 89% included lability (rapid fluctuations in intensity of emotions) (89%), property
destruction (86%), impulsivity (86%), bed wetting (80%), nail-biting (72%), nervousness (66%),
physical aggression (57%), and daytime wetting or soiling (54%) (Dykens & Smith, 1998). The
authors were also able to make strong correlations between the length of day time naps, and
aggressive behaviors and attention problems exhibited, noting that as naps increased in length,
aggressive behaviors and attention problems decreased (Dykens & Smith, 1998). This finding is
important in understanding the environmental factors associated with certain behaviors of
individuals with SMS.

**Developmental characteristics of individuals with SMS.** In a study of 19 children
between the ages of 2 and 12, Martin et al. (2006) found that the majority of children had
relatively low IQ scores, ranging from 39 to 84, with 67% of the children meeting the criteria for
mild or moderate retardation based on the classifications outlined in the Diagnostic and
Statistical Manual of Mental Disorders – Fourth Edition (Martin et al., 2006). The authors also
found children with SMS to have significant learning problems as described by their parents, and
found that adaptive functioning in all areas studied was delayed. The authors did however find
that of the children studied, socialization skills proved to be a relative strength (Martin et al.,
2006). Typically, children with SMS have been often described as friendly, affectionate, and
outgoing (Loveland & Kelley, 1991).

Socialization skills are not the only area of strength being reported out for individuals
with SMS. Dykens et al. (1997) found that individuals with SMS were strong at completing
certain tasks, including naming a partially completed drawing, naming a common person, place,
or thing, and letter/word recognition. Each of these tasks, though different, assesses “long-term
memory, fund of information, alertness to the environment, and attention to meaningful visual
Individuals with SMS showed strengths in long-term memory, alertness to the environment, visual memory and fund of information, as well as a well-developed expressive vocabulary. Additionally, Dykens et al. (1997) found that individuals with SMS also had relative weaknesses in certain areas, which included sequential processing, short-term memory, learning, and retaining information.

Delays were also found in a variety of other areas with individuals with SMS. Through parent and physician observation, Madduri et al. (2006) found language delays in 84% of the 57 individuals they studied, visual-motor problem delays on 72% of those studied, and gross motor delays in 62% of those same individuals. The research supported the findings of Martin et al. (2006), highlighting socialization and communication skills as relative strengths, but found daily living skills to be a weakness in comparison (Madduri et al., 2006). These findings are similar to those of previous research highlighting high levels of maladaptive behaviors by those with SMS (Dykens and Smith, 1998; Hodapp et al., 1998).

Sarimski (2004) studies communicative competence in more detail, reporting similar findings that communication was a relative strength. Sarimski found that “the majority of parents reported a considerable understanding of everyday conversation” with 13 of 20 children capable of understanding complex sentences, and half being able to build complex sentences (p. 350). Sarimski (2004) also found that in spite of this competence, individuals with SMS “suggest a high level of inappropriate initiation of dialogue, stereotyped conversation and lack of use of conversational context” (p.351). Many parents reported a number of communicative stereotypies which included their children talking to anyone, telling people things they already knew, treating everyone the same regardless of social status, and turning the conversation to a
favorite theme of their own. Older children were reported as often talking too much, and talking repetitively (Sarimski, 2004).

Complicating matters somewhat more for individuals with SMS, is a unique pattern of sleep disturbance that is a prevalent of many with the syndrome. Due to an inverted rhythm of melatonin secretion, individuals with SMS experience sleep problems that include prolonged awakening at night, early sleep onset, daytime napping, and decreased sleep duration (De Leersnyder et al., 2006; Laje et. al., 2010). These disturbances often correlate to behavior problems throughout the day, with children exhibiting morning tiredness as well as frequent napping throughout the day, and tantrums often occurring when melatonin levels rise. While there have been many medical modifications made to balance the sleeping patterns of those with SMS, there is no cure or permanent relief from this disrupted sleeping pattern (De Leersnyder, 2006).

Given the variety of developmental and behavioral problems present in individuals with SMS, it is important to understand the supports necessary to assist individuals with this complex syndrome. Unfortunately, research on the supporting the needs of individuals with SMS is limited, and a comprehensive study on the experiences of students with SMS in a school setting is non-existent. The little research that does exist, offers some insights into interventions and supports that may offer some assistance to those with SMS in a number of settings.

**Educational characteristics of individuals with SMS.** Udwin et al. (2001) studied 29 children with SMS and found that of those children 26 of them attended special schools mostly for those with mild to moderate learning difficulties, two of the children attended mainstream schools, and one attended a remedial class within a mainstream school (Udwin et al., 2001).
Speech delays tend to be more prevalent than motor delay, and expressive language is often more impaired than receptive language acquisition (Chen et al., 1996; Moncla et al., 1991). Children with SMS are often described as eager to please, loving and caring, and with a good sense of humor. They react well to structure and consistency, and many love music, which can be used as a reinforcer (Finucane et al., 1994; Webber, 1999). Dykens et al. (1997) discuss the need to recognize and support their weaknesses in sequential processing, while also taking advantage of strengths in visual reasoning and non-verbal cues (Udwin, 2003). Udwin (2003) goes on to state “the use of visual cues in the form of pictures and symbols can aid recall of more complex sequential tasks and generally help with comprehension” (Udwin, 2003).

Within the classroom, a number of situations may trigger outbursts, self-injury, or both (Haas-Givler & Finucane, 1995; Horn, 1999; Webber, 1999). These situations may include, transitions, changes to routine, sleep deprivation, and being reprimanded. In an attempt to avoid situations that may trigger these behaviors, teachers and parents may want to use explicit instructions with the child, prepare them well in advance for routine changes, provide rewards, distract the individual from triggering events, even ignore the situation entirely or let it run its course (Udwin, 2003). Elsea and Finucane (2009) expressed the need for educators and parents to develop an individual education program, coupled with a behavior support plan for individuals with SMS. According to the authors, these plans are “essential in maximizing academic and social attainment in school-aged children” (p.5). These plans support a structured school program that can be highly effective in meeting the needs of this diverse population of students (Elsea and Finucane, 2009).

The most significant and in depth information available for supporting educators in understanding the classroom needs of students with SMS comes from two unpublished articles
written for the Spectrum newsletter, a newsletter developed by Parents and Researchers interested in Smith-Magenis Syndrome (PRISMS). Barbara Haas-Givler and Brenda Finucane used anecdotal evidence to support their findings. Haas-Givler (1994) found three attributes that affect the learning process, SMS attributes that negatively affect learning, positive attributes of students with SMS, and positive attributes that can become negative. Attributes that could negatively affect learning included attention seeking behavior, aggression, tantrums, self-injury, impulsivity, negative reaction to changes in routine, attention deficit disorder, preservation (repeatedly asking the same question, or staying on the same topic as class has moved on), and sleep disturbance. As one teacher explained, “If I could provide constant, unwavering, one-on-one attention to this child throughout the day, she might never have another tantrum” (Haas-Givler, 1994). Positive attributes included an engaging and endearing personality, excitability, responsiveness to structure, motivation by a variety of reinforcers, eagerness to please, communication, fascination with electronics, a good sense of humor, identifiable causes of tantrums and aggression, and the ability to be redirected if needed. Positive attributes which can become negative included adult-oriented behaviors which can monopolize time, affectionate characteristics that can be overly aggressive, remorsefulness to gain or maintain attention, and visual learning that results in over stimulation by visual stimuli (Haas-Givler, 1994).

In the article What’s a Teacher to do? Classroom Strategies that Enhance Learning for Children with Smith-Magenis Syndrome, Haas-Givler and Finucane (1995), offer the only information specifically designed to support classroom teachers in helping students with SMS. The authors use their own experiences working with students with SMS to create somewhat of a roadmap of key issues teachers need to be aware of in servicing the needs of students with SMS. The authors found that students with SMS typically require an abundance of adult attention, and
when students do not receive their desired wants, the results may include tantrums, outbursts, verbal and physical aggression, self injury, and property destruction. To combat these issues, Haas-Givler and Finucane suggest that teachers create a calm, consistent classroom using a non-emotional tone with children with SMS to “neutralize the child’s perceived reward for attention-seeking behaviors” (Haas-Givler and Finacune, 1995). Positive emotional support is encouraged, but should be well earned and not arbitrary. Additionally, negative emotions should also be controlled, as they may actually reinforce negative behaviors. A small class size to support more one-on-one attention, reinforcers and motivators during activities to help manage behaviors, and visual reminders to support sequential processing are also important strategies supporting the needs of students with SMS (Haas-Givler and Finacune, 1995).

The experiences of students with SMS are complicated. Behavioral, developmental, and educational challenges are prevalent, and these factors create situations that alter significantly how those with SMS interact with the school environment. Understanding these factors is an important first step in providing a school environment that is supportive of those with Smith-Magenis Syndrome.

**Parental perceptions of the educational experiences of students with developmental disabilities.** The second body of literature looks specifically at the educational experiences of children with developmental disabilities similar to those with SMS. This section reviews these experiences through the lens of parental perceptions. Disability is defined, as “the set of limits imposed by the interaction of the physical and social environment with persons who are atypical in body, intelligence or emotions on these persons’ activities, social interactions, pleasure, happiness, self-respect, identity, freedom, independence, safety, social and economic status or even ability to survive, to the extent that these limits differ from those that are imposed on
persons who are not atypical” (Jahiel, 2007). The sections outlined represent emergent themes related to disability studies and parental perceptions. The first section focuses on the varied parent satisfaction levels that exist across syndromes, while the second focuses on the complex partnerships between home and school. In both sections, parents of children of different disabilities have found some variance in how their levels of satisfaction, as well as the partnership that exists between home and school. Palmer et al. (1998), while studying parental perceptions of inclusive practices in school determined that parental views on practices like this differ “based on a broad range of interlocking variables rather than on a single determinant, such as the cognitive profile of their child” (Palmer et al., 1998, p. 279). This is important, as additional understandings related to how parents of children with Smith-Magenis Syndrome perceive schooling still need to be understood. The variance across parental perceptions supports the notion that the voices of parents of children with SMS have not been heard in an academic manner as of yet. There is enough variance to argue that parents of children with SMS also view schooling in different ways, dependent upon the unique abilities of their child.

**Parent satisfaction.** A 2005 national study by The Office of Special Education Programs found that while most parents were satisfied with their child’s schooling, a sizable group of parents gave their children’s schools low marks in supporting their child’s needs. Parents of elementary and middle school children reported higher marks than parents whose children attended secondary school. One in five parents of secondary school students in special education programs were dissatisfied with their child’s school, and in general parents whose children received special education services were typically more dissatisfied than parents whose children were in regular education programs (Newman, 2005). These findings were consistent with those found by Starr et al. (2006), regarding the perceptions of parents of children with Autism.
Spectrum Disorder, Down Syndrome, and learning disabilities. The authors found that while 40.9% of the population surveyed was satisfied with the education their child received, 30.7% were dissatisfied with the overall process and that over 25% of those with learning disabilities had been suspended from school at least once. While overall parental satisfaction tends to be lower with students with disabilities, studies have shown that the satisfaction levels of parents is typically higher from parents when those students fall under the category of pervasive developmental disorders (PDD), or those within the category of mental retardation (Starr et al., 2001; Newman, 2005). This presents an interesting juxtaposition between pervasive developmental disabilities, and less pervasive learning disabilities. Students with Smith-Magenis Syndrome would more appropriately fall within the category of PDD.

Parents of children with disabilities have also been found to desire more interventions at times, and in particular areas. Fidler et al. (2003) found that 33.3% of parents of children with Down syndrome surveyed mentioned that they wished for improved services in speech therapy, while only 8% of parents of children with Prader-Willi syndrome, and 4.2% of parents of children with Williams syndrome wished the same. Similar findings were concurrent with these populations as it relates to reading services, with parents of those with Down syndrome requesting significantly more services in this area. Fifty percent of parents of children with Williams syndrome mentioned wanting more classroom aide services, with only 17.9% of those parenting children with Down syndrome stating the same. The analysis continues, with differences in parental concerns or requests as they relate to music services and physical education (Fidler et al., 2003). This study highlights the importance of understanding the experiences of students with disabilities on a basis related to their actual situation, rather than on a more generalized understanding of disability as a whole. Additionally, it shows the variance in
needs for students of different syndromes, which is essential in understanding and providing appropriate supports for these students on an individual basis.

A 2008 study analyzed the satisfaction levels of parents of children with Autism Spectrum Disorder (ASD) against the levels of other disabilities. The authors determined that while most parents reports that “the quality of the services their children received was good or excellent (86.8% for ASD and 90.1% for other disabilities)”, for certain aspects parents of children with ASD reported less satisfaction (p. 1513). More than a quarter of parents of children with ASD felt that their child did not spend enough time with typically developing peers, compared to 12% of parents of children with other disabilities. These parents also reported higher levels of need regarding the services they wished their child had received in the school setting (Bitterman et al., 2008).

Parents of students with disabilities have also raised concerns related to their children’s experiences in inclusive settings. Whitaker (2003) found that of 172 parents of autistic children surveyed, almost 40% of these parents were dissatisfied by their child’s schooling, comprising a “substantial minority” of those studied. These numbers of dissatisfaction seem particularly high when compared to the parental perceptions of children with autism in specialized schools, where fewer than one in ten described dissatisfaction. Of the parents who did describe their child’s schooling as satisfactory, a large number of them identified significant areas of concern. Of these concerns, social experiences were especially worrisome for parents (Whitaker, 2003). Parents have also expressed anxiety over sending their children to inclusive schools, concerned with inadequate training of teachers, attitudes of general education teachers, appropriate support services, and social integration (Leyser & Kirk, 2011). Concerns also arose regarding the
communication and partnership between the school and home (Frederickson et al., 2004; Lovitt & Cushing, 1999).

**Parent and school partnerships.** One of the prevalent themes parents have raised in supporting their children in school is the need for high quality communication between parents and schools, and school to home partnerships. These partnerships allow for increased communication to support individuals in schools with disabilities. A dominant theme throughout disability literature is the somewhat divisive partnership that often exists between home and school. Extensive literature has suggested that parental involvement can positively impact student success (Eccles & Harold, 1993; Koegel, Koegel, & Schreibman, 1991; Newmann & Wehlage, 1995).

While partnerships are important, these relationships have not always been successful. In a survey of 539 parents regarding their roles within early intervention, many parents conveyed that the services that their child received were different than that of what was requested (McWilliam, 1995). Many families have also reported levels of dissatisfaction with regard to the lack of collaboration and communication that has occurred between school and home (Covert, 1995). Kohler (1999) conducted interviews with 25 parents of preschool- and school-age children with autism, with more than 50% reporting that the services the school provided were either ineffective or not related to the needs of their child. Even more of these families reported that they had problems regarding communication by the school.

Ryndak et al. (1996), studying parental perceptions of thirteen families of students with disabilities across various school districts, found that many parents have felt “powerless” in determining proper educational settings for their child, and that concessions have been made to
what some parents believed were school “experts” (p. 112). “The overall unhappiness and frustration that parents expressed about the process used to decide the location in which their child would receive services suggests that parents are not valued members of their child’s education team, or that school districts are not sufficiently open to discussing the pros and cons of services in various types of settings” (p. 116). Parents also expressed the desire to become more influential members of the Individualized Education Program (IEP) team. When suggestions were accepted, parents felt that there was a greater focus on their child’s strengths rather than deficits. Ryndak et al (1996) concluded that schools need to make modifications to their practices in order to decrease levels of parental frustration, and recognize that parents play a crucial role in partnering with the school to support their child (Ryndak et al., 1996).

Parents of children with Angelman syndrome, a severe and complex disability, have called for better partnerships between the school, family, and other professionals. They have also offered suggestions to educators, asking teachers to “Talk to her, not down to her”, “Have lots of patience”, and “Love working with these special children” (Leyser & Kirk, 2011, p. 87). These same parents expressed some dissatisfaction with the school district’s administration, with many indicating that more services were needed for their children and improved communication (Leyser & Kirk, 2011). Parents of children with autism have reported similar difficulties with both services and communication. In a study of 25 families of children with autism, more than half of these families expressed that school based services were “either ineffective or unrelated to their child’s most pressing needs”, and 60% of them expressed significant communication problems between home and school (Spann, Kohler & Soesnksen, 2003, p. 229).

These communication problems may be a result of some teachers’ lack of belief that families are credible sources of information (Gilliam & Coleman, 1981; McAfee & Vergason,
1979), even though research indicates that parental involvement can positively impact a child’s success in school (Eccles & Harold, 1993; Koegel et al., 1991). Bacon & Causton-Theoharis (2012) discuss the need for parents and educators to be teammates in supporting students with disabilities. The authors noted, “schools undertake a variety of practices, which undermine equity of participation between parents and schools” (p. 687). Medical deficits of children often controlled the conversation at schools, and were a driver of many school decisions. Language of professionals has also created a barrier between parents and schools, again citing deficits in large part over a child’s strengths. Structural elements as well, from tightly scheduled meetings to cumbersome IEP tools created situations that also created divisiveness between parents and schools (Bacon & Causton-Theosaris, 2012).

In an analysis of conflict between parents and schools related to special education, Lake and Billingsley (2000) also found that parents believed schools did not focus as much on the strengths and abilities of students with disabilities. The lens in which parents and schools viewed children with disabilities seemed to differ, and while parents reported that schools focused primarily on weaknesses, schools reported that parents often became one dimensional in their focus (Lake & Billingsley, 2000). In a study involving 13 families of children with ASD and Down Syndrome, a prevalent theme that emerged was a focus by the parents on celebrating what the child could do, as opposed to the deficits that may have existed (King, 2011). Former studies have also detailed an imbalance of power within the relationship of schools and parents, with school controlling more of this power (Fish, 1990; Strickland, 1982). To create greater levels of collaboration, it is important for schools to be able to explain their goals for students with disabilities, without diminishing the goals of parents as well (Lake & Billingsley, 2000).

The perceptions and concerns of parents of students with special needs are important.
They provide a framework that can provide valuable feedback to schools (Garrick, Duhaney & Salend, 2000; Leyser & Kirk, 2004; Seery, Davis & Johnson, 2000).

**The Environmental Context**

Parental understandings are important because they can also give us insights into various aspects of schooling, including the environmental constructs that support, or often inhibit, the success of students with disabilities. Understanding the environmental context is critical in putting together the various pieces that help to determine the experiences of students with disabilities, and in this case SMS, and how we can work within this context to better the outcomes.

As described earlier in the theoretical framework, the work of Thompson et al. (2010) focuses on the PEI framework with relation to students with disabilities and the implications of such. The PEI model has the potential to enhance the educational opportunities of students with disabilities by focusing on the environmental context and providing supports that enhance student capacity (Thompson et al., 2010). Adapting the environmental context in which students with disabilities learn supports a process in which interventions can continually be adapted to meet the needs of students, rather than expecting the students themselves to adapt to their current environmental constructs.

The environmental context can be defined using a number of variables, including the physical environment, instructional modifications, and social construction. Sandra Doctoroff (2001) states that physical environmental changes can positively support a child’s ability to both manage behaviors and learn (Doctoroff, 2001). Allen and Schwartz (1996) argue that environments that allow children with special needs to “be included easily and naturally, convey
a powerful message about human values” (Allen and Schwartz, p. 224, 1996). High noise levels might impede communication during social play, and a lack of varied materials that meet diverse ability levels may hinder the performance of students with disabilities (Doctoroff, 2001). Socially, it is important for teachers to create an environment in which peer play can occur, a process that is often difficult for many students with special needs. By setting the stage for peer play, teachers can provide opportunities for students with disabilities to be successful in social settings (Doctoroff, 2001). In addition, Doctoroff (2001) notes the importance of creating a well-organized environment, specifically designed to meet the needs of individual students within their class (Doctoroff, 2001). Classroom seating arrangements that promote peer exchanges between students with disabilities and their classmates is important, as well as creating a positive school ethos in which students with disabilities are included in regular activities (Center et al., 1989; Rouse & Florian, 1996). By creating an environment that supports students with disabilities, schools also increase levels of social ability and participation. Many students with disabilities often have restricted participation in schools in comparison with their peers, the result of which is a daily routine that is often less varied (Law & Dunn, 1993).

Carter and Kennedy (2006) highlight the importance of peer relationships for students with disabilities in the environmental context, stating “the general curriculum provides a natural context for peer interaction as students work together on shared learning tasks, providing a meaningful context for acquiring social-related skills, accessing social supports, meeting additional classmates, and developing new friendships" (p. 12). However, "absent well-crafted support strategies, students with severe disabilities may be physically present in general education classrooms, but remain academically disengaged and socially isolated from peers" (p. 4). The authors argue that providing peer supports may relinquish some of these concerns, and
can support many social and academic objectives, (Carter & Kennedy, 2006).

Hodapp and Fidler (1999) discuss four approaches when considering environmental factors concerning students with genetic mental retardation syndromes, including those of students with Smith-Magenis Syndrome. 1) Environmental interventions can help improve behavioral functioning in children with genetic mental retardation disorders. 2) Individual differences exist within any genetic mental retardation disorder. 3) All behaviors result from many factors. 4) Children with genetic mental retardation disorders change as they grow older (Hodapp & Fidler, 1999). These are important considerations, and ultimately help educators in understanding that adaptations can be made within the environment. It also espouses the understanding that individual differences will exist between students of varying genetic disorders (Smith-Magenis Syndrome vs. Down Syndrome), that these differences will change over time, and that they are a result of many factors that should be considered.

Smith (2006) provides some context in which environmental factors can inhibit the development of students with disabilities. This is an integral understanding, as students with SMS may be experiencing similar issues. She states that while “special education reforms have focused on access and equity” they have not “adequately addressed the complex issues of exclusion and discrimination at individual or institutional levels…segregation, exclusion, integration, and inclusion are highly complex phenomena involving volatile issues of hierarchy, ethics, power, privilege, hegemony, and construction of "the other." In my experience, students who have "significant cognitive disabilities" are part of this ‘other’” (Smith, 2006, p. 335).
Chapter Three: Research Design

Research Questions

The research questions used in this study have been developed to compliment the PEI framework and Four-fronts approach. They are as follows:

1. How do parents of children with Smith-Magenis Syndrome perceive their child’s interactions with the educational environment?

2. What aspects of the educational experience are parents of children with Smith-Magenis Syndrome most and least satisfied with in the K-5 setting?

3. What can we learn from parents of children with SMS that can be applied in the classroom?

4. How can the educational experiences of those with Smith-Magenis Syndrome be improved in the K-5 setting?

Each of the research questions outlined are process questions. These questions do not focus on relationships or variables, but rather how things happen or how they are (Maxwell, 2005). According to Maxwell (2005), qualitative research is more suited to determining how things happen, and hence focus on three types of questions more appropriate for process theory: (1) questions about the meaning of events and activities to the people involved, (2) questions about the influence of the physical and social context on these events and activities, and (3) questions about the process by which these events and activities and their outcomes occurred (Maxwell, p. 75, 2005).

These research questions generate new understandings and insights related to the educational experiences of students with Smith-Magenis Syndrome. The theoretical framework
associated with this research provides an analysis from an individual and environmental perspective of those with SMS.

**Research Design**

This research uses a basic qualitative approach, in an attempt to establish meaning, “from the views of participants” (Creswell, 2009, p. 16). A qualitative approach allows for a collection of data that aligns to the perception of participants. In doing so, a comprehensive and nuanced understanding of the experiences of students with SMS has surfaced. In addition, a qualitative approach has allowed the research to develop a narrative in which personal values and stories are validated, and collaboration between the researcher and participants is most present (Creswell, 2009). Participant’s meanings are valued in this research, allowing for their experiences to drive understandings. This research did not however employ a phenomenological lens, due primarily because the understandings of the parents in relation to their child’s experiences are in many ways third party to the school experience. Due to the unique variance of school experiences, and the nature of human subjects as naturally different, a basic qualitative approach has allowed for this concept to be understood in varied ways. This particular concept also needs to be understood further, and “because little research has been done on it, then it merits a qualitative approach” (Creswell, 2009, p. 18). Also important is understanding the purpose of this research in concert with its audience. This research has gathered information that will support families and educators, from a variety of experience levels. A basic qualitative research design takes into account the format in which this research can be delivered so that it is understood and useful to key audience members.
Maxwell (2005) makes the case for five intellectual goals and three practical goals, all for which qualitative studies are particularly suited. These intellectual goals include understanding meaning, understanding context, identifying unanticipated phenomena and influences, understanding process, and developing causal relationships. For this research, understanding meaning and context are particularly important.

Maxwell (2005) contends that qualitative research also is advantageous in addressing three practical goals; generating results and theories that are understandable and experientially credible, conducting formative evaluations that intend to help improve practice, and engaging in collaborative or action research with participants. Most relevant to this research, is ensuring that these results and theories are understandable and experientially credible, as well as conducting formative evaluations to help improve future practice.

This research has been developed to capture what Saldana (2014) calls, “a strong handle on what real life is like” (p. 11). It has created an opportunity in which rich understandings present themselves, and complexities are revealed in an authentic context. New meanings are established as qualitative research lends itself to discovery and the exploration of new areas (Saldana, 2014). By conducting qualitative research, this study has been positioned well to both understand the school experiences of children with SMS through the perspectives of others, but also allow for relatable and practical results to emerge that can support future understandings of interested parties.

This research incorporates a basic interview study of parental perceptions regarding the educational experiences of students with Smith-Magenis Syndrome in K-5 settings. The decision to study parents rather than students or educators is based on the idea that (a) parental
perceptions are important in understanding the experiences their children have in school, (b) students with Smith-Magenis Syndrome in K-5 settings may not be able to appropriately convey their understandings of their own experiences, and (c) the perceptions of teachers, though important, may not fully comprehend the unique circumstances that surround students with Smith-Magenis Syndrome due to lack of educational research available coupled with the rarity of the syndrome. Additionally, the most comprehensive information available regarding Smith-Magenis Syndrome is the parent driven non-profit organization, PRISMS (Parents and Researchers interested in Smith-Magenis Syndrome, www.prisms.org). The choice to study the perceptions of parents of K-5 settings is twofold. First and foremost, the purpose of this research has been to elicit new understanding and insights in the hopes of providing literature that would assist parents and educators in supporting students with Smith-Magenis Syndrome. By using the K-5 setting, this research aims to support students with Smith-Magenis Syndrome at a young age, when interventions and supports are critical to development, and will provide parents of young children with Smith-Magenis Syndrome a starting point in understanding the educational experiences of children with SMS.

In each interview, participants have been asked to describe the educational experiences of their child, using their understandings to contribute to supporting the educational needs of students with SMS. A qualitative interview study has allowed for an authentic look at the unique experiences of parents of children with SMS, and has helped elicit unknown understandings about this population of students. A basic qualitative interview has offered an opportunity for participants to provide historical data, and has allowed me to navigate questioning to elicit deeper understandings of each unique situation. This approach has provided this study with an unfiltered look at each experience as unique, building an
understanding of how individual students with SMS experience their educational surroundings. These questions have been linked to the four primary research questions, relating the information gathered by a common language, which has been coded.

Currently, there are an estimated 600 people diagnosed with Smith-Magenis Syndrome worldwide. The syndrome is severely under diagnosed, with some estimates suggesting that 1 in 25,000 people born may have the genetic disorder (Greenberg et al., 1991; Finacune et al., 2001). The target population for this study is small, and considering that this research was designed to understand the experiences of children in K-5 settings, it has made the sample population even smaller. Due to the small target population, this study has employed purposeful selection in selecting the participants to interview. Purposeful selection is a strategy used to intentionally gather certain information that may be difficult to obtain otherwise (Maxwell, 2005). According to Maxwell (2005), the four possible goals for purposeful selection are; (1) “achieving representativeness or typicality of the settings, individuals, or activities selected”, (2) “to adequately capture the heterogeneity of the population”, (3) “to deliberately examine cases that are critical for the theories that you began the study with, or that you have subsequently developed”, and (4) “to establish particular comparisons to illuminate the reasons for differences between settings or individuals” (Maxwell, 2005, pp. 89-90). Purposeful selection is an appropriate sampling strategy for this study, considering the small target population that exists.

The research participants included in the study are parents of children with Smith-Magenis Syndrome who are currently enrolled in grades K-5 in the United States. To gain access to participants, I’ve utilized social media formats to engage the SMS community. Seven parents were recruited to participate in semi-structured interviews. Due to the limited number of
people diagnosed with SMS and how widely they are dispersed, the interviews took place via Skype.

**Data Collection**

Throughout this research, data was collected to help answer the research questions posed. The research questions have helped formulate the study’s focus, but it was the development of interview questions that helped gain depth and understanding of the experiences (Maxwell, 2005). Asking “real questions”, not “contrived questions designed to elicit particular sorts of data” has supported an authentic approach to the research and has helped elicit knowledge that was not anticipated (Maxwell, 2005, p. 92). It has been important to conduct this research in a manner that keeps the meaning as it relates to the participants, rather than that of the researcher (Creswell, 2009; Moustakas 1994). This study is important because it is specifically designed to get at the perception of the educational experience of children with SMS through the lens of the parents, not anyone else.

The semi-structured interviews used topical guidelines but were open-ended enough in order to allow for the full understanding of the participants. They utilized an informal and interactive process, and began with a social conversation that helped create a more relaxed and trusting atmosphere (Creswell, 2009; Moustakas 1994). While an interview protocol was used to help keep the interview focused on the intended purpose, its open-ended nature created a more holistic understanding of the participants’ perceptions (Creswell, 2009; Moustakas 1994). Both Moustakas (1994) and Creswell (2009) suggest creating a protocol, or interview guide in conducting qualitative research. The interview protocol developed for this study ensured that each participant interview followed a similar pattern in order to increase reliability. This study
used the format proposed by Creswell (2009), which included a heading, instructions for the interviewer, questions, probes for each question, and a final thank you statement to the participant (Creswell, 2009). Each interview was also audiotaped to ensure an accurate transcription, and transcribed following the interview. Each participant received a copy of his/her transcript and were asked to review for accuracy. They were asked whether they might like to add any more information, or if there are any parts they want omitted. This level of detail allowed for greater reliability of the perceptions discussed in each interview. Interview questions sought to reveal the meanings behind human experiences, uncover qualitative factors in behavior and experience, and engage “the total self” of the research participant (Moustakas, 1994, p. 105). Topical and sub questions helped to elicit understandings of the participants (see Appendix A).

Considering the fact that research for Smith-Magenis Syndrome is limited, I believe there was some intrinsic motivation for parents to participate in this study. While I believe this to be true, I understood that an acknowledgement of appreciation was important to those participating (Maxwell, 2005). To show appreciation, each interview participant received a $15 Visa gift card, and a personalized thank you note for their contribution to this study.

Data Analysis

With regard to data analysis, this study used an approach influenced primarily by Miles, Huberman & Saldana (2014), and supported by the work of Creswell (2009) and Maxwell (2005). Analysis was conducted in a manner that supported “three concurrent flows of activity”, data condensation, data display, and drawing and verifying conclusions (Miles, Huberman & Saldana, 2014, p. 12). Data condensation, in essence makes data stronger by involving the processes of “selecting, focusing, simplifying, abstracting, transforming, and or transforming the
Data condensation allows a researcher to provide strong focus on their initial data sets, focusing and organizing in a manner that strengthens the analysis. This process allows the researcher to organize their thinking to in support of drawing and verifying conclusions (Miles, Huberman & Saldana, 2014). This study used an ongoing process of “continual reflection”, the asking of analytic questions, and memoing (Creswell, 2009, p. 184). Regularly writing memos helped to capture “analytic thinking”, “facilitate such thinking”, and “stimulate analytic insights” (Maxwell, 2005, p. 96). This process allowed for a coherent analysis of the research, in correlation with each interview rather than in isolation from one interview to the next. Beginning this analysis immediately, and continuing to analyze as data collection continues, allows for simultaneous analysis of the information (Maxwell, 2005). “The experienced qualitative researcher begins data analysis immediately after finishing the first interview or observation, and continues to analyze the data as long as he or she is working on the research, stopping briefly to write reports and papers” (Maxwell, 2005. p. 95). Throughout the study, open-ended data allowed for in depth understandings of the perceived experiences of study participants.

Data display refers to an “organized, compressed assembly of information that allows conclusion drawing and action” (Miles, Huberman & Saldana, 2014, p. 12). A common form of qualitative data, extended text, is overwhelming to the researcher and it is recommended that data displays be used to develop more organized and coherent understandings. This creation of displays, is in and of itself an element of data analysis as well, and should be considered a process in which greater analysis can be made (Miles, Huberman & Saldana, 2014).
Lastly, Miles, Huberman & Saldana (2014) refer to a third stream of data analysis, drawing and verifying conclusions. This is a function of interpretation through “noting patterns, explanations, casual flows, and propositions” (p. 13). Conclusions need to be verified during analysis, and final conclusions may not be drawn until the entirety of the data collection is over (Miles, Huberman & Saldana, 2014).

Creswell (2009) suggests using specific steps in order to conduct and analyze qualitative research, but encourages an interactive approach to analysis, rather than a linear or hierarchical approach (Creswell, 2009). Creswell (2009) provides a general approach, which is as follows:

1. Organizing and preparing data for analysis: This includes transcribing interviews, scanning material, memoing, sorting and arranging data.

2. Reading through all the data: obtaining a general sense of the information.

3. Beginning a detailed analysis using a coding process: organizing material into segments before bringing meaning to the information.

4. Using the coding process to generate descriptions: this involves setting and people, and categories and themes for analysis.

5. Creating a narrative passage in which to “convey the findings of the research”: a discussion of events, themes, or interconnectedness.

6. Interpreting, or making meaning of the data: asking explicitly what has been learned? (Creswell, 2009, pp. 185-190)

An important aspect of this study was in the coding of data to find meaning. Throughout this study data had to be splintered, and rearranged into “categories that facilitate comparison between things in the same category and that aid in the development of theoretical concepts”
(Maxwell, 2005, p. 96). Allowing codes to emerge throughout the process of data collection was essential to this study, rather than pre-determining the codes that might exist. This study has helped shape conclusions based on the proposed questions and purpose of the study, but themes also emerged naturally throughout the period of analysis. As themes emerged, this study utilized some of the many different first cycle coding approaches, including descriptive coding and In Vivo coding among others (Miles, Huberman & Saldana, 2014). This is particularly important given the dearth of research available on this topic. Throughout the analysis, coding was done by hand primarily to ensure a deep understanding of the research. Reading the interview transcripts and notes, along with listening to the interview tapes prior to transcription also provided an additional level of analysis. Second cycle coding, where segments of coding are organized and patterns emerge, was be used to help develop well-organized displays of data. Matrix and network displays were utilized to create visual representations or organized thought (Miles, Huberman & Saldana, 2014). Finally, jottings and memoing were used throughout the data analysis process to support concurrent analysis during research, as well as organize thoughts and ponderings in the moment. The processes of memoing, coding, and connecting strategies each contributed to the deep analysis of data necessary to support this research (Maxwell, 2005, Miles, Huberman & Saldana, 2014).

**Validity and Credibility**

Creating and maintaining validity throughout the research process has played a critical role in supporting the research presented as credible and worthwhile. A number of elements were considered to protect against threats of validity. Validity as a part of research design “consists of strategies you use to identify and try to rule out these threats” (Maxwell, 2005, p. 105).
An important threat to consider in qualitative studies is researcher bias, which involves the subjectivity of the researcher (Maxwell, 2005). While it is “impossible to deal with these issues by eliminating the researcher’s theories, beliefs, and perceptual lens”, maintaining integrity through personal communication about these personal beliefs provides the necessary validity throughout the study (Maxwell, 2005, p. 108). This was especially true in this study. As a father of a child with SMS, and as a school administrator, I certainly held beliefs regarding the educational experience of students of varying abilities. What’s important to note, is that with no existing published research on the educational experiences of students with SMS, I too was left with a complete unknown as to what these experiences may look like. I had existing beliefs regarding the education of students with special needs, and believe that the difficulties in schools present with students of other disabilities may likely be similarly to those of children with SMS. Through the research design however, and the Four-front approach, this research has intentionally looked at multiple angles of the schooling experience of students with SMS, focusing on both strengths and weaknesses of the educational environment.

Creswell (2009) states “qualitative validity means that the researcher checks for the accuracy of the findings by employing certain procedures” (p. 190). The procedures put in place to ensure this study’s validity have included the following: First, the study incorporates rich data, using detailed interviews with various participants to ensure deep understandings of the experience. Maintaining verbatim transcriptions, as well as notes have allowed for a comprehensive analysis of the information. Secondly, this study utilized “respondent validation” by explicitly soliciting feedback by interviewees to ensure that the information presented was accurate and representative of their understandings (Creswell, 2009; Maxwell, 2005). Interviewees had the opportunity to read their personal transcripts, and add information or clarify
misunderstandings as necessary. An important aspect in this study was triangulating methods of collecting data to ensure a more reliable and accurate depiction of the educational experiences of students with Smith-Magenis Syndrome. Due to the rarity of the syndrome, and sparse locations of potential participants, data collection for this study was somewhat limited. While observing students with SMS would prove beneficial, the logistics involved made it incredibly difficult. To improve reliability, this study used semi-structured interviews from a number of participants, respondent validation, and memoing to elicit understandings about the experiences of students with SMS. Conducting interviews gave insights into the educational experiences of students with SMS without the difficulty of observations. It also helped to provide a perspective that only the interviewee could provide, which is important in answering the research questions for this study. This study also utilized reliability procedures outlined by Gibbs (2007), which include checking transcripts to ensure that they do not contain misinformation or mistakes, and maintaining consistency through coding procedures (Creswell, 2009).

**Protection of Human Subjects**

In order to maintain proper ethical procedures and protect the rights of human subjects, this study employed a number of ethical considerations throughout its design. Throughout this study, each participant involved in interviews volunteered at their own will, and no human subjects were be put at risk in any way. All participants were above the age of 19, mentally competent, and were read and verbally agreed to informed consent prior to participation. The consent included the following:

1. The role of the research
2. Identification of the researcher
3. Indication of how they were selected
4. Benefits for participating
5. Identification of the level and type of participant involvement
6. Notation of any risks
7. Guarantee of confidentiality
8. Assurance that the participant can withdraw at any time
9. Contact information if questions arise

(Creswell, 2009, pp. 89)

It was important that both the researcher and participants benefited from the study in some way, and that participants felt comfortable in collaboration throughout. Anticipating that this study might bring up sensitive issues was important, and being prepared to discuss these intimate issues was necessary throughout (Creswell, 2009). This study protected the anonymity of the participants and their family members by using pseudonyms for names and locations, including the students and their schools. The data collected for this research was kept in private electronic data storage files, which allowed access to no one but the researcher.

Primarily, anonymity and securing private data information was critical throughout this research. Informing participants of consent prior to the study helped to outline the procedures that took place, and ensured that all protections were kept.

Summary

This study has attempted to make sense of how parents of children with SMS perceive their child’s educational experiences. By developing further understandings of these experiences, my hope is that this research can serve as a source of information for supporting
students’ with SMS. It is also my hope that this research helps to encourage other studies related
to student with SMS.

To accomplish this, this study grounded itself in Person-Environment Interaction Theory
and the Four-front approach, creating the opportunity to examine these experiences through
environmental considerations, and by presenting both the strengths and weaknesses associated
within these experiences. The following research questions helped to lead this study in a
direction that supported a comprehensive analysis of the perceptions parents have about their
child’s experiences in school: (1) How do parents of children with Smith-Magenis Syndrome
perceive the educational experiences of those with SMS in K-5 settings? (2) What K-5 school
based educational interventions/strategies do parents of children with Smith-Magenis Syndrome
find supportive of their child’s needs? (3) What aspects of the educational experience are
parents of children with Smith-Magenis Syndrome most and least satisfied with in the K-5
setting? (4) According to parents, how can the educational experiences of those with Smith-
Magenis Syndrome be improved in the K-5 setting?

Through these research methods, this study examined the perceptions of parents as they
related to the educational experiences of students with SMS. Interviews served as the primary
means of data collection, and a rich look at data informed our understandings of these
experiences. It is my hope that with this research the community of parents and researchers
interested in SMS will have critical information in support of young people with SMS. In doing
so, it is my hope that we can continue to support efforts to both understand, and provide the
necessary means to assist students with SMS in having successful school experiences.
Chapter Four: Findings

The purpose of this chapter is to report out key findings of the research, and to construct analysis into meaningful context. This chapter will first reintroduce the problem of practice and research questions. The second section will provide the context for study, followed by the third section, which will briefly describe participant profiles. The fourth section of this chapter will highlight common themes and findings that emerged from this research. Finally, this chapter will conclude with a summary of findings that complement and help to answer the study’s guiding research questions.

Problem of Practice

Students with SMS face significant educational challenges that are vastly different than their peers. These differences require further study to fully support an understanding of their unique needs, as well as an understanding of the supports that may benefit them. A lack of educational literature focused on the needs of students with SMS is a significant issue and the need for specific research targeting their educational experiences is important. Without research relevant to the school experiences of students with SMS, these students will continue navigating an educational environment that may not fully understand their needs. To address this, the following research questions were used to guide this study:

1. How do parents of children with Smith-Magenis Syndrome perceive their child’s interactions with the educational environment?
2. What aspects of the educational experience are parents of children with Smith-Magenis Syndrome most and least satisfied with in the K-5 setting?
3. What can we learn from parents of children with SMS that can be applied in the classroom?

4. How can the educational experiences of those with Smith-Magenis Syndrome be improved in the K-5 setting?

Throughout this study, these research questions provided a basis of questioning that led to its findings. Each of these questions has helped guide these new understandings.

**Study Context**

This research was conducted using a basic qualitative approach, examining the educational experiences of students with SMS through the perceptions of their parents. This approach has helped develop a narrative in which personal values and stories are validated. This research study used a basic qualitative approach rather than a phenomenological approach, due to the fact that parental understandings of their child’s school experience were in many ways third party to the actual experience of the child. This study incorporated a basic interview study of parental perceptions regarding the educational experiences of students with Smith-Magenis Syndrome in K-5 settings. All interviews were conducted via Skype. Following the interviews, memoing and coding ensued to help identify themes and understandings. To broaden understandings, a second round of interviews was conducted to further saturate the emergent themes. This was done to ensure that participants could speak directly to the emergent themes, and add more context and information as needed. Additionally, I would be remiss not to include myself as somewhat of a co-participant. As a father of a child with SMS in kindergarten, I find myself often living with similar experiences as the participants. Maintaining my voice and
understanding throughout this research has helped me to think in parallel with what other parents of children with SMS might also be questioning or considering.

Considerations were taken to ensure validity, including the use of rich data, detailed interviews, verbatim transcripts, and respondent validation. Respondent validation allowed participants to respond to the transcribed interviews in the event they wanted to add information, or clarify a misunderstanding. During this study, one participant chose to re-clarify their thinking following interview, further strengthening the value of participant’s voices, as well as the validity of this research.

**Participant Profiles**

Eight parents were interviewed through the course of this study. The study included seven students, with both parents interviewed for one of the students. Their children ranged in ages of six to twelve, and were in grades kindergarten to fifth. Five of the students were male, two female. Five of the students attended public schools, with two attending private schools. Of the seven students, five were in self-contained classrooms and two were in general education classrooms with the support of a 1:1 teacher aide. Self-contained classrooms have a smaller number of students, often between 5-10, and are led by a special education teacher. General education classrooms are designed more for typically developing students and are generally larger. These participants reside in various regions of the country, the Pacific West, Midwest, Mid-Atlantic, and Northeast United States. Due to the rarity of Smith-Magenis Syndrome, coupled with small community of parents whose children are in a K-5 school setting, it is important that these participants remain anonymous. Pseudonyms were used for all names, and locations of participants regionalized.
Profile one: Glenn, Grace, and Lucas. Glenn and Grace are parents to Lucas. They live in the Mid-Atlantic region of the United States. Lucas is a twelve-year-old fifth grade boy who attends a special needs private school. He is in a self-contained setting, and was diagnosed with SMS at almost three years old. Lucas loves listening to music and playing with trucks.

Profile two: Hannah and Connor. Hannah resides in the Pacific West with her family, and is Connor’s mother. Connor attends his local public school in a self-contained setting. He is seven years old and in the first grade. Connor was diagnosed with SMS at 2.5 years old. He enjoys watching cartoons and spending time on his iPad.

Profile three: Genevieve and Josh. Genevieve is the mother of Josh. They live with their family in the Mid-Atlantic region. Josh attends a private school for students with special needs and is in a self-contained class. He is in fifth grade, is eleven years old, and was diagnosed at 2 years old. Josh likes to take things apart, play with technology, and socialize.

Profile four: Sabrina and Ashley. Sabrina is Ashley’s Mother. Sabrina and Ashley live in the Northeast where Ashley attends fifth grade at her local public school. Ashley is eleven years old and is in a self-contained setting. She was diagnosed with SMS at four years old. Ashley is an excellent swimmer and has a great sense of humor.

Profile five: Kayla and Nathaniel. Kayla is the mother of Nathaniel, a seven-year-old boy who attends public school. Nathaniel is in the second grade and is in a general education setting with a 1:1 teacher aide. Kayla and Nathaniel live in the Northeast region of the United States, and Nathaniel was diagnosed with SMS at 6 years old. Nathaniel loves bright colors and textured board books, as well as listening to his iPod shuffle.
Profile six: Jody and Mathew. Jody is mom to Mathew. Jody and Mathew live in the Midwest where Mathew attends a public school. Mathew is in a general education setting with the support of a 1:1 teacher aide. He is six years old and is in kindergarten. Mathew was diagnosed with SMS at seven months old. He loves construction vehicles and can name almost any vehicle on the road.

Profile seven: Carson and Jillian. Carson is the father of Jillian. Jillian is an eight-year-old girl who attends her local public school in the Mid-Atlantic region. Jillian is in the third grade and in a self-contained setting. She was diagnosed with SMS at seven years old. Jillian loves to play video games and to go to the park.

Table 1

<table>
<thead>
<tr>
<th>Participant (Child)</th>
<th>Sex of Child</th>
<th>Age of Child</th>
<th>Region</th>
<th>Child’s Grade</th>
<th>Child’s School</th>
<th>Child’s Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glenn/Grace (Lucas)</td>
<td>M</td>
<td>12</td>
<td>Mid-Atlantic</td>
<td>Fifth</td>
<td>Private, Special Education School</td>
<td>Self-Contained</td>
</tr>
<tr>
<td>Hannah (Connor)</td>
<td>M</td>
<td>7</td>
<td>Pacific West</td>
<td>First</td>
<td>Public</td>
<td>Self-Contained</td>
</tr>
<tr>
<td>Genevieve (Josh)</td>
<td>M</td>
<td>11</td>
<td>Mid-Atlantic</td>
<td>Fifth</td>
<td>Private, Special Education School</td>
<td>Self-Contained</td>
</tr>
<tr>
<td>Sabrina (Ashley)</td>
<td>F</td>
<td>11</td>
<td>Northeast</td>
<td>Fifth</td>
<td>Public</td>
<td>Self-Contained</td>
</tr>
<tr>
<td>Kayla (Nathaniel)</td>
<td>M</td>
<td>7</td>
<td>Northeast</td>
<td>Second</td>
<td>Public</td>
<td>General Ed/1:1 Aide</td>
</tr>
<tr>
<td>Jody (Mathew)</td>
<td>M</td>
<td>6</td>
<td>Midwest</td>
<td>Kindergarten</td>
<td>Public</td>
<td>General Ed/1:1</td>
</tr>
</tbody>
</table>
Introduction to Results: Common Themes

Through a thorough analysis and coding methods, common themes began to emerge in the research. While many of the experiences of participants varied, the themes presented in this research carry a commonality that is important. Five overarching themes were uncovered, each with subthemes within. Many of the subthemes are titled with quotes. Subthemes titled with quotes from parents are designed help to create a more descriptive narrative of the section.

School Environment

The school environment is a critical component in understanding the experiences of students with SMS. This section briefly defines what the environment is like for students with SMS in relation to their environmental setting. The environmental setting refers to class setting, staff allocation, class size, resources, and provided services. This section provides a foundation to support understandings of the physical and programmatic constructs that categorize the experiences of students with Smith-Magenis Syndrome. In each case, parents noted that class sizes were low, and there was a low adult to student ratio. Supplementary resources and supports were in place to tend to a variety of student needs, and each student received related services. These services included a variety of interventions and therapies to support development.

Low adult to student ratio. Participants detailed the level of support their children received in school, with each noting low adult to student ratios in relation to their child’s schooling. When asked about the classroom setting, Carson stated that “they’ll take no more
than twenty [students]…and I know they have one main teacher…and a couple assistants that help out.” Genevieve echoed this sentiment, noting that for her child “it's typically been anywhere from five to seven students, and one special education teacher with three to five aides in the classroom. It's pretty much almost one to one aides in the classroom.” This low adult to student ratio has provided parents with feelings of satisfaction. In thinking about her child’s experiences having more adult support, Hannah explained the benefits it afforded Connor.

There's always somebody there to pick him up when we drop him off. They come outside, they get him, they get his stuff, and they take him directly to his classroom, that's one of the aides. You know, he's never left alone, or to his own devices. There's always somebody there. We feel fortunate that he's not in a classroom with 20 kids and one teacher…there's four adults in the classroom at any given time. We feel fortunate that he's…watched after. I know that when I send him to school that he is in a safe environment…I don't have to worry about him running off or disappearing.

Glenn also explained that the small class size was supportive, noting that his son Lucas was in a class with few students. “I believe last year, there were six or seven children in his class. So that is a huge benefit.”

The low adult to student ratio has manifested itself both in the self-contained setting, which is traditionally smaller, as well as in the general education setting where both Nathaniel and Mathew have a 1:1 teacher aide supporting them. Kayla explained that they originally tried putting Nathaniel in a self-contained class but it turned out to be a “disaster.”

He is in a regular education classroom with a one-on-one aide. It's a smaller school district…they only have one special needs classroom and they said that it was too
contained for him…we tried to put him in the smallest class that they have.

There is one teacher and then he has his own one-on-one.

**Supplementary resources and supports.** Additional supports and resources were provided to each of these students in their respective schools. These resources are specialized beyond the regular curriculum, and help to enhance the experiences of each student. When asked about these resources, Glenn explained that his son’s school has developed systems to support him throughout his day. He noted that there are “a ton of visual aids…to help him set up his day.” Glenn continued:

So, there's a board in his classroom where they try to set up the day so that he can visually see that, "9 o'clock, I'm gonna go here. 10 o'clock, I'm gonna go here." And they'll go over it with him and explain to him what's going to go on through the day, so he's not surprised by anything.

Genevieve explained that her son Josh is aware of these extra supports, “…he knows he's got a schedule, and he knows that he's going to get some privileges. So, I think when he gets to school, he knows exactly what's going to happen. It's organized for him.” She also referenced the additional ways the school supports his needs:

The teacher has a lot of activities in the room, and rewards…His classroom has pets in it, animals and things to take apart. So, it's a very busy classroom, which is very distracting for him, but it also gives him a lot of opportunities to do things besides just sit for 40 minutes and do math…it's really hard for him to keep his attention that long.

Beyond visual supports, parents discussed other ways the schools designed programs to support their children throughout their day. Kayla mentioned that her child’s school used music
as a method of support to calm Nathaniel down. Glenn’s wife Grace added that the school even provided a trampoline for Lucas to support with sensory input. Glenn described additional features that assisted with the sensory needs of their son:

[T]he building is very sensory seeking, like it's very...There's always some kind of sensory thing going on that...There's different kinds of sensory boards, water table, there's a sand table, there's the rice one, and then even on the wall...there's felt and there's shiny stuff, so when they're walking along the wall, they can touch and feel all this sensory stuff on the wall.

**Related services.** For each case, participants stated that their child received related services in their school setting. Related services received by these students included speech services, occupational therapy, physical therapy, counseling, and orientation mobility. Related services support students in further enhancing areas of their physical or social well being that may not be fully developed. In this study, each student received related services at their school site in some form or fashion. The table below outlines the related services that each student received at their school:

Table 2

*Related Services*

<table>
<thead>
<tr>
<th>Student</th>
<th>Speech Services</th>
<th>Occupational Therapy</th>
<th>Physical Therapy</th>
<th>Counseling</th>
<th>Orientation Mobility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lucas</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Connor</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Josh</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Behavioral Characteristics

This section outlines the common behavioral characteristics that were highlighted by parents with regard to the child’s functioning at school. In the first section, parents describe some of the best qualities of their children, what makes them special, and where some of their strengths lie. The second section provides further context with regard to sleep deprivation issues that are experienced by students with SMS, and how this correlates with their well being in the school setting. The last section, discusses behaviors that students with SMS present that are at times aggressive, or disruptive to their own learning as well as the learning of others.

“Very sweet and kind.” When parents were asked about the behavioral qualities of their child that they considered strengths, they were not short of descriptors. It became increasingly clear through this work that students with SMS have immeasurable qualities that are often summed up by the feeling and emotions they emit to others, a topic that will be explored in more detail later. Parents spoke of immense joy about their children, despite the various challenges they often present. Overwhelmingly, parents described their children as sweet. In fact, six of the seven parents used that exact term in describing how their child acts toward others. From a school setting, it should be stated that these children have numerous strengths, and exhibit
behaviors that should be valued within a school community. This section examines these qualities further.

Children with SMS present challenging behaviors that characteristically define them. While these behaviors are pronounced, parents used other terms when first asked to describe their child. This is important to note, because while maladaptive behaviors may manifest themselves in extreme and heightened ways, the demeanor of a child with SMS as described by their parents is more often than not sweet or caring, empathetic and loving. These positive attributes are so prevalent that students with SMS are often described by school personnel in a similar fashion, strikingly opposite to the terms used to describe their behaviors when they struggle to control their emotions. Jody described her son Mathew as a child who has a joy for life, a “joie de vivre”, who has a “little hop in his step” and is “just a really joyful little kid.” She explained that his “smile is infectious”, and that he “gets real excitement out of the small things.” She went on to say that “people really respond to it, and just think he’s charming.” Hannah described Connor as “sweet and kind…excited that it’s a new day” and both “happy and engaging.” Kayla called it “melt your heart sweet”, and described a story of when Nathaniel hugged a school psychologist he had never met. In describing Ashley’s qualities, Sabrina explained:

By far and away, she is the most loving person…she loves to cuddle, she loves just sitting with you…and when she was done having a meltdown, and she comes and she goes, "I'm sorry, mommy. I'm sorry”, yeah, by far and away, the most lovable little person you'll ever find…people in school that she deals with, they'll say the same thing. She'll tell people that she likes their shoes, she'll ask them their names…a lot of people just find her…when she's in her good mood, just to be the most adorable person.
Grace provided a beautiful story explaining the impact these endearing qualities have had on others, and how her son Lucas is “very attuned to how people feel.” During an athletic competition that raised money for a terminally ill child, Lucas embraced the girl’s mother following a speech she delivered, bringing the gymnasium to tears:

[The girl’s] mom came out, and in front of the whole auditorium or the gymnasium, was explaining to them what she deals with on a daily basis…you know all the trials, tribulations, everything. And Lucas was bawling his eyes out. In the middle of her talking, it was really quiet and you could tell Lucas was emotional, but he was trying to hold it in, [She] started to cry. So Lucas got up, went over to [her] in front of the whole gymnasium, and in the microphone said "I love you", gave her a hug, and they both just were there for good hugging, for probably a good three, four minutes. The whole gymnasium was in tears.

“I’m just really tired.” Sleep deprivation is common in children with SMS, a function of an inverted circadian rhythm of melatonin secretion. This often leads to daytime sleepiness, or shortened sleep duration. The effects of this can result in morning tiredness and frequent daytime napping, which is counterproductive to a learning environment. According to parents in this study, sleep deprivation is a significant issue seen in each child during the school day. The success of a child’s school day is often determined by sleep acquisition, as parents note a clear correlation to sleep deprivation and behavioral problems. Participants in this study point to sleep deprivation as an area that is deeply connected to their child’s well being. It is however, an area that has received little intervention in school to support. Of the seven participants, only one was able to give an example of school supports for their child in the area of sleep. The struggle of sleep deprivation, as Hannah noted, is a challenge:
Honestly, I think his biggest struggle is sleep…on the days when he gets good rest, we have no issues. He's fine. He's excited to go. On the days where he does not, which can range from sometimes two days a week to four days a week, he'll go to bed at 9:00 and wake up at 3 o'clock in the morning and doesn't go back to bed. And those days are hard because he's tired, so he won't... His body will not let him sleep, so he's just kind of a bear on those days.

Hannah continued, stating that when they started Connor in school the staff had never dealt with Smith-Magenis Syndrome before, “they had no idea what to expect.” She “told them that [they] need to maybe think about doing half days, or a whole bunch of different options because he's gonna get tired.” About mid-day, “if he hasn't had enough rest the night before, he's unbearable.” Carson thinks his daughter Jillian’s behavior would improve if she were less tired in school:

They say she usually gets tired like in the early afternoon, but she doesn't nap at school…They say she does get tired or she wants to go to sleep but she never ends up falling asleep …I think if her sleep was better throughout the night her behavior would be better throughout the day. We try to give her melatonin, it puts her to sleep, but she still wakes up about three, four o'clock. I definitely believe that her behavior would be better if her sleep was more regular.

Nighttime awakenings were common, with children often waking up in the middle of the night. Mid-day tiredness also occurred, and behaviors correlated. Glenn stated that Lucas’ behavioral issues usually arose at school when awakenings occurred:
I used to track his sleep patterns quite frequently and I did it for about three years and it seems like, historically, in the winter time when there's less sunlight and the days are shorter, we have a lot more outbursts. The awakenings are a lot earlier, 3:30, 4 o'clock, and the aggression is just unreal…it doesn't really happen at home a lot, it's usually always focused more at school.

When asked if Lucas naps at school, Glenn added that while he would like him to, he does not. Grace declared, “he fights it as much as possible.”

The lack of sleep led some parents to think through alternative schooling options so their child could find more success. Jody said to herself, “There's no way he can go five full days.” Her son had taken a nap “virtually every day of his life”, and the thought of full day schooling was a difficult concept to grasp. She knows that Mathew is tired, but calls him “a trooper.” “He's kind of working the night shift all the time even though everyone else is on the day shift…he's just tired, he's yawning…yawning all day. Genevieve has had similar experiences with Josh:

When he was in pre-school he would fall asleep at 9:00 in the morning and then he’d do pretty well… Sometimes he would lay his head down in the afternoon. Once he got to kindergarten, he couldn't really sleep. I think there was too much going on in the classroom and he didn't want to miss out on anything. There are times when his behavior got worse…he was just too tired to get through the whole day, and so, we only sent him to school for half a day. And then, once he was tolerating that well then we upped him by half an hour a day then we gradually worked up to over a year to a full day again.

Genevieve mentioned that when Josh is tired he “gets a little bit more hyper…moves faster, and he's not stoppable…he's very intense.” Josh himself recognizes the challenges, and it
would seem would prefer to sleep but doesn’t always have the self-control to do that. "You should never have put me in this situation”, he often says to his mother when tired. Genevieve acknowledged that “he understands that it's hard for him…there are times when he'll say, ‘I'm just really tired’.” Kayla explained that sleep is one of the most difficult challenges they face, noting that “sleep has been one of our biggest battles since he was a toddler.” She went on to say that Nathaniel is sleepy during school, and that he too has nighttime awakenings. In describing Ashley, Sabrina explained that since her daughter began taking a medication called Clonidine, “she doesn't sleep in school anymore. She does get tired, but she doesn't sleep…and the way that school is set up, it doesn't allow for it anyway.” Jody summed up the difficulties of sleep disturbance, stating “it's devastating to have a kid that doesn't sleep well and never will without any intervention.”

“Tables got flipped.” One of the most discussed characteristics of children with SMS in this study were the maladaptive behaviors of students with SMS that defined their school experiences. Students with SMS exhibit extreme behaviors that include aggression, tantrums, outbursts, and self-injury, all which can severely disrupt their learning experiences. During this study, parents described varying levels of behavior challenges, with some noting less common occurrences. Additionally, some children exhibited more maladaptive behaviors at school then at home, while for others the opposite was true. What is clear however, is that when these behaviors occur they require significant intervention and response. Parents feel strongly that their children have no control over these emotions, and determining triggers ranges from difficult to downright impossible for some parents and educators. Hannah described Connor’s experiences in school:
It's pretty bad. He'll topple over his desk, he'll throw things at other kids. He actually bit one of the teachers last year. He acts…like a toddler that's tired. That's the best thing I can think of, a two-year-old who is tired and acts out. He kicks, he hits, he bites, he throws things, he topples over his desk. It's embarrassing.

When asked if Connor exhibited any self-injury, Hannah noted that he does not typically self-injure. He does at times become aggressive with others:

He mostly just tries to hurt other people. He'll maybe kick a wall. He does not head bang, he never has. He might bite his hand, but it's not like what you see other kids do…I think he just battles with himself… one moment he's completely fine, doing his work, and then the next moment, he just rips it apart, and then afterwards, "Oh my gosh, can't believe I did that.”… It's himself, he's battling himself.

Hannah recounted his behaviors “like a toddler having a temper tantrum.” It’s “the hardest thing for people to understand.” While he exhibits better behaviors at home, he is “a terror at school.” Connor does not self injure at school, but Hannah explained that the school does remove him from the classroom environment so that he does not hurt himself or others.

They have a space for him…I think it's padded. They'll usually go in there with him…they will put him in there and they'll stay there with him, but they have to remove themselves because he'll bite. He's gotten into a biting pattern this year; He actually drew blood on one of the teachers. So he'll bite and he'll kick and he'll scream and he'll hit and he'll punch…then he usually could calm within a minute or two. He just needs that time of being alone.
Glenn and Grace have similar experiences with Lucas. Glenn describes Lucas as an “alpha”, someone who will try to “knock” a person out of a leadership role, whether that’s the teacher or anyone else. Lucas exhibits behaviors that are disruptive and aggressive, and Glenn and Grace fear that the school will no longer find the setting suitable for him. Glenn described his behaviors:

[H]e will do things like throw chairs, flip desks. He's cleared out the cafeteria a few times. He usually doesn't go after any of the children at all, it's just always the adults. It's always an authority figure that he will go after…one way or another he ends up getting what he's looking for.

Glenn reiterated that he can be set off easily, and that it is difficult to know when Lucas will have an aggressive moment. He can meet “a new person…walk right up to them and he'll go, ‘Oh I'm Lucas, nice to meet you,’ and shake their hand…then, you know, a minute later he can throw a chair at you. So it's hard.” Lucas’s behaviors have gotten so bad, the school was forced to place him in a four-point supine restraint. This is a restraint where his legs and arms are physically restrained. “He was actually in a supine restraint which is a four-point restraint…five individuals, two minutes in, two minutes out. He was in there eight times within one outburst.”

When asked about his triggers, Glenn and Grace responded that it was complex, and they were often unsure of what may have set him off, or sure that it was “nothing necessarily.” Glenn shared that “It could be something as much as somebody walked by and dropped a pencil, or somebody said, ‘Hey, Lucas’…he'll then yell "F you" to them and start punching himself in the face.” They continued, “nothing can set him off or something could set him off, we don't know.” These behaviors have often led to Lucas being removed from classrooms or common areas.
Glenn described that a year earlier, Lucas became so agitated that “tables got flipped” in the cafeteria. “At least three times a week, he throws his lunch and has to get taken out of the cafeteria.” Glenn expressed that he was concerned about Lucas’ future at the school:

Probably my biggest concern for him, is when that school comes to me and says, "He's not a good fit for our school anymore. We cannot handle him. You need to do something else or we need to do something else." And we've asked those questions and nobody can give me a definitive answer on what the next steps are. Because, honestly, this is the step before...I hate to say it but...putting him in an institution.

Carson mentioned behavior as Jillian’s most significant area of struggle. “Her biggest issues are behavior…she has tantrums that last hours.” While these behaviors are a challenge, Carson has felt fortunate that they have not manifested themselves at school with as much frequency as they do at home. “I've never heard of anything physical or aggressive at school. She bites her hand a lot, and they say she does that a lot at school. She kind of just hurts herself…but never towards other kids.” While Jillian’s behaviors are more manageable at school, they do not make the situation at home any easier:

Honestly, it's a daily struggle with her. Every day there's tantrums, every 10 minutes at times. To be honest, I think her best place that she probably does thrive is in school. It's getting to be where they're seeing what we're going through, but not as much…overall, she's better behaved at school…it's been so hectic lately. It's hard to focus on good times.

Genevieve has had similar experiences with Josh, who at times has become physical and violent in school. Genevieve likened his behaviors to the syndrome, but also to an inexperienced
teacher that “didn’t know how to handle him.” Genevieve said that when Josh was bored in class, “he caused trouble…everyday there was a problem.” For Josh, “things got very violent. He spent pretty much every day in the principal's office…he would sit in the chair and do nothing for two hours.” Kayla has experienced similar bouts of violence with regard to Nathaniel’s behaviors in school:

He's hardly physically aggressive, as long as he's on his medication. As soon as we take him off his meds, he gets really violent anytime they ask him to do work…he can get really, really violent if you ask him to do something he doesn't want to do, and if you keep pushing the issue, he will get more violent.

Kayla said that when Nathaniel is “raging out, it’s incredible.” Nathaniel has a safety plan that requires someone to always be within arms length, but this to has created some indirect problems. “[W]hen he goes to throw a punch or bite or kick…there's a person there that ends up getting caught in the middle of it.” Kayla continues, “As long as they don't ask him to do anything, he's nice.”

Sabrina described the feelings she believes school staff face due to her daughters behaviors. Sabrina states that people “are generally very intimidated by her…I was having a conversation with the teacher that she'll have starting next week and I can just feel it, how stressed out this woman is that Ashley is coming to her class.” Sabrina likens these feelings to a teacher’s lack of understanding as to what to do when Ashley is having a difficult time. “She is loud…like very, very loud. When she's banging her head and dropping to the floor…people don't know what to do.”
Jody’s experiences are actually quite different from those of the other parents. Her son Mathew who is in a general education class with 1:1 support is behaving very well in class. Mathew’s teachers told Jody, “Mathew’s one of the most well behaved kids in our class.” Jody continued, “it's funny because he…does really usually hold it together at school.” While Mathew does not exhibit maladaptive behaviors at school, he does exhibit them at home and in public. “I don't recall him ever scratching, hitting, kicking, biting anyone at school. That is completely not the case at home and is also not the case in some community settings.”

**The Social Portrait**

One of the most interesting themes that emerged from this research was the development and narration of a remarkable social portrait that students with SMS maintain in their school environments. Students with SMS can exhibit extreme behaviors, many times violent and aggressive, which at times resulted in teachers and other staff members being pushed, hit or kicked. At the same time, students with SMS have an overwhelmingly endearing and empathetic disposition that creates a juxtaposition from their often disruptive selves. These positive qualities and attributes have helped them become well known and adored within their communities, more so than one might imagine for a child that can turn so aggressive so quickly. Multiple parents stated that their child is known as “the mayor” at their school, a term that has even been used to describe my own son.

At the same time, these students struggle with close peer relationships in and out of school. While they are well known and well loved, many parents have explained that maintaining friendships has been a struggle for their children. Some parents were not sure if their children had true friendships in school, while others explained how their child’s behaviors often made
friendships more complicated and challenging. This section describes the social portrait of children with SMS in schools.

“The Mayor.” Parents in this study spoke positively about their child’s social standing with regard to how well loved they are school. These children have used their endearing personalities to draw people in, and thrive on engaging others into their world. At school, these students are often well known, and parents find this to be a comforting feeling. Genevieve explained that her son Josh is well “loved” at school, and known by all:

[Josh] loves walking around the school socializing…they call him the mayor…everybody knows him…I think the people just love him. His sister came in to pick him up with me yesterday and she said, "Everybody loves Josh there. Everybody knows him”…I think Josh likes to help, he likes to feel wanted and he likes to feel needed and important…I think he gets all of those at school.

When asked why she thought people were so enamored by her son, Genevieve recounted a concept called asynchronous development, something she learned from Barbara Haas-Givler and Brenda Finucane, two leading experts in the field of SMS. Asynchronous development refers to development that does not occur in sync, which occurs in children with SMS as their social and emotional development lags behind. Genevieve explained further, “emotionally [they] kind of stay in the two to three-year-old stage for decades…that charming two-year-old mentality, where they're just so innocent, they're out there to have fun and enjoy life.” She continued, explaining the dichotomy of his emotions that so many children with SMS seem to face, “He doesn't have middle emotions, he has extreme emotions. When he's happy, he's
extremely happy; when he's sad, he's extremely sad…I think there's something that people like about that…it's hard not to join in. Genevieve explained further her son’s social standing:

I was talking to his OT [Occupational Therapist]…and she said, "Oh, he's just fine. He's going to be a success one day, he is the Mayor of the school”…Then his case manager, who comes a couple times a year to visit the school, said the same thing. When kids come out of the school, he's like, "Oh, Hi, James, oh, Hi, Joe." And these are people that aren't in his class. He knows all the teachers…he doesn't have any qualms about getting to know people.

Hannah had similar sentiments with regard to why she believed school staff were drawn to Connor, similar to the notion of asynchronous development Genevieve referred to:

I think, honestly, it's because he has that child-like charm. Everybody usually loves an adoring toddler. Even though he's almost eight years old, he still, in so many ways, has that child-like wonder. That's something that we're gonna have forever. I don't love SMS by any means, but I do love the fact that he can wake up every morning when it snows and be excited. Or when he sees Santa at the store, he thinks its Santa. And he'll never lose that.

Connor has managed to receive the attention of both teachers and students alike, each group finding him to be someone whom they enjoy being around. Hannah shared a comment his teachers made at a parent teacher conference the year prior. “Everybody loves Connor. They said that he actually has an entourage of three third-grade girls who wait for him at recess and they play with him almost all the time, and they just love Connor.” Hannah believes its easy to love
Connor, “He doesn't care if you're a man, a woman, a stranger, the UPS guy. He is genuinely excited to see you, and he will give you a hug just 'cause he is just that guy.

Glenn and Grace also made mention of school personnel using the term “mayor” to describe their son Lucas. Glenn explained, “Everybody calls him "The Mayor", 'Cause like, he's so personable. You want to shake his hand and give him a high five and say "hi" to him.” Grace continued, explaining that Lucas has developed strong relationships with his classmates, but also with others in the school as well. “[T]he older kids at school, they really like him and they're not afraid of him. They've all seen him act out…but they will still approach him with a hug and a high five.” Kayla explained that Nathaniel often shows people at school a side of him that can be problematic, but he also has a side to him that people adore:

His social worker tells me that everyone there loves Nick. They all talk about Nick and how sweet he is. But he's definitely shown them his moments…but when he's not having those moments, he's so sweet that they can't... It's melt-your-heart sweet.

Carson’s daughter Jillian still has her moments as well, but the affectionate side of her often surfaces, and helps to show others around her how much she cares for them. Carson stated, “Even when she's having her bad days, she just loves the affection. She'll go up to her teacher and give her a hug. When she's not having her meltdowns, they know she's a pretty loving kid, very affectionate.” Carson added that she “loves the affection”, and at times maybe gives a bit too many hugs. “She just loves to give hugs and receive hugs. Sometimes it's a little much, as far as the teacher says…She just loves the affection, loves to give hugs.”

Sabrina described her daughter Ashley as “very friendly”. “She's really just an awesome little girl when she's not having any meltdowns. She's very social, just loves talking to people,
giving them compliments.” Sabrina also recognized that while although her daughter struggles at time with her behavior, she feels that most people understand her and “are smart enough to know that this is something that she really can't control”. She reiterated that they “know that she doesn't do it on purpose.”

Jody’s son Mathew just started at a new school, and did not know anyone before he began. She declared, that at this point he is already well known by all, and she argues that it is not because of any behavior issues:

He's only been at his new elementary school for a few months, so totally new; no one there knew him. I guess we had a IEP meeting in the spring, but most of the people that are involved in his care at school weren't there. So for all intents and purposes, no one met him until the first day of school…I would say now, I would be surprised if there's not a single staff person there that doesn't know who he is, and it's not because of any aberrant behavior…They all know his name because he's charming.

Already, Jody has received validation from school staff that her son is not only well known, but is also well valued and loved:

[His Paraprofessional] wrote us a note, a thank you note at Christmas, and she said that one of the staff at the school said to her, "I think you have the best job in this school." She said, "I think you're right, I really do have the best job in the school." So this child that I just described to you with all the difficult behaviors, people love working with him, they really do. He's charming.

“They tell me he has friends, but I’m a little torn.” For children with SMS, navigating friendships in school is complex. While they maintain endearing personalities, other barriers
persist that make building friendships challenging. There are many factors that contribute to this, including their own behaviors and struggles with peer interactions, as well as some environmental factors. Each parent indicated some form of difficulty in maintaining friendships in school, but few discussed interventions at the school level that mitigated this issue in any way. Kayla explained that she does not “know if he actually has friends or not…They tell me he has friends, but I’m a little torn”:

He was talking about this boy who was his best friend last year in school, and he handed out birthday invitations to the class. Nick's like, "There's one in my bag, there's one in my bag," and I looked, and there wasn't one…I called the teacher, and the teacher said that Nick wasn't invited…Nick hadn't been invited to a single party all year, so I kind of feel like he doesn't really have friends. They tell me he has friends, but I don't think that he really does.

When asked if Jillian had peer relationships, Carson said, “Very little”. He explained that she has had some friends, but that her behaviors sometimes complicate matters.

She actually just got a report that she punched a kid. I used to drive her up to school…around the same time another girl that's in her class gets to school…every time I'd see her, she'd run up to her and give her a hug. She's very affectionate to others, but she also has her moments.

Glenn and Grace also recognize the social challenges their son Lucas has faced. Glenn offered his belief that part of the issue is related to the fact that Lucas loses valuable social time in school due to his need to be pulled for related services. Glenn explained, “He's got counseling, one on one…plus your routine academics throughout the day…it really only leaves a limited
amount of time for him to interact and really have a good time with his friends.” This lack of time is complicated further by Lucas’ behaviors. “[H]alf the time, he puts himself in a position where he doesn't have that opportunity [to socialize], whether it be having outbursts, or behaviors.” Lucas’ behaviors have made it difficult to maintain relationship. Glenn explained a situation that involved a neighbor’s children:

There was an instance a month or two ago, where he threw a tool belt at the youngest boy, and the youngest boy didn't wanna play with him anymore…So Grace and I went and spoke to the parents and they said that, "We are afraid of what could happen."

Glenn explained that Lucas had actually “struck three of the four” neighboring children. Grace shared “Not maliciously, just out of excitement, he doesn't know what to do with himself.”

Glenn and Grace have tried to schedule play dates with kids in the neighborhood and at school, but “they’re very limited”.

Hannah has had similar experiences, noting that while friendships exist, they can be more challenging. “At school, yes, he has friends, but like I said, they have to watch him because there are days where he's lovey-lovey and there's other days where he's trying to throw things at them…his moods are unpredictable”. While Hannah does what she can outside the school environment to support her son Connor, she knows that it is difficult, and that his behaviors are in many ways who he is as a person:

I know there's nothing I can do to change the way he is…when you're in public or when you're at a friend's house and he's spitting in their child's face, you feel like, "What could I have done to prevent that?"…But you know you can't. Deep down inside in your head,
rationally, you know you can't... emotionally, you think that there must have been something somewhere you could have done. But you know you can't.

Genevieve stated that for her son Josh, what’s “hardest for him is that he doesn't have friends.” She declared that this is the “one piece that's missing for him”. She added that in her belief, the “school does as much as it can, but because the students are from so far away and they're so diverse [with needs]” its difficult getting them together. There is a parent in the class who would like to get their children together, but because “her son is not verbal”, the boys do not actually have a conversation when they play. Josh has connected with some older boys, and would be “happy to play with kids his age too”, but that does not happen often. Genevieve expressed that “it would be nice if the school had some sort of activity for kids that are more alike”, to support in their socialization.

Jody expressed a similar sentiment, noting that she does not get the “sense there's a ton of peer interaction.” Jody believes that this is in part due to Mathew’s speech and language delays, and because of a lack of understanding “it's easier for a peer to just pick out another peer” to play with. Mathew has a few friends in his neighborhood, but in school his mom is not so sure. “He's talking about a couple kids...but I don't know.” Mathew has had some positive social moments as a result of school however.

The whole class was invited to a birthday party at a place called "Bounce House", so it has like those big jumping...inflatable things. He went to this birthday party, and he has not gone to a lot of birthday parties for a lot of reasons, but he went…He seemed to be interacting with his peers, and they seemed to be responsive…a couple kids in particular really seemed to be hanging out with him.
Jody explained that at the party, there were some boys who did not know him and were trying to go around him on the bounce house ladder. One of his classmate’s said, "You need to wait for Mathew. We've got to wait for him. Everyone's gonna stay in line and take their turn.” Jody found that moment to be “really encouraging”:

It really spoke to…that they were looking out for him, but I think also felt like he was a peer. He certainly does some things differently…He probably wasn't engaging as typically as his peers, but not dramatically differently either. I felt really encouraged by that, and I think he felt really happy and confident…and was a part of it.

Sabrina’s experience has been slightly different than the other parents. While her daughter Ashley still struggles with peer relationships in school, one staff member in her school helped developed an intervention plan to support with this. Sabrina shared that while the school still needs to work with Ashley on her engagement and interaction with others, the support of this one staff member has had quite an impact:

A year and a half ago a woman, an aide came to the class... She has no training in special education, just this person's been working with children for many, many years and everybody automatically gravitated towards her. This woman started getting the girls together. And so now, over the last year plus, they've been able to form little friendships. She takes Ashley to her house and she invites the other girls too…She takes it upon herself to help them interact. And it was so interesting when the school said, "Oh yeah, they're friends, they're going to move up to the same class together." And I'm like, "That would not have happened had it not been for [her aide]."
These friendships are important for Ashley. Without them, she would have little socialization if any. “Outside of school she has zero friends. No one calls and asks to play with Ashley… she has no like, buddies or friends outside of school.”

While friendships have been challenging for students with SMS, some parents have reported that they have had more positive interactions with older students in their schools. Jody explained that Mathew “tends to gravitate toward older kids…I think just because they're more patient with him.” Grace notes that Lucas has great relationships with the “older kids at school”, explaining that they really like him and are not as afraid to interact with him. Genevieve added further context:

[A] privilege that he has is to work with older students…if he has a good morning, he earns time with a departmental student, which would be like a high school student. And he greatly looks forward to that time. He loves working with older kids, boys especially.

Hannah’s son, a first grader “has an entourage of three third-grade girls who wait for him at recess and they play with him almost all the time.” She explained his relationships with older students further:

Connor has really made friends with a group of boys that are in the sixth grade…there's a group of boys that are in the sixth grade that Connor has just clung on to. They just love him. And this year, they were all out playing football, and Connor came over and asked if he could play football with them…I don't even know if he even knows how to play football, but he went over and they gave him the ball. They threw the ball to him, he caught it and he ran, and they couldn't catch him and he made a touchdown. So that was really huge, a really, really joyful moment for me, the fact that these older boys
who…take in this special-needs child…They've taken him into their group and really, they play with him, they play football with him, and even one of them gave him one of those paracord bracelets.

**Academic Context**

For students with SMS, the academic environment can be somewhat complicated. Due to their various needs, students with SMS have unique experiences relating to academic content. Parents in this study reported that their children had greater success engaging with hands on and real world learning opportunities, and less success with academic experiences that required fine motor skills, especially in math and writing. Additionally, families made note of the struggle to complete homework, and the challenges the expectation of homework created at home for families. This section will explore the academic environment in more detail, describing what has been successful, what has been less successful, and the complexity of homework for students with SMS.

*“She thrives on that, she loves that, she needs more of that.”* During this study, parents noted a number of areas that they believed their children performed well in. Life skills, hands on experiences, and reading were academic areas that positively stood out for parents of students with SMS.

Carson explained that his daughter Jillian is in a special life skills class, and that his daughter really enjoys school. He noted that he believes the school has a strong program for supporting these skills, and that this has been beneficial for his daughter’s schooling. Genevieve noted similar successes with her son Josh. She explained that his classroom is more “life skills
oriented”, and that they “cook…go on field trips”, and recently “went to the post office and mailed” a letter to his aide from last year. Genevieve continued:

The life skills class is really right up his alley…they still do a lot of academics in there, but they shortened the amount of time. It's a 20-minute period of academics, but there's a lot of physical activity. Once or twice a week they do cooking…Josh feels good when he can do life skills...because then he can help out at home. He likes doing them at home. He does laundry at school, they clean their own swimsuits and towels and fold them. So, I think for me…the life skills aspect is the most beneficial…Josh likes to do it…and it gives him skills that he needs, that he's really gonna need.

Sabrina’s daughter Ashley, is involved in a similar style of program in her school, one that Sabrina believes has been very positive for her daughter. While her daughter is in a special skills class, Sabrina shared that “the school really sets them up to be integrated within the school as best as they can.” She continued, “I think the Social Skills program is really good…it really tries to give these children an option to play with their typical peers and model certain behaviors, and then also, to make is more socially acceptable.” This program is developed to support social skills through integration, but also incorporates life skills into the curriculum. Sabrina explained:

[It allows for] more hands on experience…so not just learning your numbers and learning to count, but doing it in a more practical fashion. Like learning to put like a recipe together…the more practical things, 'cause that's how they learn. They learn by doing…Like for Ashley, she thrives on that. She loves that. She needs more of that.

Reading was also an area that parents founds their children seemed to enjoy, and do relatively well in at school. While these students still have skill deficits and maintain reading
levels below their peers, they have found reading to be an area of enjoyment and positivity. Carson has been surprised by his daughter Jillian’s progress. “She's learning how to read and write, that's something we never thought would happen…. I never thought that would really happen but she's reading. Genevieve’s son Josh is also reading. “He still is reading primary books, probably grade levels one and two. He just started reading 'Flat Stanley.' He's just got the attention span to read a chapter of 'Flat Stanley,' but mostly, he likes to read the newspaper”.

Genevieve explained that at first it was a struggle, but that he’s developed more confidence in it:

> Reading was a struggle in the beginning, but once he started…the teacher was able to get him to read some words. He likes to be read to, but getting him to read, she was able to do that and I wasn't. Now he loves to read out loud, but also to be read to.

Hannah has also been satisfied with her son’s ability to read, and to accomplish the “small things that are huge for him”. Hannah shared that her son can learn a book at school then come home and read it, and he can also spell and recognize his own name. She stated that “He likes us to read…if somebody's reading a book, he'll sit there and let you read the book to him.” While Hannah noted that reading is an area he enjoys, she’s aware that his progression in this area is relative:

> He doesn't really have a ton of [academic] strengths I would have to say…He can read certain words if they're sight words, if they have a picture. He can do basic one plus one, he can write his name, but academically, I would say he's more on the level of like a three-year-old.

Sabrina explained that her daughter’s progress in reading has surprised her. “She actually can read…when I found out probably about a year ago I was really surprised. She reads by the
whole word approach. If you tell her a word, she'll remember it the next time which is amazing.”

The act of reading is not recognized as strength by all however. Kayla shared that Nathaniel actually finds a great deal of difficulty reading. She stated “Reading, I think is a struggle. They actually pull him out with a reading specialist to work with him on reading, because he hates it so much.”

“Sitting, writing, math…Those are very, very hard for him”. Parents of students with SMS noted that their children struggled in many academic areas, most noticeably in areas that required fine motor skills, math, and writing. While some parents explained that their children were best in areas where they could read and listen, or engage in life skills, activities that required them to engage in fine-motor related academic work presented more challenges. This section will explore further the relationship students with SMS have with some of their more challenging academic subjects.

When Genevieve was asked to discuss areas where her son Josh did not perform as well, she explained, “Sitting, writing, math…Those are very, very hard for him. She continued:

Math has been a struggle forever…He learned what coins are. In kindergarten he knew what a penny was, he knew what a nickel was, but if he doesn't repeat it for a month, then he completely forgets. That's kind of the level we're at with math. He can use a number line to find addition, but he can't remember his math facts. He can use a number line to subtract, but he really struggles with math.

Genevieve explained Josh’s struggle with writing, and the concern she had when she first entered his local public school:
Writing is very, very hard for him…I walked him to the kindergarten at the public school and I knew as soon as I walked in there that he wouldn't survive. They were all sitting there at their own desks…and they were writing, and it was quiet…I just knew that he couldn’t survive this. So, just having to sit and be quiet is just very, very difficult for him.

Hannah shared that her son Connor’s patience often gets the best of him when it comes to math and writing. She believes that he requires one on one support to complete tasks of this nature. “He just doesn't have the patience to sit and do 10 math problems. He doesn't even have the patience to do one…most of his papers come back as one big scribble…He has no patience at all.” She continued, explaining the need for additional supports. [A]nything that’s…more of him doing it on his own, it won't happen. He has to have someone there that's constantly in his ear, ‘Connor, can you do this?’ ‘Connor, can you do this?’ Otherwise, it doesn't get done”

Sabrina noted similar struggles as they relate to Ashley’s schooling. Math and writing surface as areas of challenge, as well as other fine motor activities:

Math is hard for her. She can count, but adding, it's been a challenge for her. She hates writing. She doesn't like any of the fine motor skills, so writing, drawing, coloring in lines. She absolutely hates that. She gets really angry when they try to make her do that.

Glenn’s son Lucas is also challenged by math and fine motor tasks. Glenn explained that “arithmetic would be very difficult for him”, and “anything that has to do with fine motor skills. Jody explained that for her son Mathew it too is “fine motor” skills. “It's just so hard... It's pretty hard to get him to write his name and things like that.” She explained further:

It's for sure gonna be the fine-motor stuff…He can write most letters sort of legibly when he tries, but he can't write them in a straight line. His hands are small and I think that
decreased nerve sensation and just some level of hypotonia, plus dis-tractability [means that] handwriting is hard for him. He's just not terribly interested in most fine-motor things, probably for all those reasons.

For Nathaniel, the concept of completing academic work is difficult, due in part because “he’s very weak”. Kayla explains that “He dislikes pretty much anything that involves work…if it means he has to do work to get to it, it's not going to happen. Kayla affirmed that these difficulties include writing:

He hates writing. He can come up with all kinds of stories. He'll repeat stories galore, and he wants to color pictures to go with the stories, but the whole idea of having to hold a pen or a crayon for more than a few seconds is painstakingly difficult to get him to do. They actually have his aide at school do what they call scribing. So he'll have to write the first two or three words, or letters or whatever they can convince him to write, and then she'll write whatever he says after that for him.

“Homework, it doesn’t get done.” Another theme that surfaced in this research was the resistance of some students with SMS to complete homework, and the often expectation of schools to provide it. Some parents noted homework as a real struggle, complicating matters at home so much that one parent requested that their child’s teacher stop providing it.

Hannah mentioned that Connor struggles significantly with completing homework. Much of this has to do with a number of variables including his attention span as well as high levels of fatigue upon returning home. “If he comes home with homework, it doesn't get done. He refuses. He has very short attention span.” She continued:
I'm making dinner and he's just exhausted from being at school all day. And usually, those times are the hardest because the kids are doing their homework and he is just a mess and it is chaos. But we try not to go outside of our bubble during those times because we know that he can't help it, and there's nothing that any of us can do to change things.

Hannah stated that Connor is often physically incapable of completing the task when he returns home. Both physically and mentally, when Connor returns home from school he is simply exhausted and the concept of homework is extremely difficult:

I mean honestly when he comes home from school…when we pick him up off the bus…that's it for him, he's wiped. We get home and we struggle to keep him awake…the homework thing has been a really hard thing for us 'cause he just can't, mentally he cannot do it, he's done.

Jody has similar sentiments when it comes to homework, and recognizes that at times her child may have difficulty completing it especially when tired. She explained that when he’s tired, “it's certainly not like we're gonna be able to do anything that's high-demand, like homework…” Kayla has taken the issue a step further, advocating on behalf of Nathaniel to his school. She explained that she had to “put a stop to teachers forcing him to do homework.” The homework issue for her son had even become punitive. “They were punishing him and taking away his free-time and his recess because we stopped making him do homework.” She continued:
It was becoming a violent issue at home. It was turning into a violent angry battle. He wasn't getting it. He was behind, and they have to send him the same curriculum as the other kids have. And I don't understand the reasons fully but they gave me reasons.

**School to Home Partnerships**

For parents of children with SMS, school to home partnerships have been an important aspect of their child’s education. While some parents noted some positive outcomes of the partnerships that exist between school and home, many felt that their school simply did not understand their child. Each parent in this study expressed some level of misunderstanding that made the school to home partnership more challenging. Many parents believed that their schools often did not partner with them in a meaningful way to improve their child’s experience. Parents noted that at times their schools’ made assumptions that were not accurate about their child, or did not heed the advice of parents in a way that could have benefited the child more appropriately. This section will explore further the school to home partnerships, and often misunderstandings that exist between parents of children with SMS and their respective schools.

*It “fell on deaf ears”.* Parents in this study have expressed various levels of frustration with regard to the misunderstandings present between their school and what’s best for their child. Each parent noted examples of misunderstanding that often exasperated an issue, or delayed a process to support their child. Carson explained the misunderstandings he has felt with regard to Jillian’s schooling:

This teacher that they have now, she really didn't understand Jillian or understand the disorder so...that's been tough...We gave her a pamphlet on the SMS...sometimes at school I don't think they understand the nature of SMS, the behavioral issues. They
should be a little more understanding…Every day she would send home a journal, a daily journal and there'd be notes…that she had a bad day and exclamation points…So it was frustrating reading it and just the way she wrote it, it would seem like she was mad at Jillian…Like I said I don't think she truly understands the SMS disorder as well as [she] should.

Carson explained further that in his belief, none of his daughter’s aides seem to understand her either. He described an approach in which teacher aide would attempt to “be kind of stern” with Jillian. “Knowing Jillian, my wife is like, ‘That's totally going to backfire. You'll never get anywhere with Jillian if you try that approach.’” Carson noted that he believes his daughter needs a “little extra attention, that extra affection, even when she's bad”:

[I]f you go the stern route, it's never going to get anywhere with her. We just know her that well. It gets frustrating because her main teacher that deals with her, she says she understands the disorder, but then clearly she doesn't when she tells us things and she doesn't understand why she does it. We have to tell her its part of the disorder.

Hannah’s experiences are similar, noting that any time Connor enters a new situation or new school year with different staff members, that people do not “necessarily understand him” or have “false expectations of him.” She explained that at the start of the year, his new teacher stated a set of expectations that were unreasonable for Connor. She thought to herself, "this is not gonna work for us because he can't do that." She added that his special education teacher had to provide supports to help his new teacher fully understand his needs. In addition, she noted that his aides at school “have a hard time with him because I don't think they really understand him.” Genevieve also experienced misunderstandings related to school personnel, stating that
even though his teacher “read a lot of information, I don't think it really registered with her. I think she felt like a lot of his behavior was more under control than it was.”

Glenn and Grace provided further context as it related to misunderstandings or false assumptions they have faced as special needs parents. They have found that their advice has often gone unheard, making matters more difficult for Lucas:

I think that another big problem that we ran into is we were the parents…and this is only my assumption…they've dealt with other special needs individuals and this isn't any different. And anytime that we give them any advice on how to deal with Lucas, what they should and shouldn't do, it really fell on deaf ears and no one took our advice. And in the end, Lucas's the one who ends up being hurt by the whole process.

Sabrina expressed that for her, she feels that the frustration is felt often on her daughter’s end, with regard to dealing with educators who may not fully understand her situation or syndrome completely. Sabrina stated that her daughter “likes being in school because she gets to interact with a lot of different people”, but also believes that its “frustrating for her when she has to deal with people who don't understand her or don't realize sometimes she's tired and she wants to be left alone.” She added that her daughter is constantly “being challenged”, when people “don’t understand what makes her upset”.

For Jody, the frustrations regarding misunderstandings were palpable. Jody felt strongly that her son Mathew’s needs were not fully recognized, and often minimalized. When speaking about one of his teachers she expressed her frustration in relation to the recognition of his sleep deprivation issues:
I felt like she really minimized our issues….She was really pushing for full-day kindergarten for him. And she said to me…it was kind of an irritating situation, but she said "Well, all kindergarteners are tired, at least till winter break, so he'll be fine."…I found that so maddening because she was really minimizing a sleep issue and comparing a child with a dramatic and very difficult to fix sleep disorder with a typical kindergartener…you can hear how angry I still am about that, because I feel like of all the SMS things, the behavior is hard for sure…but it's not totally unique, but the sleep piece is pretty darn unique. There are not many disorders with the sleep thing too, and I feel like when people don't get the sense of that, and what a big impact it has for the kid, for the family, it enrages me…it's devastating to have a kid that doesn't sleep well and never will without any intervention.

Misunderstandings related to sleep issues were also noted by Kayla, who expressed frustration as to how school personnel still seemed to be unaware of the need even after it being placed on her child’s IEP as a special alert:

We told the school he had it, and they added it to his IEP, and teachers still cannot seem to figure out how it works…They put all the alerts at the top and his alert is that he has sleep disturbances, and already two weeks in school have a note home saying, "Do you think you maybe know why he is tired in class?" [Its] just a little bit frustrating.

When asked about the misunderstandings Kayla stated that she felt like in her child’s situation, they were “glazing over it”. She said that they have offered the school “tons of information”, but that “they don't seem to care.”
Summary

Throughout the course of this research, the aforementioned themes presented themselves in various ways, each of which helping to paint a picture of what students with SMS experience in schools. At present, no published research exists that has examined the school experiences of these students. What we have learned so far is paramount in understanding what it might be like for them on a day-to-day basis. These themes have significant implications in providing us with important understandings about their experiences. Collectively, their stories paint a portrait of the experience of a student with SMS, an experience that is often misunderstood, often fraught with great challenges, and at times filled with an immeasurable joy that positively impacts others in profound ways.

These themes do not tell a complete story though. They do however scratch the surface of some emergent themes that deserve further examination. What we have learned, is that there are a number of experiences that have taken similar root with respect to these students. We know now that these students experience school in typically smaller settings, with a variety of supplementary and related services that address their needs. We know that they are incredibly loving and kind children, whom often struggle with a sleep disorder that creates unique challenges throughout the school day. We also know that these sleep challenges, along with other factors contribute to aggressive behaviors that make learning more difficult. We know that these students are well loved and admired, but that they struggle to develop close peer relationships. We also know that they perform better with hands on experiences related to life skills, and enjoy reading and listening to stories. They struggle however with many aspects of academics that involve fine-motor skills, including writing and mathematics. We have also learned that the expectation of homework creates challenges at home that complicate matters greatly. Finally, we
have learned that school staff often misunderstand these students, and that these misunderstandings make an already difficult school experience even more challenging. What we have also surfaced is that there is a lot more learning to do with respect to the school experiences of students with SMS.

**Chapter Five: Discussion**

This chapter will begin to develop a further analysis of the research findings, placing this analysis in the context of both practical understandings as well as future considerations. This research has helped to identify aspects of understandings related to the school experiences of students with Smith-Magenis Syndrome, as well as generated new questions that should be explored further.

The purpose of this study was to understand further the school experiences of students with SMS. This study used a qualitative research design, interviewing eight parents using a semi-structured approach to gain further insights. This research was guided by four research questions:

1. How do parents of children with Smith-Magenis Syndrome perceive their child’s interactions with the educational environment?
2. What aspects of the educational experience are parents of children with Smith-Magenis Syndrome most and least satisfied with in the K-5 setting?
3. What can we learn from parents of children with SMS that can be applied in the classroom?
4. How can the educational experiences of those with Smith-Magenis Syndrome be improved in the K-5 setting?
This chapter will help to articulate conclusions, which have surfaced in relation to the findings presented in chapter four. These conclusions will be presented through a lens that relate to the theoretical framework used in this study, as well as the relevant literature and research presented in chapter two. This chapter will also outline implications of this research, as well as discuss the limitations of this study that surfaced.

**Intersection of Theoretical Framework**

Person-Environment Interaction Theory, and Wright and Lopez’s (2002) accompanying Four-front approach provided the framework and lens in which this study was designed. Person-Environment Interaction Theory provides a framework that supports environmental factors in playing a role in the interrelation between individuals and their surroundings, and supports the notion that these behaviors can be altered through influences within the environment. (Lewin, 1935). The Four-front approach examines the behaviors of persons within the environment, focusing specifically on the following: 1) Deficiencies and undermining characteristics of the person. 2) Strengths and assets of the person. 3) Lacks and destructive factors in the environment. 4) Resources and opportunities in the environment (Wright & Lopez, 2002).

This study has used these frameworks to help understand the experiences of students with SMS, engaging participants in interviews and questions that directly examined their individual child’s behaviors in school relative to their own makeup, as well as engaging in conversations related to the school environment itself. By analyzing both the individual and the environment, this study has been able to develop an intersection of understanding between the two, helping to depict how individuals with SMS interact with their school communities, and how these school communities support or in some ways hinder the development of these
students. As themes within this research emerged, each related in some capacity to either the individual or environmental context in which these frameworks are based, often intersecting the two in a manner that has helped to further define the school experiences of students with SMS.

**Overview and Discussion of Findings**

This section will further discuss the themes that emerged within this study, and their relation to the theoretical frameworks and relevant literature.

**The school as it relates to environment.** For students with SMS in K-5 schools, the environment is an important factor in supporting student development. In this study, each school community developed supports and resources designed to alter the environment in ways that would assist students with SMS. Low adult to student ratios, supplementary resources, and related services all provided supports that enhanced the student’s daily experiences. These environmental adjustments relate directly to fourth principle of the Four-front approach, resources and opportunities in the environment.

These environmental supports often have a positive impact on student learning, as well as a student’s ability to manage behaviors (Doctoroff, 2001). Additionally, by receiving additional services, students with SMS may have benefited from improved behavioral functioning in school, a concept seen with other students with developmental disabilities who receive similar supports (Hodapp & Fidler, 1999). In examining the resources and opportunities within the environment of the students in this study, we can determine that the schools in which these students attend have developed strategies within the environment to provide supports. In each scenario, schools have lowered the adult to student ratio to provide more intensive supports, creating smaller class settings or aligning a one-to-one aide to assist. This is consistent with best
practices determined by Haas-Givler and Finacune (1995), noting that small class sizes support more individualized attention for students with SMS, and reduce the risk that students will tantrum or have outbursts when their individualized needs of attention are not being met (Haas-Givler and Finacune, 1995).

Schools have also changed the environmental context through visual aides, organizational systems, positive reinforcers, and sensory integration. Visual reminders, as well as reinforcers are important strategies in supporting students with SMS (Haas-Givler and Finacune, 1995; Udwin 2003). Additionally, these schools have made programmatic decisions through related services that have created a layer of supports with regard to speech, occupational, and physical therapy, as well as in some cases counseling and orientation mobility. Developing a well-organized environment designed for individual needs is an important factor in supporting students in schools (Doctoroff, 2001).

With regard to this study, schools have made positive steps toward altering the environment in ways to support a more individualized learning environment for students with SMS. These environmental changes are critical components to the success of students with SMS. Schools should continue to support students with SMS in smaller classroom environments that provide more access to adult supports, and provide related services in the areas of speech, occupational, and physical therapies as needed. Additionally, schools that support students with SMS should use the classroom environment as an extension of learning, providing visual and sensory modifications, as well as utilizing positive behavior intervention strategies (PBIS) to increase student outcomes. Developing supports proactively to address the needs of students with SMS is a critical component in creating school environments that are prepared to educate
these students. Modifying the environmental components of a school or classroom should be at the forefront of thinking when it comes to preparing schools to support these unique students.

**Behaviors of students with SMS.** This study has highlighted some of the unique characteristics of students with SMS in school, from their sweet and loving demeanor, to their maladaptive and challenging behaviors in school. Additionally, sleep issues create even more complex situations within schools that make navigating the environment more challenging. These behavioral attributes have been viewed through the lens of the Four-front approach through the deficiencies and undermining characteristics of the student, as through the student’s strengths and assets (Wright & Lopez, 2002). Additionally, the Four-front approach highlights lacks and destructive factors in the environment, an important factor when considering the supports students may not be receiving. By examining both the positives and negatives of human behavior, as well as elements lacking within the environment, remediation possibilities become more pronounced, and schools can align resources more effectively to support development (Wright and Lopez, 2002).

This study confirmed many of the behavioral characteristics highlighted in previous research, however also added significant depth to understanding these students through their positive attributes. In prior published research, discussion related to the positive attributes of students is often surface level, noting briefly the child’s eagerness to please, sense of humor, loving and caring nature, and engaging and endearing personalities, but failing to dive deeper into these attributes (Haas-Givler, 1994; Haas-Givler and Finacune, 1995). This research has helped to confirm these findings, but has also added a layer of understanding that has helped to legitimatize the impact that these students have on others through their caring demeanors. With 6 of 7 families describing their child as “sweet”, as well as parents noting that school personnel
overwhelmingly saw their children in a similar fashion, it is worth noting that while so much research focuses on the maladaptive behaviors of people with SMS, perhaps we have minimized their positive attributes so significantly that they have been somewhat mischaracterized. By developing the stories of the parental experience related to their child’s positive attributes, coupled by their positive social identities in school, educators should consider more closely how positively students with SMS interact within their school communities. These types of understandings could prove beneficial in developing effective programs for students with SMS.

With that said, the prevalence of maladaptive behaviors can not be understated. It is also important to understand the impact that these behaviors have within a school community. While the research on the behaviors of people with SMS is more significant than most other areas related to the syndrome, no published research has examined these behaviors within the confines of a school community. This research further confirms the disruptive behaviors displayed by those with SMS. In the majority of cases, students with Smith-Magenis Syndrome exhibited disruptive behaviors within the school environment, making learning challenging for them and those around them. Those with SMS typically have characteristics that include severe behavioral problems, maladaptive behaviors, impulsivity, aggression, and self-injury (Dykens and Smith, 1998; Finacune et al., 2001; De Leersnyder et al., 2001). Families and professionals have also reported that these behaviors are “extraordinarily disruptive and hard to manage” (Dykens & Smith, 1998). In this study, parents noted that their children often had difficulty managing their behaviors within school, with many becoming physically aggressive and having tantrums and outbursts that were hard to control. Parents were also convinced that their children had little control over their behaviors at times, and triggers for these behaviors were often elusive and difficult to determine. Additionally, we have learned that schools have to manage the behaviors
of these students in a variety of ways, some more effective than others. Along with less restrictive intervention methods, schools in this study also utilized intervention methods that included removal from the environment, trips to the principal’s office, placement in a padded room for safety reasons, as well as physical restraint. While each situation is different, and the physical and aggressive behaviors that surfaced are real, it is worth noting that children with SMS in schools are often faced with restrictive intervention methods for the purposes of their own safety as well as the safety of others. In lieu of this, considerations should be made in thinking through how these methods might impact a child with SMS’s experience within their own school. Schools should recognize the importance of maintaining the least restrictive methods possible, but also know that when more restrictive methods are needed that the use of these may negatively alter the school experience of someone with SMS. Awareness of this is important, and schools should be proactive in ensuring students with SMS are not only physically safe, but emotionally safe as well.

This research has also helped to confirm and further develop understandings of just how difficult and challenging it is for students with SMS to navigate within their school communities, especially with regard to their sleep needs. Sleep deprivation is an issue that is prevalent in these students, as well as others who have been studied in a similar context (Elsea & Girirajan, 2008; Dykens & Smith, 1998; Finacune et al., 2001; De Leersnyder et al., 2001; Smith et al., 1986). Students with SMS maintain sleep issues that include prolonged awakenings at night, daytime sleepiness, and decreased sleep duration (De Leersnyder et al., 2006; Laje et. al., 2010). It is worth noting that parents in this study have highlighted sleep deprivation as a significant issue related to how their child interacts within the school environment. Sleep deprivation with regard to students with SMS is strongly correlated to aggressive behaviors and attention problems. As
Daytime naps increase in length, aggressive behaviors and attention problems in those with SMS decrease (Dyken & Smith, 1998). With this said, the majority of schools supporting these students have failed to develop strategies that helped to mitigate this issue of sleep deprivation. Only one school related to this study implemented a strategy to resolve patterns of sleep issue in school. Parents in this study note a correlation between lack of sleep and behavior issues in schools, though the majority of parents can not speak to how schools have looked to provide interventions of support in this area. When considering the correlation between sleep disturbance and maladaptive behaviors, students with SMS need greater environmental supports to assist them in managing their sleep needs within their school communities. Schools play an important role in providing intervention directly related to student needs, and in this instance schools should seriously consider the impact that sleep deprivation has on students with SMS and develop strategies to support. Schools face a unique circumstance in supporting students with SMS, as its typically counter intuitive for a school to allow a student to sleep in class. For students with SMS however, it may prove to be essential in allowing them to remain in a more productive state of learning. Providing opportunities for students with SMS to sleep in quiet and safe areas during school is an important consideration that schools should make. Additionally, providing educators with training and professional development with regard to this might reduce the stigma attached to sleeping in school, and help to create a more empathetic and understanding environment where students with unique sleep needs are supported more thoroughly. Considering the impact that students with SMS have on an environment when they are expressing challenging behaviors, and the correlation that exists with regard to sleep deprivation, its imperative that school environments develop the strategies necessary to support students in managing their sleep needs.
The social dichotomy. For students with SMS, socialization and relationship development is complex. This research has shown that students with SMS often find themselves with high levels of social clout and recognition, but often with little to no authentic school-related friendships. This research has surfaced an understanding of the socialization of students with SMS, loved and cherished by many, but lacking close personal friendships. Its important to think through this dynamic from a theoretical perspective, examining the social relationships of students with SMS by considering the deficiencies and undermining characteristics of the person, as well as the person’s strengths and assets (Wright & Lopez, 2002). For students with SMS, their positive attributes play a role in their popularity, while their maladaptive behaviors and communication delays often create barriers to friendships.

Children with SMS are often considered friendly, affectionate, and outgoing (Loveland & Kelley, 1991). Socialization skills are also a relative strength for kids with SMS (Martin et al., 2006). In this study, parents confirmed these findings through their descriptions of the socialization of their children, often being referred to as “The Mayor” of the school, as students who were typically very well known. Parents in this study had positive experiences as they related to their child’s social standing, and felt strongly that people were genuinely drawn to their children for positive reasons. Students with SMS use their positive attributes in a manner that defines their school experiences much differently than one might expect considering the maladaptive behaviors they exhibit. More often than not it seems, students with SMS are positive contributors to their school environments and are appreciated and well loved community members. This is a new understanding with regard to how students with SMS interact with their school environments. It should serve as an important reminder to all of those involved in the education of a student with SMS, that the positive impact of these students should not go
unnoticed, and should provide a new lens in which to view the experiences of students with SMS.

Despite that fact that students with SMS have high social standing within their school communities, they struggle greatly in developing authentic friendships. The majority of parents stated that they did not believe their child had a true friend at school, and many noted that this was similar outside of school as well. This is certainly concerning, but not surprising. Children with SMS face a variety of challenges that make friendships more difficult. Children with SMS often “suggest a high level of inappropriate initiation of dialogue, stereotyped conversation and lack of use of conversational context” (Sarimski, 2004, p. 351). Additionally, they present a variety of behavioral challenges that make friendships problematic, as noted by parents in this study. While these challenges create barriers, environmental constructs could work to support greater levels of peer-to-peer socialization within schools for students with SMS. Only one parent in this study referenced a support that the school had put in place to encourage greater levels of peer relationships. Other parents noted that they had hoped that their child’s schools created more opportunities for peer-to-peer interactions.

Like many students with special needs, developing peer relationships is difficult, and it is important that educators create an environment where students can engage in peer play (Doctoroff, 2011). Beyond play, environmental interventions should be considered within the classroom as well, through seating arrangements that promote dialogue, and inclusive activities that support integration of students with special needs into general education settings (Center et al., 1989; Rouse & Florian, 1996). Social interventions that are intentional and purposeful can help to mitigate environmental factors that may already inhibit socialization with peers. Without structured supports by schools, students with SMS may experience some levels of social
isolation and fail to develop authentic relationships on their own accord. In consideration of this, schools should develop strategies to promote greater levels of socialization for students with SMS that contribute to authentic relationships. Additionally, schools should recognize that many of these students may be educated outside of their home districts due to their educational needs, and as such may be generally apart from peers within their own communities. Schools should consider implementing approaches to ensure that students with SMS outside of their home districts have an opportunity to develop relationships with peers closer to home, even if these peers do not attend the same school. Schools could employ a “bridge class”, in which students with SMS visit with the school in their home district on occasion, helping to foster relationships. Additionally, schools could create connections for students with SMS to their home districts by engaging in pen pal letter writing, video conferencing, and ensuring that the students with SMS are included in class communication, both formal and informal. These connections will allow students with SMS to not only engage with students in their own schools, but to also engage with peers in their home districts, fostering relationships within their own communities that are essential to social development.

**Curricular considerations.** Students with SMS have shown similar characteristics when it comes to the academic context in which they either thrive, or struggle. While students with SMS still face challenges across a variety of academic components relative to their typically developing peers, they have found relative success in some areas. This section utilizes the Four-fronts approach by considering the lacks and destructive factors in the environment, as well as the resources and opportunities that exist (Wright & Lopez, 2002).

In examining the curricular considerations of students with SMS, little research existed in relation to how students with SMS engaged with specific curricular content, specific subjects, or
other programmatic opportunities with the school environment. In speaking with parents in this study, it was determined that students with SMS had greater success engaging with hands on, real world learning opportunities. They had less success with academic experiences that required fine motor skills, especially in math and writing. Additionally, families noted that their children struggled to complete homework, and that often these struggles created significant challenges at home. Parents noted that they believed that their children might struggle due in part to the fine motor requirements of some content areas, particularly those that involve writing. Additionally, students struggled in content areas where they were asked to be more sedentary. In understanding this, schools might consider taking note of the needs of student with SMS and their relative success with more hands on activities to further develop strategies that might assist in the subject areas of math and writing. Using hands on manipulatives, and employing opportunities for students with SMS to engage with technology to assist with writing functions might prove beneficial. Additionally, it is important for all students to have positive experiences within their home environment, and with many families expressing the challenges that homework presents within their households, including violent outbursts, it is worth considering whether homework is necessary, or if it could be modified in a manner that was more strengths based. Asking parents of students with SMS to manage a status quo homework regimen may in fact do more harm then good. Modifying the assignments, or expectations of homework completion might more positively support students with SMS.

Partnering with parents. This study has helped to further qualify the importance of school to home partnerships that has existed in prior research, as well as further noting the disconnect that is often present between schools and families of students with disabilities. This section is influenced through the lens of “lacks and destructive factors” within the Four-fronts
framework (Wright & Lopez, 2002).

What is known is that parent partnerships are important. They can often have a positive impact on student success in school (Eccles & Harold, 1993; Koegel, Koegel, & Schreibman, 1991; Newmann & Wehlage, 1995). While this is known, the relationship that has existed between schools and parents of students with disabilities has not always been a successful one. Many families note levels of dissatisfaction with relation to communication and collaboration with their child’s school (Covert, 1995). Families have also noted that services provided by schools for their child were at times ineffective (Kohler, 1999). It is important to recognize the value that parents can provide in assisting schools. The perceptions of parents of students with disabilities help to provide a valuable framework for schools to consider (Garrick, Duhaney & Salend, 2000; Leyser & Kirk, 2004; Seery, Davis &Johnson, 2000). During this study, we have learned that partnerships with parents of students with SMS are lacking, often leaving schools with a misunderstanding of the child. Each parent reported some level of misunderstanding that complicated the school to home partnership. They noted that schools made incorrect assumptions about their child, and often failed to take the advice of the parent’s in considering their child’s school experience. Considering the rarity of the syndrome, coupled by the fact that no published research articles exist outlining the school experiences of students with SMS, parent partnerships are critical in understanding and supporting these students further. As schools begin to work with these unique students, it is important that they utilize parents as a resource to support their process in educating children with SMS. Finding ways to engage parents in this process is an important step in defining school programs that truly meet the needs of these students.
Implications for Practice

When considering implications for practice, it is important to be reminded of Hunt’s (1975) discussion on individual differences:

The way in which we regard individual differences may thus depend upon the way we consider them to have come about. If we think of them as error, their information value is nonexistent. On the other hand, if we understand their genetic as well as their environmental base and understand them to be integrated to the evolution that all behavior can be assumed to have undergone, individual differences become highly important in the search for behavioral determinants (Hunt, 1975, p. 222).

Individual differences are not in fact error, and schools need to make important environmental changes to accommodate the individual differences that exist with regard to students with SMS. While parents have reported that schools have made some modifications in this study, these same schools have missed on critical modifications that would ensure students with SMS a more tailored learning environment.

**Altering the environment.** Schools should continue to provide environments that consist of low adult to student ratios, and develop their environments in a way that provide supplemental resources and interventions as needed. Students with SMS benefit from modifications within the school environment that include visual cues, structured days, sensory integration, positive behavior intervention supports, and related services to support developmental delays. Maintaining environments such as this help to proactively create learning environments conducive to supporting the needs of students with SMS. Schools should also take a proactive approach to thinking through unique modifications that may be supportive of these
students. Students with SMS are distinctly unique in many ways, and schools should imagine how their environments could cater to the needs of these students, rather educating these students within environments that are not suited to their best interests.

**Reframing current understandings.** To fully understand students with SMS, educators must reframe their current understanding of schooling. Schools must take a concerted effort to differentiate to support the needs of students with SMS. This study has shown that in many ways schools have failed to be innovative in their approaches to educating students with SMS. A lack of innovation has left these students traversing an environment that is not often suited for them. Students with SMS are atypical, and require atypical interventions. One such instance is their disrupted sleep patterns. To alleviate this, schools need to overcome the stigma of sleeping in school, instead recognizing the benefits that it may have for students with SMS. Schools should develop interventions and strategies to address the significance of sleep deprivation in students with SMS. Schools should provide scheduled rest breaks within the day, providing areas for students to sleep as needed, and support the professional growth of educators in understanding the need for these students to manage their sleep cycles even while in school. Schools should proactively develop such plans, and recognize the value that sleep acquisition may have on increasing student performance in students with SMS, all while decreasing the behavioral challenges that surface when these students are sleep deprived. Failure to recognize the need to adapt the environment to address sleep acquisition needs creates an environment that unfairly asks students with SMS to navigate. Schools that educate students with SMS must take these interventions seriously, and recognize the benefits it will have in educating these students more appropriately. In this study, and with my own experiences, schools have struggled with accepting the reality that students with SMS require sleep assistance in school. If students with SMS do
not receive sleep interventions, they are being deprived basic necessities. Parents and educators should demand that the sleep needs of students with SMS are accommodated, and develop schedules that allow this to become a reality in school in the least disruptive manner.

**Investing in social development.** Considering the concerns parents in this study raised regarding authentic friendships their children struggle to foster, schools and educators must work to develop interventions that support the social development of students with SMS. Classroom strategies to increase dialogue should be implemented, as well as school based programs that increase opportunities for students with SMS to form bonds with classmates in a more personal manner. Social skill development is also important, supporting students with SMS in learning appropriate strategies of forming and maintaining friendships. Additionally, schools should recognize the difficulty many students with SMS have in being educated in specialized schools outside of their home districts, and provide opportunities for these students to engage with peer groups within their own communities. One important strategy is developing a “bridge class” option with the student’s home district. A “bridge class” would allow a student who is in an out-of-district placement to return back to his/her home district occasionally (i.e. one time per week/month). By creating a formal structure in which these students have a connection to a class within their home district, they will have greater opportunities to forge relationships with children within their own community, making it more likely to engage in social interactions, and increasing opportunities for social development and authentic friendships.

Furthermore, schools must take responsibility for supporting and encouraging the social development of students with SMS. Parents in this study have noted that not only do their children lack authentic friendships, but also that the schools they attend provide little to no supports to address this need. It is important to note that students with disabilities are more like
their typically developing peers than they are different. All children require basic necessities to be successful, belonging and physiological needs are among two of them (Maslow, 1943). The fact that students with SMS in this study have attended schools that failed to address these two basic necessities is concerning. Schools should look at students with disabilities, and SMS, first as students with basic needs. If a typically developing child maintained no authentic friendships, and struggled to stay awake during the day, schools would and should recognize this as an issue and address it. This however, has not been the case with students with SMS. It is important that schools remember that all students, regardless of ability, have the right to these basic necessities. When those basic needs are not being met, school must work to remedy them.

**Curricular modifications.** When considering the experiences of students with SMS from a curricular lens, schools and educators should take note of the frustrations that surface in relation to activities that require the use of fine motor skills, or those that are of a sedentary nature. Students with SMS have little tolerance for activities like this, and modifications should be considered when students with SMS are asked to access certain curricula. Developing hands on activities, or modifying assignments by utilizing technology to limit fine motor fatigue would prove beneficial. Additionally, recognizing the low tolerance of students with SMS with regard to activities of this nature would help schools to gain a better understanding of the unique needs of these students. Again, schools must break free of the status quo of schooling and begin to think differently about approaching education with these students. Schools should utilize technology such as iPads and other means to help students with SMS both access curriculum and communicate. If writing is a challenge, rather than forcing the students with SMS to work through it, they should allow these students to access technologies that do not require the significant use of fine motor skills that are largely underdeveloped. Schools should recognize
the strengths of these students, some of which include reading and listening to stories, and use audio books to deliver curriculum. Audio books have been a proven resource in allowing students with disabilities greater access to literacy and content (Brinkerhoff et al., 2008; Esteves et al., 2011; Skouge et al., 2007).

Speaking with parents with regard to homework is also critical. It is important that schools recognize the immense challenges that students with SMS present at home, and educators must be understanding in a parents desire to eliminate or modify homework as needed. Frustrations at home that result from the need to complete homework may prove to have a negative effect at home and in school. Additionally, providing homework to students with SMS that is traditional in nature, and fails to differentiate, will continue to exacerbate issues related to fine motor frustrations. Schools and educators must thoughtfully differentiate learning activities so that parents can partner with their children in meaningful ways at home. Teachers should also be cognizant of the difficulties parents face in raising children with SMS, and recognize that any added homework responsibilities may prove detrimental, even if differentiated appropriately. Schools must partner with parents to make proper choices around the homework needs of students with SMS.

**Parents are the experts.** Schools must also recognize the uniqueness of students with SMS, and the value that parents play in providing supports related to their education. With limited research available, it is important that schools recognize parents as key participants in the education children with SMS. Schools should partner with families in meaningful ways, heeding advice when necessary and acting in unison to support positive outcomes for these students. In this study, parents expressed various levels of frustration of what they considered “misunderstandings” of their child. Schools have a responsibility to ensure that they have a firm
grasp on the needs of every child, and that they are in a position to make appropriate choices to support that child. When schools fail to truly understand a child with a disability, they fail to support them in the most appropriate ways. Schools and teachers need not only to make it a priority to learn more about students with SMS, but should recognize parents as informed experts on the subject. Additionally, schools should access available literature and provide training to staff in supporting students with SMS. With more access to information, and the utilization of parents as partners, schools can begin to understand students with SMS on a greater level, and in turn create environments that support their needs.

**Implications for Research**

Throughout this study, revelations with regard to the school experiences of students with SMS have often led to greater levels of inquiry. Based on the findings in this study, further implications for research surfaced.

**Think of the positives.** First, there is significant research related to the maladaptive behaviors of people with SMS, but very little research in identifying not only the positive attributes they maintain, but also the positive impact that people with SMS have on their communities. The social portrait in which these students navigate is truly unique, with students finding high levels of endearment across school communities, yet challenging peers and staff with maladaptive behaviors. Couple this with their struggle to forge strong friendships, and you have a social portrait that deserves more exploring. Further research should consider this unique social dichotomy in greater detail, fleshing out the social identity that these students maintain within their school communities in a more concerted way. By doing this, researchers and educators can begin to engage in dialogue that speaks more to an asset based value judgment,
rather than one that comes from a deficit mindset. This is critical in maintaining environments for students with SMS that utilize their strengths, as well as areas where they need additional supports. Our natural inclination is to try and support or help in areas of need, but it too often overshadows human elements that are profoundly more positive. The current narrative on children with SMS is that they are extremely disruptive, and have significant maladaptive behaviors. The story we have failed to tell is that they may in fact maintain a level of empathy, love, and socialization that would make most of us envious. Until we begin to focus equally on the assets these students bring to their communities, we fail to build the narrative of who these students truly are.

**Building bridges.** An interesting insight in this study that surfaced was the fact that students with SMS failed to develop authentic friendships with their peers. It was also determined that many of these students were being sent to out-of-district placements. Of the seven students in this study, only one maintained an informal connection to their home school district. This informal connection alone created greater opportunities for friendships and relationships with the student’s own community that would not have existed void of this partnership. In researching this type of agreement further, a lack of evidence exists that suggests that this is a model that is not employed often, if at all by school districts. I was so struck by this insight, that my wife and I fought and secured an arrangement like this for our five-year-old son with SMS this year. In this arrangement, our son will be sent out-of-district to a setting that could support him better, but then bussed back to a “bridge class” in his home district once a month for a half day. This agreement was added to his Individualized Education Plan (IEP), and will be maintained to ensure that he has connections with peers in his own community. The benefits for both our son and the students in his home districts were abundantly clear to all parties, and we
expect that he will develop relationships within his home community that would not otherwise have been possible. More research and supports to develop programs like this for out-of-district students is critical, and could have profound effects for students of all disabilities.

**Ask a Teacher.** Further research is also needed to better understand the experiences of students with SMS, unrelated to the perceptions of parents. Parents offer an important lens in understanding these experiences, but further understandings should be surfaced from those of teachers and school professionals as well. School professionals can offer a glimpse into the school experience that parents do not have access to, and provide deeper levels of understanding. These types of understandings will provide more depth to research of this nature, and provide educators and parents with greater resources and information in which to support students with SMS. At this time, no studies exist that specifically examine the school experiences of students with SMS from the perspective of educators. Additionally, while this research focuses specifically on the school experiences of students in grades K-5, no research exists that examines the experiences at any other level. As researchers, we should take responsibility for marginalized groups of students with whom little or no research is conducted. In the case of students with SMS, so little research has been completed on the school experiences that we can make the assumption that accurate understandings of their experiences are extremely limited.

**Limitations**

There were a number of limitations related to this study. First and foremost, research related to Smith-Magenis Syndrome is extremely limited, and research directly related to the school experiences of these students is non-existent. Because of this, there were many unknowns related to this research. These unknowns made it difficult to have narrowed the scope in certain
areas, due to the fact that no research existed that would provide a basis of any sort. Additionally, 
SMS is a relatively new syndrome, first surfacing in 1982. With less than a thousand known 
cases worldwide, understandings continue to be limited, which in turn creates limitations within 
the research. This also created barriers with relation to more intimate access to the school 
experiences of students with SMS. With so few people diagnosed with SMS, participants in this 
study were not within distance to either have face to face discussions, or to employ a case study 
that would allow for observable experiences.

Conclusion

First, this research presented unique challenges with respect to the utilization of the Four-
fronts approach as a theoretical framework, as they related to disability studies. The Four-fronts 
approach examines person-environment interactions in part by surfacing the “deficiencies and 
undermining characteristics of a person” (Wright & Lopez, 2002). This language alone makes it 
challenging to address topics related to disability studies, which do not look at disability from a 
deficit-based perspective. For the purposes of this research, the framework was used in 
considering areas in which students with SMS maintained characteristics that undermined their 
success within an environment. For future research considerations related to disability studies 
that may use this framework, it is important reframe this aspect of the approach. Instead of 
analyzing the “deficiencies and undermining characteristics of a person”, researchers should 
instead analyze the “characteristics that undermine the success of a person within an 
environment”. This change in language better supports a disability studies framework, and 
moves research away from a deficit based model.

This study has presented an important lens in understanding the school experiences of
students with SMS in grades K-5 in the United States. It has provided insights into areas that previously had not been addressed, and highlighted areas that inevitably will support others in understanding students with SMS more thoroughly. To ensure that the understandings presented within are more publicly available, I will continue to develop this research into mediums that are both parent and teacher friendly. Additionally, new insights have inspired me to look more closely at the positive effects these students have on their environments, as well as to consider further development of “bridge class” models that could be emulated by parents elsewhere. Through these outlets, I hope to fulfill my role as a scholar practitioner, using this research to enact real change within the SMS community in relation to school supports.

I think it is also important to note how powerful these stories have been for me, and for this research. The voices of parents are an important aspect in understanding what life might be like for these children. We must continue to allow the power of stories to help us in understanding the unique nature of these children, and other children who might be equally misunderstood. While these stories have been significant, further research is critical. It has become more apparent to me throughout the course of this research that people with rare syndromes face a variety of challenges, including the fact that they are understudied. This puts them at an even greater disadvantage. I think it is important as educators and researchers that we make a stronger commitment to understanding those with rare syndromes. Taking the time to delve deeper into the understanding students with SMS, and others with rare syndromes, might provide us with insights that truly benefit not only their experiences, but the experiences of those in their presence as well.

Finally, this research has helped me develop profound understandings with regard to my own positionality as both a researcher and a parent of a child with Smith-Magenis Syndrome. It
has opened my eyes to possibilities that I was unaware of before, knowing more concretely the joys and immense happiness that my own son will bring to school communities that he encounters. It also validates some of my worst fears, knowing that his behavioral struggles will continue to challenge both our family and the schools he attends. I think it is also important to note that parenting a child with SMS is wonderful in many ways, but that it is truly a difficult and exhausting feat as well. My family’s experiences have been both mentally and physically challenging, yet we also know for certain that we have all become better and stronger people because of our son. He has helped to teach us things that we needed to learn, and we feel indebted to him for helping us become better parents, educators, and people. I also know that as both a researcher and a parent of a child with SMS, I have a moral and ethical responsibility to make contributions to this field of study. In doing so, my hope is that parents and educators will have a clearer path in understanding the experiences of children with SMS in school settings.
References


Francescutti, C., Gongolo, F., Simoncelli, A., Frattura, L. (2011). Description of the person-environment interaction: Methodological issues and empirical results of an Italian large-


Appendices

Appendix A: Northeastern University IRB Approval Request Form

Appendix B: Interview Protocol

Appendix C: Social Media Statement

Appendix D: Unsigned Consent Document
Appendix A

For NU IRB use:

Date Received: 7/6/15 reviewed 7/28/15 NU IRB No. CPS15-07-03

Review Category: Approval Date

APPLICATION FOR APPROVAL FOR USE OF HUMAN PARTICIPANTS IN RESEARCH

Before completing this application, please read the Application Instructions and Policies and Procedures for Human Research Protections to understand the responsibilities for which you are accountable as an investigator in conducting research with human participants. The document, Application Instructions, provides additional assistance in preparing this submission. Incomplete applications will be returned to the investigator. You may complete this application online and save it as a Word document.

If this research is related to a grant, contract proposal or dissertation, a copy of the full grant/contract proposal/dissertation must accompany this application.

Please carefully edit and proof read before submitting the application. Applications that are not filled out completely and/or have any missing or incorrect information will be returned to the Principal Investigator.

REQUIRED TRAINING FOR RESEARCH INVOLVING HUMAN SUBJECTS

Under the direction of the Office of the Vice Provost for Research, Northeastern University is now requiring completion of the NIH Office of Extramural Research training for all human subject research, regardless of whether or not investigators have received funding to support their project.

The online course titled "Protecting Human Research Participants" can be accessed at the following url: http://phrp.nihtraining.com/users/login.php. This requirement will be effective as of November 15, 2008 for all new protocols.

Principal Investigators, student researchers and key personnel (participants who contribute substantively to the scientific development or execution of a project) must include a copy of their certificate of completion for this web-based tutorial with the protocol submission.

□ X Certificate(s) Attached
□ Certificate(s) submitted previously – on file with the NU’s Office of Human Subject Research Protection
A. Investigator Information

Principal Investigator (PI cannot be a student)  Dr. Jane Lohmann

Investigator is: NU Faculty  X  NU Staff  ______  Other  ______

College:  Choose an item.  ______  College of Professional Studies

Department/Program  Graduate Education Programs

Address  320 Huntington Ave, Mailstop 20 BV, Boston, MA 02115

Office Phone  617-756-3237  Email  j.lohmann@neu.edu

Is this student research? YES  X  NO  ______ If yes, please provide the following information:

Student Name  Steve Corbett  Anticipated graduation date  1/2016

Undergrad  ______  MA/MS  ______  PhD  ______  AuD  ______  EdD  X  DLP  ______  Other Degree Type

College:  Choose an item.  ______  Professional Studies

Department/Program  Curriculum, Teaching, Learning and Leadership

Full Mailing Address  296 Main Street, Cold Spring, NY 10516

Telephone  614-397-4452  Primary Email  Corbett.st@husky.neu.edu

Cell phone  614-397-4452  Secondary Email  stevecorbett66@gmail.com

B. Protocol Information

Title  The Educational Experiences of Students with Smith-Magenis Syndrome: Parental Perceptions
Projected # subjects **5-7 interview participants**

Approx. begin date of project **5/1/2015**  
Approx. end date **3/15/2016**

It is the policy of Northeastern University that no activity involving human subjects be undertaken until those activities have been reviewed and approved by the University's Institutional Review Board (IRB).

- Anticipated funding source for project (or none) **none**

Has/will this proposal been/be submitted through:
- NU’s Office of Research Administration and Finance (RAF) **no**
- Provost **no**
- Corp & Foundations **no**

C.

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<tr>
<th>Will Participants Be:</th>
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<tr>
<td>Children (&lt;18)</td>
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<td>X</td>
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<tr>
<td>Northeastern University Students?</td>
<td></td>
<td>X</td>
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<tr>
<td>Institutionalized persons?</td>
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<tr>
<td>Prisoners?</td>
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<tr>
<td>Cognitively Impaired Persons?</td>
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<th>Does the Project Involve:</th>
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<td>Blood Removal?</td>
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<tr>
<td>Investigational drug/device?</td>
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<td>X</td>
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<tr>
<td>Audiotapes/videotapes?</td>
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D. What are the goals of this research? Please state your research question(s) and related hypotheses.

This research attempts to accomplish a variety of practical and intellectual goals. As a father of a child with SMS, these goals are personally relevant. This research will attempt to accomplish two goals. 1) To develop further understanding of the educational experiences of children with Smith-Magenis Syndrome in K-5 settings. (2) To establish an intellectual understanding of the role that the environment plays in supporting the educational experiences of those affected by Smith-Magenis Syndrome.

To accomplish these goals, the research will explore the following research questions. (1) What can we learn from parents of children with SMS that can be applied in the classroom? (2) How do parents of children with Smith-Magenis Syndrome perceive their child’s interactions with the educational environment? (3) What aspects of the educational experience are parents of children with Smith-Magenis Syndrome most and least satisfied with in the K-5 setting? (4) According to parents, how can the educational experiences of those with Smith-Magenis Syndrome be improved in the K-5 setting?

E. Provide a brief summary of the purpose of the research in non-technical language.

The purpose of this research is to gain a greater understanding of the school experiences of students with Smith-Magenis Syndrome (SMS) from their parents’ perspectives. Smith-Magenis Syndrome is a rare genetic disorder, and currently no published research articles exist that specifically address the school experiences of students affected by SMS. By gaining a greater understanding of their experiences through the perceptions of parents, this research hopes to
provide information that can better support those who have a vested interest in supporting students with SMS, including parents, teachers, counselors, and other school based personnel.

F. Identify study personnel on this project. Include name, credentials, role, and organization affiliation.

Jane Lohmann, Ed.D, Principal Investigator, Faculty member at Northeastern University College of Professional Studies. Dr. Lohman will act as an advisor to this research, providing support as needed.

Steve Corbett, Doctoral Student at Northeastern University College of Professional Studies, Curriculum, Teaching, Learning, and Leadership. Mr. Corbett will conduct all interviews, transcription, data analysis, and presentation of findings.

G. Identify other organizations or institutions that are involved. Attach current Institutional Review Board (IRB) approvals or letters of permission as necessary.

N/A

H. Recruitment Procedures

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<th>Description</th>
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<tr>
<td>Describe the participants you intend to recruit. Provide all inclusion and</td>
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<td>exclusion criteria. Include age range, number of subjects, gender,</td>
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<td>ethnicity/race, socio-economic level, literacy level and health (as</td>
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<td>applicable) and reasons for exempting any groups. Describe how/when/by whom</td>
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<td>inclusion/exclusion criteria will be determined.</td>
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This study will solicit the participation of 5-7 parents of children with Smith-Magenis Syndrome who are currently in the K-5 school setting in the United States, or were enrolled in a K-5 setting in the United States within the last school year (2014-15). These 5-7 parents will be part of a cohort of participants whom will be part of a qualitative interview study. Inclusion criteria will include: 1) Being a parent of a child with SMS who is currently in the K-5 setting in the United States.

Describe the procedures that you will use to recruit these participants. Be specific. How will potential subjects be identified? Who will ask for participation? If you intend to recruit using letters, posters, fliers, ads, website, email etc., copies must be included as attachments for stamped approval. Include scripts for intended telephone recruitment.
To recruit participants for this study, Steve Corbett will ask for support in recruiting participants through various electronic social media formats that are open to the public and foster dialogue related to Smith-Magenis Syndrome. Steve Corbett will use Facebook, twitter, and Ning to deliver messages related to recruiting participants.

Steve Corbett will post the research components and opportunity to participate within the open public forum. Written statements detailing the research components and opportunity to participate are attached.

**What remuneration, if any, is offered?**

To show appreciation, each interview participant will receive a $15 Visa gift card, and a personalized thank you letter for their contribution to this study.

**I. Consent Process**

Describe the process of obtaining informed consent*. Be specific. How will the project and the participants’ role be presented to potential participants? By whom? When? Where? Having the participant read and sign a consent statement is done only after the researcher provides a detailed oral explanation and answers all questions. Please attach a copy of informed consent statements that you intend to use, if applicable. Click [here](#) for consent form templates.

If your study population includes non-English speaking people, translations of consent information are necessary. Describe how information will be translated and by whom. You may wait until the consent is approved in English before having it translated.

Each participant will be provided with the adequate and necessary information to have an informed understanding of the research in order to provide consent. An explanation of the research will be done both in writing and orally, and all written information will be written in the language that the person can easily understand. Written information will also be provided at an 8th grade reading level or less. Short and clear sentences will be employed for increased levels of comprehension. The consent will not include any language that waives or appears to waive their rights, and participants will be given an opportunity for their questions to be asked and answered regarding any element of this study. Information regarding the research will be provided to each participant by Steve Corbett prior to the their participation. Steve Corbett will send all
information, including the consent form to each participant electronically, and will also call each participant by phone to thoroughly explain the research orally, and provide an opportunity for the participants to ask any questions. Steve Corbett will read the consent form out loud and record responses by parents regarding it. Steve Corbett will also provide and explain procedures for safeguarding their information, which will include the declaration that their information will be confidential within legal limits. Coding identities and storage of data in locked files will support maintenance of the confidentiality of these files (see informed consent document). This research will use an unsigned consent form due to parent involvement in the study.

If your population includes children, prisoners, people with limited mental capacity, language barriers, problems with reading or understanding, or other issues that may make them vulnerable or limit their ability to understand and provide consent, describe special procedures that you will institute to obtain consent appropriately. If participants are potentially decisionally impaired, how will you determine competency?

N/A

*If incomplete disclosure during the initial consent process is essential to carrying out the proposed research, please provide a detailed description of the debriefing process. Be specific. When will full disclosure of the research goals be presented to subjects (e.g., immediately after the subject has completed the research task(s) or held off until the completion of the study’s data collection)? By whom? Please attach a copy of the written debriefing statement that will be given to subjects.

N/A

J. Study Procedures

Provide a detailed description of all activities the participant will be asked to do and what will be done to the participants. Include the location, number of sessions, time for each session, and total time period anticipated for each participant, including long term follow up.

This study will use interview participants. Interview participants will partake in a phone or Skype interview with Steve Corbett, and be asked to answer questions related to their child’s
experience in school. Each participant will be in a location of their choosing. Participants will be asked to conduct one interview that will last approximately 60 minutes. Following the interview, each participant will be sent transcribed notes and asked for support in providing any additional clarification or inaccuracies related to their comments. Following this clarification process, follow up may ensue if further information is sought. The total time estimated for each interview participant will be approximately 60-90 minutes.

Who will conduct the experimental procedures, questionnaires, etc? Where will this be done? Attach copies of all questionnaires, interview questions, tests, survey instruments, links to online surveys, etc.

Steve Corbett will conduct all interviews. Steve Corbett will conduct these interviews via phone and Skype from his own home in a private space. The interview participants will be in a location of their choosing.

K. Risks
Identify possible risks to the participant as a result of the research. Consider possible psychological harm, loss of confidentiality, financial, social, or legal damages as well as physical risks. What is the seriousness of these risks and what is the likelihood that they may occur?

There will be minimal risk to participants in this study. Participants involved in this research may face possible risks of loss of confidentiality, as they will be providing personal information regarding their child’s educational experiences. The likelihood of loss of confidentiality is unlikely. All information regarding participants will be coded and secured. Coding identities and storage of data in locked files will support maintenance of the confidentiality of these files. All hard copy information will also be stored in a locked data storage locker in the secured home of Steve Corbett, as well as in password protected computer files.

Describe in detail the safeguards that will be implemented to minimize risks. What follow-up procedures are in place if harm occurs? What special precautions will be instituted for vulnerable populations?
Coding identities and storage of data in locked files and password protected computer files will support maintenance of the confidentiality of these files. Additionally, participants will be asked to review and clarify information in order to secure correct information that is most valid. In presenting findings, all information that may be identifiable to a participant will be coded in order to maintain confidentiality. Names and locations, among other identifiable information will be altered and changed to provide greater levels of confidentiality to the participant population. No vulnerable populations will participate in this study.

L. Confidentiality

Describe in detail the procedures that will be used to maintain anonymity or confidentiality during collection and entry of data. Who will have access to data? How will the data be used, now and in the future?

Steve Corbett will be the only person with access to the information provided by participants. All hard copy information will be recorded then stored in a locked data storage locker. This locker will be secured in the home of Steve Corbett in a location that is not easily accessible to others. Digital information will also be stored in password protected computer files. Confidentiality will be maintained through strict coding, ensuring that all identifiable information is coded in a manner that maintains the personal confidentiality of each participant. Steve Corbett will work closely with his advisor to ensure that this coding fulfills the needs of confidentiality, and satisfactorily secures the personal confidentiality of each participant. Participants names will be replaced by pseudonyms in all cases, including files that are stored in locked data storage lockers and password protected computer files.

How and where will data be stored? When will data, including audiotapes and videotapes, be destroyed? If data is to be retained, explain why. Will identifiers or links to identification be destroyed? When? Signed consent documents must be retained for 3 years following the end of the study. Where and how will they be maintained?

Data will be stored in both a locked storage locker, as well as in password protected computer files. Data will be stored for 3 years following the completion of this research. All files will be destroyed following the 3-year duration through shredding procedures as well as erasure of digital files.
M. If your research is HIPAA-protected, please complete the following;

Individual Access to PHI

Describe the procedure that will be used for allowing individuals to access their PHI or, alternatively, advising them that they must wait until the end of the study to review their PHI.

N/A

N. Benefits

What benefits can the participant reasonably expect from his/her involvement in the research? If none, state that. What are potential benefits to others?

There will be no specific or measurable benefits to the participants; however, participants might appreciate the opportunity to support a study that may help to inform interested parties in learning more about a cause that is personal to them. Benefits to others include the dissemination of new information that may support the understanding of the school experiences of students with Smith-Magenis Syndrome.

O. Attachments

Identify attachments that have been included and those that are not applicable (n/a).

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
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<tbody>
<tr>
<td>X</td>
<td>Copy of fliers, ads, posters, emails, web pages, letters for recruitment</td>
</tr>
<tr>
<td>X</td>
<td>Scripts of intended telephone conversations*</td>
</tr>
<tr>
<td></td>
<td>Copies of IRB approvals or letters of permission from other sites</td>
</tr>
<tr>
<td>X</td>
<td>Informed Consent Form(s)* (<a href="#">see our templates for examples</a>)</td>
</tr>
<tr>
<td>n/a</td>
<td>Debriefing Statement*</td>
</tr>
<tr>
<td>X</td>
<td>Copies of all instruments, surveys, focus group or interview questions, tests, etc.</td>
</tr>
<tr>
<td>X</td>
<td>[Signed Assurance of Principal Investigator Form (required)]</td>
</tr>
<tr>
<td>X</td>
<td>NIH Human Subject Training Certificate(s) <em>(required if not already on file at)</em></td>
</tr>
</tbody>
</table>
**HSRP**

*(Approved forms must be stamped by the IRB before use)*

P. Health Care Provision During Study

Please check the applicable line:

---

___ X ___ I have read the description of HIPAA “health care” within Section 4 of the Policies & Procedures for Human Research Protection. I am not a HIPAA-covered health care provider and no health care will be provided in connection with this study.

_____ I am a HIPAA-covered health care provider or I will provide health care in connection with this study as described in Section 4 of the Policies & Procedures for Human Research Protection. This health care is described above under “Study Procedures,” and the Informed Consent and Health Information Use and Disclosure Authorization form will be used with all prospective study participants.

If you have any questions about whether you are a HIPAA-covered health care provider, please contact Nan C. Regina, Director, Human Subject Research Protection at n.regina@neu.edu or (617) 373-4588.

Completed applications should be submitted to Nan C. Regina, Director, Human Subject Research Protection with the exception of applications from faculty and students of the College of Professional Studies, which should be submitted to Kate Skophammer, IRB Coordinator for CPS.

<table>
<thead>
<tr>
<th>Nan C. Regina, Director</th>
<th>CPS applications only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northeastern Univ., Human Subject Research Protection</td>
<td>Kate Skophammer, IRB Coordinator</td>
</tr>
<tr>
<td>360 Huntington Ave., Mailstop: 960 Renaissance Park</td>
<td>Northeastern Univ., College of Professional Studies</td>
</tr>
<tr>
<td>Boston, MA 02115-5000</td>
<td>Phone: 617.390.3450; <a href="mailto:k.skophammer@neu.edu">k.skophammer@neu.edu</a></td>
</tr>
<tr>
<td>Phone: 617.373.4588; Fax: 617.373.4595</td>
<td><a href="mailto:n.regina@neu.edu">n.regina@neu.edu</a></td>
</tr>
</tbody>
</table>

The application and accompanying materials may be sent as email attachments or in hard copy. A signed Assurance of Principal Investigator Form may be sent as a scan, via fax or in hard copy.
Appendix B

Interview Protocol

Introductory Protocol

Thank you for taking the time to speak with me today. To facilitate our note taking, I would like to audio tape our conversation today. For your information, only researchers on this project will have access to these tapes. Additionally, you must verbally consent to participation in this research. I will read the consent form now [read consent form to participant]. Do you consent to participate in this research? [Yes/No]

Thank you for agreeing to participate.

I have planned this interview to take approximately 60 minutes. During this time I will ask several questions. If you have questions or need any clarification at all, please do not hesitate to ask. Are you ready to begin? [Yes/No]

Great, let’s begin!

Interview Questions

1. How old is your child? What grade is he/she in? Are they male or female?
2. Can you tell me a little bit about your child?
   a. What are they interested in?
3. What do you think it is like for your child when he/she is at school?
   a. Can you provide me with any specific examples?
   b. Describe a time when your child really connected with… (teacher, classmate, subject).
   c. What parts of that experience stand out? What makes them stand out to you?
   d. How do you know what kinds of experiences your child is having?
4. Can you describe an intervention(s) that has improved your child’s experience?
   a. What makes them successful/supportive?
   b. How have you learned about or come to understand this/these initiative(s)
   c. What aspects of the work are you able to witness?
5. Can you describe some aspect of your child’s experience that stands out to you as especially positive?
   a. Can you provide some specific details?
6. Can you describe particular aspects of your child’s experience that trouble you or that you believe are missing?
   a. How do you know that these gaps exist?
   b. How do you know they are a problem?
7. What experiences or opportunities do you wish your child had, or had more regularly?
a. How might these be more helpful to your child?
8. In what ways has your child found success in their school environment?
   a. Can you provide specific details?
9. In what ways has your child had difficulty in their school environment?
   a. Can you provide specific details?
10. What are your child’s strengths in school?
   a. Can you provide an example?
   b. How do you know this?
11. Where does your child struggle the most in school?
   a. Can you provide an example?
   b. How do you know this?
12. In what areas is your child’s school environment lacking?
   a. Where can it be improved?
13. What resources are most helpful for your child at school?
14. Are there any other experiences or topics that we have not yet discussed, that you think are important?

Closing

Thank you for your participation in this survey. A complete transcription of this interview will be sent to you within 30 days. In addition, you will also receive a $15 Amazon gift card. Thank you again for your time today.
Appendix C
Social Media Statement

Do you have a child with Smith-Magenis Syndrome (SMS)? My name is Steve Corbett. I am a Doctoral Student at Northeastern University and parent of a child with SMS. I am conducting research to study parents’ perspectives about the educational experiences of students with SMS in the K-5 setting. I am looking for parents of children with SMS willing to participate in a Skype interview to discuss their child’s experience in school. Skype is a tool that allows people to speak to one another face to face through the internet. If you are not familiar with Skype, I can assist you in setting up an account.

The purpose of this research is to gain a greater understanding of the school experiences of students with Smith-Magenis Syndrome (SMS) from their parents’ perspectives. By gaining a greater understanding of their experiences through the perceptions of parents, I hope to provide educators, community agencies and parents with greater understanding about what it looks like to support the ongoing development and learning of students with SMS.

I seek 5-9 parents who have children with Smith-Magenis Syndrome currently in the K-5 school setting in the United States, or were enrolled in a K-5 setting in the United States within the last school year (2014-15).

Participation in this research is voluntary and the interview should last no longer than 90 minutes. All participants are free to withdraw from participation at any time for any reason without repercussion, so volunteering does not obligate you in any way. All participants will receive a $15 Amazon gift card as a token of appreciation for contributing to the research.

For more information on how to participate, please contact me by email at Corbett.st@husky.neu.edu or by phone at 614-397-4452.
Appendix D

Unsigned Consent Document

45 CFR 46 117(c) In certain instances, an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects. In cases in which the documentation requirement is waived, the IRB may require the investigator to provide subjects with a written statement regarding the research.

Only the IRB can waive or modify the consent process. Researchers are not authorized to make this decision. When a signed informed consent is not required, this consent form may be given to participants to keep. Please modify the following information as necessary.

~~~~~~~~~~~~~~~~~~~~~~~~~~~~
Northeastern University, Department of:
Name of Investigator(s): Principal Investigator: Dr. Jane Lohmann, Student Researcher: Mr. Steve Corbett

Title of Project: The Educational Experiences of Students with Smith-Magenis Syndrome: Parental Perceptions

Request to Participate in Research
We are inviting you take part in a research study. This form will tell you about the study, but the researcher will explain it to you first. You may ask this person any questions that you have. When you are ready to make a decision, you may tell the researcher if you want to participate or not. You do not have to participate if you do not want to. If you decide to participate, the researcher will ask you to verbally consent. You can opt out of the project at any point in time for any reason without repercussion.

You must be at least 18 years old to be in this research project.

We are asking you to be in this study because you are a parent of a child with Smith-Magenis Syndrome who is in a K-5 educational setting. The purpose of this research is to gain a greater understanding of the school experiences of students with Smith-Magenis Syndrome from the perspectives of their parents. Smith-Magenis Syndrome is a rare genetic disorder, and no published research articles exist that specifically address the school experiences of students affected by Smith-Magenis Syndrome. By gaining a greater understanding of their experiences through the perceptions of parents, this research hopes to provide information that can better support those who have a vested interest in supporting students with Smith-Magenis Syndrome, including parents, teachers, counselors, and other school based personnel.

If you decide to take part in this study, we will ask you to participate in an interview about your child’s school experiences. Following the interview, we will send you a transcription of the interview and ask for support in providing any additional clarification or inaccuracies related to your comments. We may request a brief follow up interview if there are things we need clarified as we proceed with the research.

The interview will be conducted via Skype, or in person if close proximity allows for that. Face to face interviews may take place in your home or at an agreed upon private location. The interview will take approximately 60 minutes. Within one month, we will send you transcribed notes and ask for support in providing any additional clarification or inaccuracies related to your comments. This process should take approximately 30 minutes.
There are no foreseeable risks or discomforts to you for taking part in this study. I will do everything in my power to preserve confidentiality, but since the population of children with SMS is so small, there is some risk that others in the community might be able to identify particular stories. Nonetheless, loss of confidentiality is unlikely. All information regarding participants will be coded to mask identifiable features, and data will be stored in locked storage lockers and password protected computer files.

There are no direct benefits to you for participating in the study. However the information learned from this study may help others in supporting students with Smith-Magenis Syndrome in the future.

Your part in this study will be handled in a confidential manner. Only the researchers will know that you participated in this study. Any reports or publications based on this research will use only group data and will not identify you or any individual as being of this project. No reports or publications will use information that can identify you in any way or any individual as being of this project.

We will use pseudonyms in the reports that emerge from the research. In presenting findings, any information that may be identifiable will be changed to protect identity. Names and locations, among other identifiable information will be altered and changed to provide greater levels of confidentiality to the participants. All data will be secured and stored in a locked storage locker, and digital files will be stored in a password protected computer file.

Data will be stored for 3 years following the completion of this research. All files will be destroyed following the 3 year duration through shredding procedures and erasure of digital files.

There are some limits to confidentiality. If the researcher hears or sees something that gives cause for concern, they have a duty to act. Legal requirements of reporting, e.g., child abuse, will be maintained.

Northeastern University will oversee this research, and as such will have official oversight and monitoring rights. In rare instances, authorized people may request to see research information about you and other people in this study. This is done only to be sure that the research is done properly. We would only permit people who are authorized by organizations such as the Northeastern University Institutional Review Board to see this information.

The decision to participate in this research project is up to you. You do not have to participate and you can refuse to answer any question. Even if you begin the study, you may withdraw at any time. If you do not participate or if you decide to quit, you will not lose any rights, benefits, or services that you would otherwise have.

You will receive a $15 Amazon gift certificate at the end of the study.

If you have any questions about this study, please feel free to contact Steve Corbett, 296 Main Street, Cold Spring, NY 10516. Ph. 614-397-4452, Corbett.st@husky.neu.edu, the person mainly responsible for this study. You can also contact Dr. Jane Lohmann, the Principal Investigator. 320 Huntington Ave, Mailstop 20 BV, Boston, MA 02115. Ph. 617-756-3237, email: j.lohmann@neu.edu.

If you have any questions about your rights in this research, If you have any questions about your rights in this research, you may contact Nan C. Regina, Director, Human Subject Research Protection, 960 Renaissance Park,
You may keep this form for yourself.

Thank you.

*Steve Corbett*