ABSTRACT

BELL, KRISTIN MICHELE. A Phenomenological Study of Multiple Incidence Autism Families and School Administrator Perspectives. (Under the direction of Dr. Kenneth H. Brinson, Jnr.).

The purpose of this dissertation study has been to explore the experiences of multiple incidence Autism families and of school administrators who have worked with these types of families in the public schools. Phenomenological methodology was applied with the family study, while a structured, open-ended interview approach was used for administrative interviews.

Four families participated in the study, sharing rich descriptions of their memories and current experiences with familial and educational situations. Interview data resulted in individual and composite textural and structural descriptions, culminating in the essence of the experience. Common themes or topics from family interviews included narratives that addressed: early signs of children’s behaviors, the evaluation and diagnostic process, early interventions, the impact on family and relationships, school experiences, perspectives of school administration, stressor identification and coping strategies, and outcomes and celebrations.

Educational themes that emerged from parental interviews were used to compose administrator interview questions. These interviews were structured in such a manner that encouraged administrators to share additional educationally related experiences and perspectives. Four administrators participated in the study, bringing experiences from the elementary, middle, high school and central office
arenas. Insights on administrators’ backgrounds and experiences with students with Autism and their families, characteristics and observations of parents, creating an environment of acceptance, leadership for special education, and administrative preparation were provided.

Data are related to existing literature, from an educational standpoint, and implications for practice and further studies are provided. The study contributes to the limited body of literature on multiple incidence Autism families and administrative perspectives. Listening to the voices and stories of parents, along with an examination of current educational practices, suggests changes for leadership theory and practice. Revisions to leadership standards and evaluations are also reviewed and related to needed changes for special education leadership at the school and district levels.
A Phenomenological Study of Multiple Incidence Autism Families and School Administrator Perspectives

by
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A dissertation submitted to the Graduate Faculty of North Carolina State University in partial fulfillment of the requirements for the Degree of Doctor of Education

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BIOGRAPHY

Kristin Bell received a Bachelor of Science in Special Education from Southern Connecticut State University and a Master of Arts in Special Education with a focus on Learning Disabilities and Behavior/Emotional Disabilities from Ball State University in Muncie, Indiana. She obtained her Master of Arts in School Administration from Indiana University in Fort Wayne, Indiana.

As a career educator, Kristin has taught students at the elementary, middle and high school levels in resource, inclusive and residential settings. Additionally, Kristin served as an Exceptional Children’s Programs Coordinator, supporting special education programs and services in the public schools, in Indiana and in North Carolina. She has served as Director of Studies at The Hill Center in Durham, North Carolina and is currently working with The Hill Center’s Outreach Programs as a project coordinator.
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other projects and responsibilities, you took the time to meet with me and to provide
the feedback I did not know I needed at the time.
DEDICATION

This research is dedicated to the parents and administrators who participated in my study, as well as to those whose journeys will follow similar pathways. Parents, your willingness to share such personal experiences is so greatly appreciated, and your commitment and resilience is inspirational. Administrators, your work with children and families will have an impact that will resound well beyond your professional commitments.
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CHAPTER 1

INTRODUCTION OF CHAPTER

“There is no friendship, no love, like that of the parent for the child” (Henry Ward Beecher, 1813-1887).

Parents’ dreams for their children are often sown and thoughtfully tended well in advance of the child’s arrival into the world. In eager anticipation of this phenomenon that will genetically and spiritually represent the parent, a universe of possibilities is born as parents envision who this new being will become. One commonality among expecting parents is the wish to have healthy children. When a child is born with health problems or other unanticipated challenges, parents must cope with understanding and meeting the child’s needs. For parents who have children with Autism, discovery of the diagnosis may occur several years or more into the child’s life and result in pervasive changes to familial lifestyles and relationships. The existence of multiple incidence Autism families poses even greater challenges to parents who are learning to meet the diverse and often complicated needs of more than one child with the developmental disability. And when the children begin their schooling experiences, parents may be faced with an entirely new and often daunting set of challenges as they encounter unfamiliar language, policies, procedures, and expectations. Add to the complications the fact that the etiology of Autism remains unknown, though research is exploring multiple possibilities. Multiple incidence Autism families are a phenomenon, and there are limited studies on families with multiple children diagnosed with Autism.
As a researcher, these are my interests— the stories individuals tell through their words; the exposure of vulnerability for the sake of sharing moments and memories; the human experience. Listening to the stories of parents in multiple incidence Autism families may result in a better understanding of this phenomenon. As an educator, I hope that these stories will help other educators to empathize, reflect on practice and delve slightly inward to internalize the experiences to improve future interactions between school personnel and parents and to better inform educational decision-making for children with Autism.

The combined knowledge and experiences of parents and school personnel can result in powerful and effective learning environments for students. School administrators are in positions that demand various types and levels of leadership.

North Carolina’s 21st Century school administrator standards, approved by the State Board of Education in December of 2006, redefines building level administrators as school executives (NC State Board of Education, 2006). The new vision of school leadership is founded on the need for administrators to build systems of change and to construct relationships with staff so that shared understandings of values, beliefs and goals can be formulated and pursued. The new school executive responsibilities incorporate business model ideals and structures that are based on distributed leadership practices, those which are designed to share leadership responsibilities and actions and to empower others in decision-making processes.
The altered conceptualization of school leaders as change agents, no longer managers of complex operations, aligns with the belief that the position of leadership does not create a leader (Gorton, Alston, & Snowden, 2007). Rather, the person’s behavior while in the position determines one’s capacity as a leader. The school executive’s ability to provide leadership that ultimately impacts student learning is not limited to general education programming. School leadership must extend to all aspects of schooling and address the diversity of the student body, faculty, parents, and other stakeholders. The new standards for school executives focus on multiple types of leadership required within a school organization: strategic, instructional, cultural, human resource, managerial, external development and micro-political.

**Statement of the Problem**

In this era of school accountability and standards-based assessment, many public schools struggle to meet the requirements of *No Child Left Behind* and the *Individuals with Disabilities Education Act*. At the same time, the identification of students with Autism is increasing; the needs of these students can range from mild interventions and accommodations in the regular classroom to more complex strategies that involve specialized training and implementation within a variety of educational settings. As the pressures to meet the needs of a diverse population of students increase, public schools must continue to incorporate parent involvement in various levels of decision-making. Subsequently, parents can serve as valuable “experts” in their child’s education, assisting the educators in understanding the manifestation of the disability in their child and in effectively employing strategies
that will promote educational success. The perspective and knowledge of the parent may be accessed only on surface levels, addressed only through certain questions that must be asked in the IEP process, for example. For parents to be truly incorporated in the team process, genuinely invested time must be devoted to hearing and learning from their voices.

Public school administrators also face a myriad of challenges to provide leadership as the ebbs and flows of educational policy mold pedagogical, philosophical, and curricular beliefs and practices. Expertise in special education law, policy, and best practices may be possessed by school and district personnel in specialized positions. The building administrator may also delegate special education related issues and needs to such personnel, since administrative training and background may have had a more general and global focus or school leaders must distribute responsibilities in order to adequately address the numerous needs of their schools.

Parents are the key constituents of any school, and the decision to live within a district and to enroll one’s child is a major life decision for many families. For parents who are raising a child with a disability, navigating the educational pathways can seem like a veritable obstacle course at times, as parents struggle to understand the vernacular of special education while figuring out how to best advocate for their child. Hence, there is a need for school and district administrators to acquire and sustain a working knowledge of special education policies and
procedures and to possess at least a fundamental understanding of characteristics of the disability categories.

Perhaps most important is the need for administrators to become involved in special education decision-making at their buildings, to communicate with parents and provide leadership to school teams as they plan educational programs for students with disabilities. Autism has rapidly increased in diagnoses, with the latest statistics indicating Autism occurs in one every 150 births (CDC, 2007). Based on the researcher’s experience as a special education administrator in public schools, the increase in diagnoses has challenged many schools’ capacity to provide adequate services and keep up with research and professional development needs for all faculty.

As an educator whose career has been dedicated to improving special education programming for students, it is my conviction that the impetus for change and positive supports stems from understanding and empathy. Too often, we are quick to judge and draw conclusions in situations involving students and parents, without fully understanding the breadth and depth of their often complicated circumstances. This phenomenological study will delve into the experiences of multiple incidence Autism families with the intent of extracting understanding that will assist those who work with these students and families in the schools. It is an assumption that parenting more than one child with Autism, a pervasive disability, requires a different type and level of effort, understanding and commitment than parenting one child that is identified. Cashin’s phenomenological study (2004)
revealed that “Autism interpermeates into the self of the parent, or the parent is sucked into the way of being that is Autism” (p. 172). There is acute risk to the parent’s self, according to Cashin. Since there can be such profound impact on the parents of a single identified child, the dynamics of raising multiples may be significantly intensified.

The experiences of school administrators who have and currently work with multiple incidence Autism families are equally valuable. In fact, the collection and analysis of data from both groups are critical to the understanding of the experience. Each of our lives is a story, and to each of us, that story is essential and defining. The moments and memories constitute the whole of our experience, and none of those in isolation can necessarily capture our beings, essences, and meanings.

**Chapter Overview**

Chapter one opens with a general overview of Autism, including a brief recapitulation of some of the major historical evolutions in terminology, diagnostic criteria, and treatment. Differences between the terms, Pervasive Developmental Disorder-Not Otherwise Specified, Autism, Autistic Disorder, Asperger’s Disorder, and Autism Spectrum Disorders are made to provide clarification of the specific vocabulary associated with the disorder. This chapter also engages in a general discussion of educational options and services for students with disabilities, providing a synopsis of significant federal legislation that has impacted the education of students with Autism. Issues facing parents of children with Autism and challenges for school administrators are addressed.
A statement of the problem addressed by this study, as well as the purpose of the study, is detailed in this chapter. Specific research questions are outlined to provide clarification of the direction and intention of the study. Since specialized terminology is allied with special education issues; policy and legislation; Autism; and the mental health profession, terms are defined in a manner that reflects their application to this study. Also, a section of the chapter is devoted to reiterating the significance of the study, justifying the need for a phenomenological study on multiple incidence Autism families and analyses of administrative perspectives. Chapter one concludes with an overview of the phenomenological approach and a description of the organizational structure of the study.

**Background Information**

The high prevalence of evaluations, diagnoses, and needed treatment and services of children with Autism places great demands on families and schools. Autism, a life-long developmental disability, affects 1 out of every 150 children in the world today (CDC, 2007).

In 1911, Eugen Beuler, a Swiss psychiatrist, first applied the term, Autism, to adults with schizophrenia. It was not until 1943 when Leo Kanner of John Hopkins University described Autism for the first time following a study of eleven children observed over a five-year period. Throughout the 1940’s and 1960’s, the medical community’s lack of understanding of the disorder resulted in many would-be autistic diagnoses as schizophrenia. Deeper understandings of the symptoms and
treatments of Autism began to develop in the 1960’s (Tager-Flusberg, Joseph, & Folstein, 2001; Wolff, 2004).

The American Psychiatric Association publishes the Diagnostic and Statistical Manual of Mental Disorders (DSM) which is used by mental health professionals, clinicians, and researchers in the United States to diagnose mental health disorders. Autistic Disorder and Asperger Disorder are included in the DSM. Though the most recent edition is the DSM-IV (1994), a text revision resulted in the 2000 publication of the DSM-IV TR. No changes were made to the diagnostic criteria of Autistic Disorder or Asperger’s Disorder.

Since Kanner’s early descriptions of Autism, changes in diagnostic criteria and treatments occurred, making it difficult to ascertain accurate prevalence rates over time. The broadening of criterion for diagnosis resulted in the term, Autism Spectrum Disorder (ASD). Kanner’s *infantile Autism* was replaced by the concept of Pervasive Developmental Disorder in 1980. Specifically, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), has become the most widely used ASD diagnosis (Tidmarsh & Volkmar, 2003).

Currently, the ASD diagnosis can include milder or high-functioning subtypes, as well as those considered lower-functioning with varying degrees of mental retardation. Asperger’s Disorder, named after the research and discoveries of the Austrian psychiatrist, Hans Asperger, is the current diagnosis for a higher functioning form of Autism, absent a clinically significant delay in language, communication or cognitive delays. Asperger disorder was first included in the publication of the
Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (1994). Discussion amongst psychiatrists, researchers, and practitioners continues regarding the definition and prevalence of Asperger’s disorder and its relation to the more general Autistic disorder. Autism Spectrum Disorder is professional terminology that incorporates the complex ranges of Autism, recognizing that Autism symptoms can present in a multitude of varying degrees of intensity and severity in various domains (i.e., social interaction; communication; restricted repetitive or stereotyped patterns of behaviors, interests, or activities; cognition; adaptive behavior) (DSM, 1994; Stiefel, Shields, Swain, & Innes, 2008).

In the past, many students with disabilities received educational services in facilities separate from their neighborhood schools. Since the implementation of the federal Education for All Handicapped Children Act (1975), public schools have been mandated to provide free and appropriate services to students with disabilities. The landscape of public education special education opportunities for students with Autism has experienced dramatic changes over the past thirty-plus years. Revisions to the 1975 mandate have occurred via reauthorizations and creation of the Individuals with Disabilities Education Act (IDEA, 2004, § 2647). In addition, the No Child Left Behind Act (NCLB, 2002, § 6301 (3)) places new standards of accountability for schools to meet the needs of students with disabilities and to provide highly qualified teachers to deliver instruction for all.

Special education legislation charges Individualized Education Plan (IEP) teams to place students in the least restrictive environment (LRE), the educational
setting which is most comparable to one in which those students without disabilities receive instruction (Friend, 2008). Inclusion is a term that has been pervasive in special education programming for several decades now. Marilyn Friend defines inclusion:

Inclusion is a belief system shared by every member of a school as a learning community—teachers, administrators, other staff members, students, and parents—about the responsibility of educating all students so they reach their potential. Although the physical location of students in schools and classrooms is one dimension of inclusiveness, inclusion is not about where students sit as much as it is about how adults and classmates welcome all students to access learning and recognize that the diversity of learners in today’s schools dictates that no single approach is appropriate for all. (p. 20)

Though the terminology of inclusion is not included in current federal legislation, the concept and associated practices generate great dialogue and debate as educators and parents struggle with decisions of how to best serve students with disabilities. Placement decisions for students with Autism spectrum disorder can be complicated depending upon the severity of the child’s symptoms and amount and quality of resources and specialized knowledge practitioners within a school possess.

Parent involvement in educational decisions has been at the forefront of school efforts for many years now. In the early 1950s, the National Association for
Retarded Citizens (NARC) began advocating for parental participation in educational matters for their children (Turnbull & Winton, 1984). Another impetus for parental participation in multiple levels of decision-making has been the various federal mandates such as the *Individuals with Disabilities Education Act* (2004). Schools have made radical changes in their policies and practices to accommodate this need. For parents of students with disabilities, the involvement can become intensified through the evaluation, identification, and IEP planning processes.

**Purpose of the Study**

The purpose of this phenomenological study is to explore the educational experiences of parents with multiple children identified with Autism Spectrum Disorder. For parents with more than one child diagnosed with Autism Spectrum Disorder, navigating the educational process can be a challenging experience that can provide insights to school and district-level administrators as they analyze their philosophies and practices of working with these families. Perspectives of administrators who have directly worked with multiple incidence Autism families will be obtained in order to broaden the scope of the study and provide information from the educational administrative realm.

**Research Question Development**

Multiple incidence Autism families are interesting, and there are limited studies about them, because of their relative rarity in occurrence. A phenomenological study seeks to understand the “essence” of the phenomenon, the meanings of the human experience. The research question is designed to reveal
qualitative, rather than quantitative, aspects of the experience; refrains from determining causal relationships and predictions, and relies on thoughtful and complete descriptions that are accurate and descriptive in nature (Moustakas, 1994). Amedeo Giorgi, founder and original editor of the *Journal of Phenomenological Psychology* and pioneer of the Duquesne Phenomenological Research Method (DPRM) discusses one of the researcher’s roles in phenomenology:

She seeks an ordinary person in the lifeworld and asks for a careful, concrete description of a situation in which the participant has lived through the experience of the phenomenon being researched. The reason for this is that the phenomenological psychologist is interested in *how* the phenomenon is lived. He lets the participant select the situation and of course that situation reflects the participant’s understanding of what the phenomenon is. (Giorgi, 2008, p. 40)

Hence, this study’s interview questions for parents will be abstract in nature to begin, allowing the participants to reflect and define the phenomenon as experienced by only them. It is not the role of the researcher to determine what will be shared and how participants make sense of their reality, though probing questions will be posed in order to obtain elaboration of shared reflections. Questions of administrators will assume a more directed role as that portion of the study veers from phenomenological methodology and becomes more structured. Essentially, it is the parents who experience the phenomenon being studied, yet
school administrators who experience the phenomenon in an indirect manner through their school interactions.

**Research Questions**

The following research questions, based on the fundamental principles of phenomenological research, guide this study:

1) What are the experiences of parenting multiple children diagnosed with Autism and navigating the educational realm?

2) What are the perspectives of public school administrators who have worked with the children and parents of multiple incident Autism families?

**Definition of Terms**

An understanding of the following terms is essential to the comprehension of this study. Thus, definitions for the following terms specific to the foci of this study are provided to enhance the reader’s understanding of topic-specific terminology located in this study.

1. **Adaptive Behavior**: Age-appropriate behaviors that facilitate independent and safe functioning with daily living skills. Adaptive behavior domains may include interpersonal relationships; play and leisure time activities; receptive, expressive and written communication; personal safety; and fiscal management (Burgess, 2007; IDEA, 2004, § 2647).

2. **Autistic Disorder**: Also referred to as “Autism,” this is a neurological and developmental disorder that usually manifests within the first three years of a child’s life. Diagnosis is based on assessment of social interaction,
communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities. Delays on social interaction, language for social communication, and symbolic and imaginative play also exist (DSM, 1994).

3. **Asperger Disorder**: Manifested by deficits in social interaction and by restricted repetitive and stereotyped patterns of behavior, interests and activities but with no clinically significant delays in language or cognitive development. Typical functioning is also observed in relation to self-help skills, adaptive behavior, and interest in the environment during childhood years (DSM, 1994).

4. **Autism Spectrum Disorders (ASD)**: The broader diagnosis that includes Autistic Disorder and Asperger’s Disorder, also referred to as Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS). The spectrum includes the full range of symptomology severity and intensity (Sicile-Kira, 2004).

5. **Multiple Incidence Autism**: The occurrence of more than one child diagnosed with Autism Spectrum Disorder in a particular family (Piven, Palmer, Landa, Santangelo, Jacobi, & Childress, 1997).

6. **No Child Left Behind Act (2002)**: Federal legislation that increases accountability for public schools by requiring academic standards for all students, establishing annual assessments for students in grades 3-8, requiring schools to publicly report on performance data for all identified
student groups (i.e., race, gender, disability, English language proficiency, and socio-economic status), and requiring teachers and paraprofessionals to be highly qualified, among other regulations. A goal of NCLB is for all students to be performing at or above grade level in reading and math by 2013-2014 (NCLB, 2002, § 6301 (3)).

7. **Individuals with Disabilities Education Act (2004):** The reauthorized federal law previously known as the *Education for All Handicapped Children Act* (PL-94-142) of 1975 which mandates a free, appropriate, public education for students deemed eligible and in need of specialized services or instruction (IDEA, 2004, § 2647).

8. **Special Education:** Specially designed instruction, at no cost to parents, to meet the educational needs of an eligible exceptional student, including classroom instruction, out-of-school instruction, instruction in a special school or residential setting and instruction in other settings, including the workplace and training center. Special education also includes assistive technology devices and services, physical education, vocational education, or other curricular offerings when modifications are necessary to meet the individual needs of exceptional students (IDEA, 2004, § 2647).

9. **Individualized Education Program (IEP):** A legal document that details the specific performance levels of performance and academic needs of a student who is eligible and in need of special education services. The IEP is developed by a team of school personnel and experts, the parents, and
the student when appropriate. Components include annual goals and objectives, special education services and related services, needed accommodations or modifications, and other information specific to the child (IDEA, 2004, § 2647).

10. **Inclusion**: The term often used to describe the *inclusion* of students with disabilities in the general education program or setting. The Individuals with Disabilities Education act does not use the term, inclusion, so there is no definition provided by the Department of Education. Rather, federal law mandates that schools place students in the Least Restrictive Environment (LRE) with their non-disabled peers to the maximum extent appropriate. Required services and supports for all placements are detailed in the student's Individualized Education Program. Inclusion is frequently referred to as a philosophy that embraces the concept of students with and without disabilities and special and general education teachers and other specialists collaborating and working together to meet the educational needs of all students (Friend, 2008).

**Significance of the Study**

This research is significant to the domain of education as it extends the knowledge base that currently exists in the field; furthermore, there are few studies that explore the perspectives and lived familial and school experiences of multiple incidence Autism parents. Due to the pervasiveness of Autism, identified individuals may experience communication, social, cognitive, and adaptive challenges not only
over the course of their educational careers, but throughout their lives. Parent perspectives of these unique experiences with their diagnosed children are wide-ranging and longitudinal.

Advances in assessment, changes in eligibility criteria, and earlier identification of Autism could mean that some parents are immersed into the public educational processes from a child’s birth through the age of twenty-one. Having more than one child identified with Autism can also lead to intensified experiences that shift with changing legislation, local policies, human resources, and transitions from one educational level to the next (i.e., pre-school to elementary, elementary to middle school, etc.).

Sharing these experiences will add to the paucity of literature that currently exists on the subject of multiple incidence Autism families. The results of the study may also provide insights and enhancements in administrative practices to strengthen school supports and responsiveness to parents who often find themselves sifting through familial issues and needs while stumbling through a quagmire of confusing and seemingly ever-changing educational processes and policies and frequent misinformation and misunderstanding from educators, as well.

**Overview of Approach**

Phenomenological research is discovery-oriented and is immersed in descriptions that precede scientific perspective (Giorgi, 2008), meaning that the research is not directed by hypotheses or theories. The approach is atheoretical and non-speculative as the researcher attempts to "grasp a typical essence of a
psychological phenomenon” (p. 51). Discovering the essence of an experience necessitates a qualitative approach, one that relies on eidetic means to represent the richness and fullness of an individual’s experience. Phenomenology is constructivist in that it is founded on the belief that individuals construct meaning from their experiences and interactions with the world (Grbich, 2007). The individual’s interactions with environmental stimuli influence their cognitive structures. There is no ultimate Truth to be obtained. Rather truth is defined by the individual and the knowledge and meaning they have derived their personal experiences through the processes identified above.

Qualitative research involves the collection of data in the natural setting, where the participants experience the issue (Creswell, 2007). Information is gathered from direct conversation with people and observing them within their particular context. Multiple data sources are used in order to triangulate, or cross-examine, the information (Yin, 2003). Triangulation also helps to enhance the accuracy and authenticity of any findings.

This study embraces the principles of phenomenological research, a qualitative approach. Parents in multiple incidence Autism families were interviewed using an informal, open-ended interview format to explore the essences of these unique experiences. The interview process included broad questions with hopes of evoking deep and substantive descriptions from the participants (Moustakas, 1994). The goal, according to Giorgi (2008), is to describe the meaning of the phenomenon, since “what is sought is a description of a situation as lived and understood by the
participant from the perspective of the natural attitude” (p. 38). After the interviews were conducted, the researcher reflected on the data and organized the information into meaningful units that were clustered into themes, resulting in textural and structural descriptions of the experience (Moustakas, 1994).

The collection of data through individual participant interviews resulted in individual textural descriptions. For this study, the individual textural descriptions, detailed accounts from participants, were derived from the transcripts. Individual structural descriptions, clear depictions of principal dynamics that involve themes and qualities for how feelings and thoughts are connected to the phenomenon studied, were then delineated from the individual accounts through data coding and analysis.

Essences, also known as invariant structures, are aspects of the experience that are common to all participants. Analysis of administrative data and themes were then discussed in relation to the essences, and implications for educational practice and future research are discussed.

The themes, common topics of conversation pervasive throughout the narratives, evolved from the data coding process, after all parent interviews were transcribed, read, and reread several times. They represent stories and discourses all parents shared about their experiences with multiple incidence Autism. From an in-depth analysis of individual and composite textural and structural descriptions, the essences of the experiences are derived. Essentially, textural descriptions address what happened and structural descriptions detail how the phenomenon was
experienced. Synthesis of all levels of textural and structural descriptions resulted in identified essences, aspects of the experience that were common to all participants.

After the textural and structural descriptions were synthesized and the essences identified, the school-specific interview questions were presented to building level administrators who have worked with multiple incidence Autism families. Administrators were interviewed for their reflections and perspectives. The researcher was interested to learn in which ways administrator perspectives corroborate, contradict, or lead to different findings unaddressed by the parents and possible reasons for these occurrences.

**Organization of Study**

Chapter 1 defines the problems which arise for parents and school administrators as they cope with children's Autism diagnoses; discusses the purpose of the study; outlines the research questions to be explored; defines terminology specific to the study; reiterates the significance of the study, and concludes with an overview of the phenomenological approach that is utilized. Chapter 2 is dedicated to a review of the literature as it pertains to Autism, parental perspectives of familial and educational experiences, and administrative challenges. Phenomenology as a research method is also described. Chapter 3 describes the methodology used in this study, including site and sample selection for the multiple incidence Autism participants and administrators in this phenomenological study, data collection and interview processes, data analysis procedures, and research validity and reliability. Chapter 3 concludes by discussing ethical issues that were anticipated and how they
were addressed to protect participants and to maintain a high level of ethicality throughout the study. Limitations of the study are also included in this chapter. The findings of the study are shared in Chapter 4. Chapter 5 involves a detailed discussion of the findings and their relation to the literature as well as philosophical, policy, and daily operational and application implications for school and district administrators.
Chapter 2

LITERATURE REVIEW

Introduction

In chapter two, literature is reviewed and analyzed to provide a context for and to substantiate the significance of the problem, to share research previously conducted in relation to the issues being studied, and to advance knowledge on the topic of multiple incidence Autism families. Critical analyses were conducted pertaining to phenomenological study and hermeneutics, parent perspectives of familial experiences, and parent perspectives of school experiences and expectations. Research, focused on special education programming and services, is also analyzed to address the perspectives of educators and school administrators and to contextualize some of the challenges experienced within the educational realm.

Purpose of the Literature Review

A fundamental outcome of conducting a literature review is that by engaging in a thorough exploration of information about a topic, the researcher becomes more knowledgeable about the proposed study and better equipped to advance data on the particular topic (Hart, 1998). By reviewing the results of other similar or related studies, the researcher can then critically evaluate the information while taking into consideration their own concerns and framing of the defined problem. The reviewed literature is weighed for its relevance to the questions posed by the researcher (Fraenkel & Wallen, 2008).
Hart (1998) identifies several purposes of the literature review. The researcher should be prepared to make a distinction between research that has been conducted and research that needs to be executed. Rather than simply summarizing or highlighting certain portions of the literature, the researcher will identify significant factors as they relate to the topic, synthesize information to formulate new perspectives and discover relationships between theoretical concepts and application in practice. The literature review also helps to establish a framework, helping the researcher to justify the relevance of problem and to define and refine how the problem will be explored and analyzed.

Further expanding the conceptualization of the literature review, Torraco (2005) extols the value of the integrative review, a form of research that develops new perspectives on a topic through the application of critiques and synthesis of applicable information on a topic. Mature or new, emerging topics are often the focus of this type of research. The lived experiences of multiple incidence Autism families is an emerging topic that has not received comprehensive study to date; therefore, according to Torraco, an integrative review “is more likely to lead to an initial or preliminary conceptualization of the topic (i.e., a new model or framework) rather than a reconceptualization of previous models” (p. 357).

A critical evaluation of studies in an integrative literature review helps the researcher determine how existing information represents the topic and results in a critique which pinpoints strengths and important contributions (Torraco, 2005). The
critique associated with an integrative review examines “deficiencies, omissions, inaccuracies, and other problematic aspects of the literature” (p. 362).

The study of multiple incidence Autism families, having received a limited amount of attention in the literature, lends itself to an integrative review. Literary deficiencies or omissions on this specific topic, though, do not mean that parallel or related topics will not yield useful or pertinent data. Torraco (2005) states that such problematic areas or gaps in the literature are what lead to contributions to an enhanced knowledge base on the topic.

**Autism in the Public Schools**

In 2007, the Centers for Disease Control (CDC) released the results of a study indicating Autism rates in the range of 6.7 per 1,000 or one in 150 children (CDC, 2007). Research on concordance rates in twins indicates that if one identical twin has Autism, there is a 60-91 percent chance that the other child will be diagnosed, as well (Betancur, Leboyer, & Gillberg, 2002). Though such concordance rates do not prove a genetic cause to Autism, they do suggest possible correlations to hereditary links. Additional twin and family studies have also suggested a possible genetic liability (Piven, Palmer, Jacobi, Childress, & Arndt, 1997; Freitag, 2007; International Molecular Genetic Study of Autism Consortium, 2001).

Though the causes of Autism are currently being researched and no conclusive evidence regarding etiology has yet been determined, there are multiple explanations for the increases in diagnoses. For one, *The Diagnostic and Statistical Manual of Mental Disorders* (DSM) which provides criteria for psychiatric disorders,
did not even address Autism until the third edition in 1980 (Gernsbacher, Dawson, & Goldsmith, 2005). From the third edition to the most current version of the DSM, the fourth edition (1994), the quantity of criteria changed from six to sixteen optional criteria; the language transformed from severe to become more inclusive; and diagnostic categories changed from two to five. The broadening of diagnostic criteria may be a contributing factor to the increases in eligibility.

Recent research has intensively studied the causes of Autism. Such studies are examining links to genetics, environmental sciences, and epidemiology to understand possible causes (Autism Research Institute, 2008). Exploration of possible correlations of Autism to toxicant exposure, diet, prenatal hormone levels, vaccines, exposure to metals, molecular influences, and biological and neurological factors are some of the current research projects.

For parents of children with Autism and school personnel who work with identified children, the inconclusiveness of research can be frustrating, as they struggle to understand the diagnosis, implications and appropriate educational treatment options.

Prior to 1975 and the passage of the Education for All Handicapped Children Act (PL 94-142), educational services for certain identified children were either not available or accessible only at locations separate from the public school where non-disabled peers were educated. Parental advocacy and legislation stimulated from court decisions resulted in a special education movement to eliminate the exclusion of children with disabilities from the public educational arena. Eventually, the act was
reauthorized as the *Individuals with Disabilities Education Act* (1990) and has undergone two revisions to date (1997 and 2004). Up until the 1991-1992 school year, Autism was not included as an area of disability according to the *Individuals with Disabilities Education Act* (1990). Public schools may have included these students in child counts under existing disability categories at the time, such as traumatic brain injury, behavior-emotional disorder, developmental delay, or learning disabled, for example. Since different states have different reporting systems to calculate identified students in specific disability categories and eligibility criteria and procedures can vary, the longitudinal data regarding the number of students identified with Autism in the public schools is difficult to gauge (Gernsbacher, Dawson, & Goldsmith, 2005).

**Hermeneutic Phenomenology**

According to Moustakas (1994), one of the leading experts on humanistic and clinical psychology, the empirical phenomenological approach aims to portray “the essences of the experience” (p.13). By selecting individuals who have experienced a particular phenomenon, the researcher requests data, often obtained through interviews. Analysis of the data ultimately produces a description of the experience that all participants have shared (Creswell, 2007). The essence “has been adequately described in the language if the description reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner” (Van Manen, 1990, p. 10). Phenomenologists seek to investigate conscious structures in
order to understand the essential aspects of an experience, resulting in meaning and clarity (Polkinghorne, 1989).

Though statistical relationships among variables, social perceptions and influences, and emphasis on occurrence or frequency of behaviors—components often found in the study of other disciplines—are not present in phenomenological study, the methodology remains scientific. Phenomenology is systematic, explicit, self-critical, inter-subjective, and involves the human world. In contrast to other research approaches, phenomenology also possesses a sort of artistry. Van Manen (1990) describes phenomenology as poetizing activity:

As in poetry, it is inappropriate to ask for a conclusion or summary of a phenomenological study. To summarize a poem in order to present the result would destroy the result because the poem itself is the result.

The poem is the thing. (p. 13).

Phenomenological study requires the researcher to engage in *epoche*, abstaining from judgment of those recounting the phenomenon in order to procure comprehensive descriptions of the lived experience (Moustakas, 1994). The philosopher, Edmund Husserl, first coined the term “bracketing” (Husserl, 1985 & 1999) to describe the researcher’s need to suppress outside, worldly influences and perceptions in order to become fully immersed in the phenomenon. Moustakas (1994) elaborated on Husserl’s concept of bracketing:

The world is placed out of action, while remaining bracketed. However, the world in the bracket has been cleared of ordinary thought and is
present before us as a phenomenon to be gazed upon, to be known naively and freshly through a “purified” consciousness. (p. 85).

Husserl (1985 & 1999) wrote about bracketing, also referred to as parenthesizing. Assumptions are not eliminated, but they are cordoned off so the phenomenon can be explored and observed without judgment. Postulates are modified by being temporarily parenthesized out of the action, permitting the researcher to maintain acknowledgement of the natural world’s existence and consciousness. To experience the phenomenological, according to Husserl, requires the exclusion of theories and the absence of validity:

The whole prediscovered world posited in the natural attitude, actually found in experience and taken with perfect “freedom from theories” as it is actually experienced, as it clearly shows itself in the concatenations of experiences, is now without validity for us; without being tested and also without being contested, it shall be parenthesized (Husserl, 1999, p. 65).

Embracing epoch and bracketing the world allows the researcher to better remain free from external influences and personal experiences that could lead to subjective thought and interpretation of the phenomenon. To engage and to remain in phenomenological research in epoch provides the researcher with an original vantage point that allows transparency, an allowance of all that is displayed and described to be viewed with naïve and neutral perspective (Moustakas, 1995).
By nature, phenomenology is a descriptive methodology; there is a concerted focus on representing experiences as they appear (Van Manen, 1990). Understanding of phenomenological descriptions involves a hermeneutical approach, an interpretive methodology which results in text that undergoes metamorphosis with an end result of producing an accurate reflection of the author’s intended meaning (Husserl, 1985 & 1999). However, since all remembrances and reflections of experiences are already altered from the original experience (Van Manen, 1990), the task of hermeneutically preserving total accuracy of the author’s intended meaning is not possible. Van Manen states, “…the upshot is that we need to find access to life’s living dimensions while realizing that the meanings we bring to the surface from the depths of life’s oceans have already lost the natural quiver of their undisturbed existence” (p. 54).

**Parent Perspectives of Familial Experiences**

While there are numerous studies (Benson, 2006; Boushey, 2001; Cashin, 2004; Fleischmann, 2004; G.A. King, Zwaigenbaum, S. King, Baxter, Rosenbaum, & Bates, 2006; Gray, 2002 & 2006; Hutton & Carron, 2005; Kasari, Freeman, Bauminger, & Alkin, 1999; Kuhn & Carter, 2006; Mercer, Creighton, Holden, & Lewis, 2006; Ross & Cuskelley, 2006; Trepagnier, 1999; Twoy, Connolly, & Novak, 2007) of familial and parental experiences of parenting and living with a child with Autism, there are limited studies focusing on multiple incidence Autism families. A review of existing literature yields information on narrative accounts of mothers,
social and emotional impact on families, familial coping strategies, parental perspectives on etiology, and sibling adjustment problems and coping strategies.

The *Diagnostic and Statistic Manual, Fourth Edition* (1994), indicates that for an Autistic Disorder to be diagnosed, delays or abnormal functioning must be present, prior to age three, in at least one of the following areas: social interaction, social communication language, or symbolic or imaginative play. An Asperger’s Disorder diagnosis does not require delays in language, cognition, self-help or any other important areas of functioning prior to a certain age. Therefore, depending upon the severity of the child’s symptoms, a diagnosis of either Autism or Asperger’s can occur anywhere from birth to adulthood. Parent coping strategies and the level of impact on a family may vary and correlate with the age of the child when the diagnosis was administered (DSM, 1994).

In a study of parents who were the primary caregivers for their children, Hutton and Caron (2005) found that the majority of parents started to notice irregularities in behavior at around fifteen months of age on average. Though most diagnoses occurred during the child’s pre-school years, ages at diagnosis ranged from eighteen months to twelve years of age, with most parents being initially referred by a pediatrician or specialist for an evaluation.

In a hermeneutic phenomenological study of the lived experiences of parenting a children with Autism, Cashin (2004) interviewed nine parents of children with a diagnosis of Autistic Disorder or Asperger’s Disorder, describing the experience as “an enforced change that happens in a pervasive and progressive
manner not unlike the motion of being sucked into a vortex” (Cashin, 2004, p. 166). Having to engage in consistent, literal communications with their children and avoid abstractions, resulted in less spontaneity and the absence of humor and teasing as modes of communication. Spontaneity was also compromised for the sake of providing routine and predictability in daily life activities. Parents also experienced a decline in social contact, as the need for structured routine and the sensitivity to judgments of others influenced their abilities and desires to engage in social activities. Financial limitations due to cost of services and the child breaking items led many parents to have fewer possessions. Cashin discusses how these parents of children with Autism experience a loss of self:

The parent’s self is transformed. All other roles of self are impacted upon. The parent’s sense of ease or personal comfort is eroded, there remains a constant sense of anxiety and exhaustion that arises from the act of care, frustration, hyper vigilance (including monitoring others in their relationship with the child) and communication effort. It would appear that Autism is dominant in the relationship and begins to dominate at the level of self of the parent (p. 168).

Cashin’s study (2004) reported positives in parent and child connections, times when both parent and child “were focused on the same activity and it was clear what both parties were thinking and feeling in relation to this activity” (p. 168). Parents talked about the rarity of such connections along with the extreme enjoyment when such experiences occurred. After the frustration and exhaustion
that comes from attempting to understand the child’s communications, the
uncommon opportunities to share moments of connection resulted in great pleasure
for both child and parent.

A study of multiple incidence Autism parents (two children with Autism or
more) and parents of children with Down Syndrome [Piven, Palmer, Landa,
Santangelo, Jacobi, & Childress, 1997] found personality and language
characteristic differences between the two groups. Multiple incidence Autism parents
demonstrated higher rates of rigidity, aloofness, hypersensitivity to criticism, and
anxiousness. Autism parents also experienced greater deficits in speech and
pragmatics and had a decreased quantity and quality of friendships. The
researchers suggest genetic implications but concede that environmental factors
could also impact the results. Multiple incidence Autism families are likely to
experience a notable increase in burdens and stressors which could impact social
relationships. It is also arguable that the noted elevation in personality
characteristics could be attributed to non-negotiable changes required to support
and maintain the child’s routine and need for structure. Even parental speech and
pragmatic behaviors could be reflective of the absorption of the parent’s self into the
relationship not only dominates that relationship but also begins to act on the self of
the parent” (p. 168).

Parents and families with children with Autism encounter a wide range of
emotions and coping strategies over time. Gray (2006) found that, initially, parents
tended to rely more on service providers, family support, social withdrawal and individualism, but as time after diagnosis advanced, parents relied more on religious faith and strategies which were more emotion-focused. Changes in coping may be due to parents’ aging and development and access to different strategies. Additionally the transformation of problems in the children—improvements and minimized behavior-related disruptions, services available for treatment, more routinized family life and reduced levels of distress may have contributed to parents’ coping abilities over time.

A qualitative analysis (Fleischmann, 2004), of various self-published, web-based stories of parents with children diagnosed with Pervasive Developmental Disorder, a broad diagnostic term that includes autistic disorder (DSM-IV, 1994) revealed that parents experienced a “watershed event” (p. 35) the day they received their child’s diagnosis of Autism. Parents shared that their lives were forever altered after learning of their child’s diagnosis, yet by publicizing their experiences on the world wide web, parents transformed themselves from victims to “daring mountain climbers” (p. 41). Still, many experienced a variety of emotional responses and phases, including fear, disbelief, shock, and depression, after the diagnosis. Publications of personal experiences were designed to help others who would travel similar paths and to create a networking system of support groups.

In *On Death and Dying* (1969), Elisabeth Kubler-Ross detailed a cycle of five emotional states experienced by many terminally ill patients—denial, anger, bargaining, depression, and acceptance. The initial stage is preceded by shock that
comes from awareness of the illness. Through conversations with the terminally ill, their family, and medical professionals, Kubler Ross attempts to describe the effects of death and the process of dying have on those close to the patient. Referring to medical school training, the author speaks of the absence of focus on intimacy and humanity, suggesting:

If we could combine the teaching of the new scientific and technical achievements with equal emphasis on interpersonal human relationships we would indeed make progress, but not if the new knowledge is conveyed to the student at the price of less and less interpersonal contact. What is going to become of a society which puts the emphasis on numbers and masses, rather than on the individual? (p. 26).

A search of the literature was conducted to discover if the Kubler-Ross grief cycle had been applied in the realm of disabilities studies. Parents learning of an Autism diagnosis and coping over time experience many emotions and stages. The literature review did not reveal studies which paralleled Kubler-Ross’ stages to the coping experienced by parents receiving news of a child’s disability. Rather studies tended to focused on matters of death or chronic illness (Telford, Kralik, & Koch, 2006) or coping strategies in general. One article (Boushey, 2001) specifically depicted the story of a mother with a child diagnosed with high-functioning Autism. Boushey (2001) explicitly relates her experiences to Kubler-Ross’ stages of grief. Whether coping with an illness or with the disability of a child, the need for
interpersonal human relationships, as addressed by Kubler-Ross, is substantively embraced by those closest to the situation, those deeply affected by the emotional pangs that, though may ebb and flow over time, never seem to completely dissipate.

As intended by Kubler-Ross, the stages of grief are dynamic, not representative of a static or finite theoretical structure that is unresponsive to individual human nature. Individuals can experience different emotions not demonstrated by Kubler-Ross’ model, transition through the model at different rates, and even encounter all of the stages but in a different order than that which is proposed. Boushey (2001) reiterates this point in her description of how she experienced different emotional phases in a non-linear way.

Adding to the stressors of parenting a child with Autism are etiological uncertainties. There are speculations as to the causes of the disorder and much research is being conducted; however, scientific inquiry has yet to determine definite causes. For many parents, not knowing the reasons for the child’s Autism creates internal, emotional struggles as they grapple with understanding why and how.

Mercer, Creighton, Holden, and Lewis (2006) provided questionnaires to forty-one parents of children with Autism spectrum disorder to analyze parent perspectives on the causes of Autism in their children. Genetic influences, perinatal or prenatal factors, diet and vaccines were all cited as possible causes. Parents stressed the importance of needing to understand as a critical component to the coping process. In addition to knowing the etiology, parents indicated that natural history, treatment options, access to services, and contact with other parents were
important pieces of information after diagnosis. Guidance regarding appropriate parenting strategies and knowing how to obtain advice about the condition from others were also seen as important factors in the coping process.

In a study (Kuhn & Carter, 2006) of one hundred twenty mothers of children with Autism, associations between maternal self-efficacy, defined as feelings of competence in the parenting role, and parenting cognitions, characterized as the thoughts, attitudes or beliefs about the parenting role, were explored. The researchers discovered that agency, the degree to which a mother is actively involved with and engages in interactions with her child, and guilt were significantly associated with maternal self-efficacy. Mothers who reported higher levels of interaction with their child demonstrated elevated levels of maternal self-efficacy, and mothers who indicated higher degrees of guilt were found to possess lower levels of maternal self-efficacy. High levels of correlation were noted between mothers’ stress scores and depression measures. In discussion, the researchers advocate for greater informal support, such as assistance from friends and family, rather than formal support, which is often provided by the health care profession, in order to reduce parenting stress in such situations.

Raising a child with a disability can impact parents’ belief systems, values and priorities, and views of the world, resulting in a life-altering experience, as reflected in a study of families of children with Autism or Down Syndrome (King, Zwaigenbaum, King, Baxter, Rosenbaum, & Bates, 2006). When first learning of the child’s disability, some parents described the experience as a powerful event that
ultimately impacts every other portion and moment of their lives. Some parents felt a loss of hope for the future, as expectations for the child and the parents’ own future, are modified in the wake of diagnosis and need to grieve for the altered dreams they once possessed. Many families adapted over time and are compelled to examine their beliefs and values, and for some, the ability to feel hope and future opportunities for the child lead to an increased sense of control and empowerment. Raising a child with a disability, for some participants, resulted in changed world views and personal values.

The landscape of parental coping with a child’s disability cannot be reduced to certain qualities or methods—various factors impact how parents deal with learning of diagnosis and raising a child with a disability. Individual personality traits and genetics, partnership interactions, communications and values, extended inter-familial supports and intra-familial dynamics, and the type of diagnosis and severity of symptoms can all influence how parents cope with the child’s disability. Benson (2006) analyzed stress proliferation, which refers to the development of new stressors that are caused by primary stressors, in parents of children with Autism Spectrum Disorder (ASD). Results indicated that parental depression was predicted by the child’s symptom severity and stress proliferation. Marriage, family, and work were identified as secondary stressors which became significant influences on the parents’ social and emotional welfare. Additionally, parents of children with higher levels of symptom severity experienced higher levels of stress proliferation and depressive symptoms. The impact of multiple children with Autism, with varying
levels of symptom severity, on stress proliferation and depression within a family would be a noteworthy addition to the literature.

The literature (Benson, 2006; Boushey, 2001; Fleischmann, 2004; Gray 2002 & 2006; Hastings & Lloyd, 2007; Hess, Molina, & Kozleski, 2006; Kuhn & Carter, 2006; Ross & Cuskelley, 2006; Telford, Kralik, & Koch, 2006; Twoy, Connolly, & Novak, 2007) on parental coping strategies with Autism tends to assume a retrospective or reflective approach, as numerous studies involve interviewing or surveying parents to gain an understanding of their lived experiences and perspectives. Most studies have focused on how parents have coped rather than how they are coping in the present.

Gray’s ten-year longitudinal study (2002) of families of children with Autism provides a rare view of experiences and veers from the more traditional cross-sectional research which examines families at certain points in time rather than following their experiences over substantially longer periods of time. In this study, though self-reports of psychological stress had decreased, the child’s disability still resulted in high degrees of anxiety and depression in many of the parents. Career problems seemed to affect mothers more than fathers, as many mothers experienced restrictions with employment hours and type of employment due to the nature of the child’s disability. Gray also found that socializing experiences of other children within the family, though still a parental concern, had improved. The reasons for the positively reported changes were related to the aging of the non-disabled and child and increased exposure to larger peer social networks. The
maturing of the typical child contributed to his or her increased social experiences. As with the siblings, parents’ social experiences had been altered over time. While children with Autism still experienced varying degrees of difficulty with communication and language skills, disruptive or destructive behavior, or inappropriate social behaviors, many parents had changed with the significance they had assigned to certain problems. This change in point of view of coping problems may have been due to improved abilities of children to communicate and for parents to understand or a change in expectations about the child’s communicative skills. In general, parental hopes for their children’s futures had declined over the course of this study. Original expectations for independence and self-sufficiency had dwindled over time as children’s adaptive skills did not reach expected levels and limitations on residential options and treatment services were encountered. The coping strategies found in the initial study—use of treatment services and reliance on family members, religion, social withdrawal and various forms of individual activities—were no longer predominant strategies for these parents. The most notable change was the reduction in treatment services available to parents, primarily due to limited options in the geographic region of the study. Gray suggests that parents had engaged in a long-term process of coping which allows skills and perspectives to change over time and better equip parents to deal with the challenges they experience with a child with Autism (Gray, 2002).

The resiliency of parents of children with Autism is also supported by a study conducted by Twoy, Connolly, and Novak (2007). Using The Resiliency Model of
Family Stress, Adjustment, and Adaptation (McCubbin, Thompson, Thompson, & Fromer, 1998), the researchers analyze parent coping strategies. The resiliency model suggests that a family will experience an *adjustment phase* when a *stressor* is introduced. During this period, families vary in how they problem-solve, cope, and access available supportive resources. Since Autism is a life-long disability that impacts all aspects of familial life, the demands on a family can be monumental and adjustment capabilities will vary. During the next stage of the model, the adaptation phase, parents struggle to meet the needs of the child by employing new or modified strategies for defining and solving problems and coping, and accessing and utilizing resources.

Results of the study (Twoy, Connolly, & Novak, 2007) revealed that supports from close friends and extended families were beneficial to parents dealing with disability-related stressors. Spiritual support was not reported as a significant factor for the population, but it was more influential in families where parents used English as a second language. Networking and communicating with individuals from other families in similar circumstances was a common strategy to gain advice on how to deal with difficulties. Many parents in this study utilized passive appraisals, evaluations of their circumstances that reflect an inability to directly impact outcomes, as coping strategies.

**Parent Perspectives of Educational Experiences**

The federal *Individuals with Disabilities Education Act* (2004) mandates a free, appropriate public education for students with special education needs.
Eligibility for special education services is determined by a multi-disciplinary team often consisting of an individual who can interpret the instructional implications of evaluation data, a special education and a regular education teacher, the parent, a representative of the school system, and other individuals who have knowledge or expertise of the child. Once the child is determined to be eligible and in need of specialized services, the team develops and educational plan called the Individualized Education Program (IEP). Main components of the plan include a description of the child’s present levels of functioning (which can involve statements regarding the child’s communication, behavioral, adaptive, cognitive, and academic strengths and needs), annual goals and objectives based on identified needs from the evaluation and other assessment data, necessary related services (i.e. assistive technology, occupational or physical therapy, transportation, speech language services, counseling), special education placement based on the least restrictive environment (based on a continuum of placements and determined in relation to the amount of time during the school day spent with non-disabled peers), time and duration of services, and information regarding how goals and objectives will be measured and progress will be reported (IDEA, 2004).

A diagnosis of Autism may be provided by the school evaluation team, based on specific criteria, or the diagnosis may come through a private evaluation conducted by a medical doctor or a psychiatrist, for example (IDEA, 2004). Autism is one of eleven eligibility categories under federal law. Regardless of the derivation of the diagnosis, a child must be found eligible by the school’s evaluation team.
Evaluation and diagnosis can occur as early as the child’s birth, since a portion of the Individuals with Disabilities Education Act provides for identification and early intervention services for infants, toddlers, and their families from birth to three years of age. School age children may be eligible and receive special education services between the ages of three and twenty-one years of age.

Learning about a child’s diagnosis of Autism has been described as a “life changing event” (Fleischmann, 2004), and in the school environment, depending upon the professionalism and sensitivity of the educational team, initial evaluation results meetings can be conducted compassionately, with information understandably presented to parents. Conversely, such meetings can be handled in a manner where diagnostic information is concretely delivered and educational and evaluative terminology apathetically strewn across the conference table in incomprehensible and even frightening ways, leaving parents feeling confused, alienated, or even angry. Whaley’s study (2007) of eighty-four parents of children with Autism Spectrum Disorder found that parents often perceived professionals as realistic, compassionate, and listened carefully when discussing diagnostic information with them, while other professional behaviors such as seeming anxious, tenseness of body, and showing pity were rated lower in this study.

The world of special education possesses its own terminology, rules and procedures, settings, and specialized staff which, in combination with parents struggling with the meaning and familial implications of the disability, can place parents in vulnerable situations. For some parents, a dichotomous situation evolves,
where they find themselves choosing between assuming a role that requires passive compliance with educational decisions and one that places the parent as advocate for the child. Acquiescing to school positions on services when parents have different perspectives on what would constitute appropriate service delivery is not an option for some. The perception that school teams fail to implement an individualized approach to the child’s educational plan, opting for more of a one-size-fits all, streamlined method of developing plans and determining student need encourages some parents to assume a stronger advocacy role, as well (Hess, Molina, & Kozleski, 2006).

Parents’ participation in special education meetings vary. The dynamics of the team, comfort and knowledge levels of the parents, and school processes can be important factors in the quality and frequency of parent participation. In a study examining parents’ involvement in and perceptions of special education services, Spann, Kohler, and Soenksen (2003) interviewed parents and found that the majority rated their involvement in Individualized Education Program meetings as moderate to high. The same parents rated their knowledge of special education processes at similar levels. Though the majority of parents in the study reported high levels of satisfaction with how the meetings were conducted, several parents indicated the Individualized Education Program had been developed prior to the actual meeting, rendering the parents unable to make contributions to what is supposed to be a team process. Other problems experienced by some of the parents included not having the necessary individuals at the table for the meeting,
not being provided a copy of the Individualized Educational Program or other pertinent documents, and feeling that school personnel were failing to adequately address goals set forth in the child’s plan.

Parents in the Hess, Molina, and Kozleski (2006) study also recounted varying levels of experience with participation in educational planning meetings for their children. At times, conflict between parents and school personnel occurred as parents advocated for services while feeling not included in meetings. The researchers suggest that the “tension might arise from the competing demands of developing an efficient, standardized process for identifying children experiencing difficulties and the parents’ need to understand and process the meaning of their child’s disability” (p. 152). The school team’s drive for efficiency of meetings is likely to be incompatible with the particular needs of the parents involved.

The expectations parents have for their children are often addressed in individualized education program meetings, but they are frequently only lightly touched upon by a short, simple statement or prompt within the plan. The design of many IEPs results in limited space to reflect parent concerns, leaving teams to encourage parents to briefly summarize concerns and expectations. An expectancy theory-based study of parents of children with Autism sought to answer questions pertaining to parents’ expectations, visions of future outcomes, for their child in comparison to parental ratings of the likelihood and importance of the child fulfilling certain achievements in life (Ivey, 2004). Parents indicated statistically significant differences between their ratings of importance and likelihood for categories of peer
social networks, physical safety, educational possibilities, and procreative options. Thus, importance rated higher than the possibility that the outcome would be achieved. Personal happiness, community acceptance, and leisure opportunities were also higher for importance than likelihood by the parents.

Failure to address all areas, academic and nonacademic, of need in the student’s plan results in procedural violations which have been challenged in a court of law (Yell & Drasgow, 2000), an outcome that can result from contention between parents and school personnel.

The Quality of Life (QoL) model can be used to evaluate an individual’s life domains to improve conditions, often measuring treatment success in the medical and psychology realms. While broad domains are generally agreed upon, research and discussion continues regarding specific indicators of Quality of Life (QoL) for people with Autism (Burgess & Gutstein, 2007). Physical functioning, emotional functioning, social functioning, and school functioning are commonly accept domains for youth. Correlations between pediatric psychopathology and quality of life have been studied and research suggests that quality of life can improve with alternative treatments that specifically target these domains, as routine treatment methods may not directly improve the quality of life for children with psychopathological needs (Bastiaansen, Koot, & Ferdinand, 2005). Expanding on the commonly used outcome measures of cognitive functioning and academic achievement for students with Autism, Burgess and Gutstein (2007) suggested more specific quality of life
indicators: social support, academic success and preparation for satisfactory employment, family life and self-determination.

While more research is needed to assess if these indicators can be indicative of quality of life in students with Autism, it is the researcher’s opinion from professional experience that it is an attempt to reach beyond the limited foci of cognitive and academic measures to provide data that spans deeper life domains. Since Autism is a pervasive disorder, the effects create constant ripples throughout the child’s world and family life. Educational planning teams may be more successful in addressing the complicated needs of students with Autism if they incorporate quality of life domains and indicators to assist with development of goals and objectives and placement and service options.

The researcher’s experience working with families of children with special needs indicates that by more precisely identifying and individualizing student need, educational planning teams can be more accurate in their delineation of services. Educational services and placements for students with disabilities can be controversial and contentious when parents and school team members differ in their assessment of what constitutes the least restrictive environment. The concept of inclusive education has become a predominant philosophical movement in education, as the notion of including students with disabilities with their non-disabled peers to the greatest extent appropriate and bringing services to the child begins to replace the practice of mainstreaming. Mainstreaming begins with the child being
placed in the special education setting and earning time in the regular education setting with non-disabled peers.

Though the determination of placement and services is made by the educational planning team, disputes between parents and the school system over various details in the child’s individual educational program have resulted in numerous legal actions, leaving the courts with influential decision-making authority in educational policy. Since 1990, multiple factors have stimulated increases in policies specific to the educational programming of children with Autism (Mandlawitz, 2002). Increases in identification of children with Autism also resulted in the reclassification of students who were previously identified for special education services under different eligibility categories. Competing instructional methodologies, such as the applied behavioral analysis model developed by Dr. Lovaas and the pedagogy advocated by the Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH), began to surface and receive notable attention, especially by parents who advocated for a certain program or methodology for their child. As parents learned of options for their children with Autism and shortages of qualified special educators ensued, due process hearings increased. Within a five year span in the early to mid 1990’s, there were a reported forty-five due process hearings and court cases where the school districts’ proposed educational programs were challenged by parents who sought specific treatment programs such as Lovaas (Yell & Drasgow, 2000).
Placement matters are complicated when parents’ perceptions of inclusive educational placements are mixed. In a review of the literature on this topic, Garrick Duhaney and Salend (2000) found that the majority of parents were supportive and had positive perceptions of inclusive placements, reflecting the social, emotional and academic benefits. Parents expressed concerns over availability of qualified personnel and the provision of services that were individualized for their child. Some parents related concerns about the child’s loss of services, mistreatment and isolation from peers if the child was transitioned into inclusive programs. Excessive parental time demands, difficulties obtaining inclusive programming, and limited expertise from administrators and teachers were cited as additional parent concerns. Interviews of parents with students with Autism and Down Syndrome revealed differences in parental perceptions on inclusion based on several factors. Autism parents were more likely to prefer mainstreaming over inclusion; concerns about their children’s deficits in interpersonal relationships and understanding social situations impacts the perceptions. Optimal educational environments for children with Autism typically involve a highly structured environment with minimal distractions, so inclusive settings may not be perceived as beneficial when compared to a special education setting with specially trained personnel who may have more opportunities to manipulate the learning environment for the child with Autism. Special settings may also be viewed by parents, as well as educators, as more appropriate for the implementation of evidence-based methodologies specific to Autism (Kasari, Freeman, Bauminger, & Alkin, 1999).
Educational Administrative Perspectives and Challenges

Based on the researcher’s professional experiences with working with special education programs and personnel, there is evidence that many school administrators face numerous challenges as they navigate the current, ever-changing, topography of the educational world. Adhering to legislative requirements, managing district policies and procedures, coping with micro- and macro-political dynamics, all the while ensuring that students receive a quality education in a safe learning environment, poses an important and demanding task for administrators.

Difficulties parents of children with Autism face with the regard to special education processes fall into the hands of building level and central office administrators, many of whom lack training and expertise with special education, let alone possess specific knowledge of Autism.

Lasky and Karge (2006) examined the formal special education training and basic knowledge of special laws and practices of principals and found that the quantity of time spent as a principal did not correlate with knowledge or ability. They also found that most respondents’ education was learned on the job.

The Individuals with Disabilities Act (2004), which sets forth specific mandates for the administration of special education services and procedures, can present challenges to administrators who are unfamiliar with the details contained within. In addition, the No Child Left Behind Act (NCLB, 2001) explicates requirements for states to raise the academic achievement levels of all students,
with severe implications for non-attainment of goals over time. The implications for students with disabilities are profound.

*No Child Left Behind* (NCLB, 2001) specifies that all teachers of core academic subjects are “highly qualified”; teachers must possess a minimum of a bachelor's degree, state licensure or certification, and prove they know each subject they teach (NCLB, 2001). Alternative routes to highly qualified status can be pursued for those deemed as veteran teachers. Special education teachers are held to the same standards. Data on teacher effects on student achievement indicate that teachers have a significant impact on student learning (Nye, Konstantopoulos, & Hedges, 2004; Darling-Hammond, 2004), though it is suggested that more research is needed to determine significant teacher variables, differences between grades and subject matter, and long-term outcomes (Bressoux & Bianco, 2004; Ding & Sherman, 2006; Luyten, 2003).

For school administrators, already faced with high attrition rates of teachers in special education, obtaining and retaining highly qualified special education staff is an on-going battle (Billingsley, 2004). The cost of hiring unqualified special education teachers or having to consistently locate and hire new teachers due to a high attrition rate impacts student instruction. Continued differences in special education licensure requirements from state to state (non-categorical versus specific disability category certification), compounded by a lack of teacher preparation standards in the field of Autism (Scheurermann, Webber, Boutot, & Goodwin, 2003), place administrators in charge of hiring at quite a disadvantage. As many parents
demand specialized programming for their children, administrators are besieged with obstacles that impede the hiring of truly qualified special education teachers. Certification, as required by the state, does not necessarily equal qualification or competency, especially in the field of Autism where specialization within multiple domains (i.e., communication, behavior management, social skills, fine and gross motor therapy) may be required for appropriate service delivery as detailed in individualized education programs.

Paraprofessionals, frequently required to provide support services to students with Autism, depending upon the severity and individual student need, also fall under the highly qualified provisions of the No Child Left Behind Act. For some, increasing qualification standards for paraprofessionals is a positive step toward improving student progress, yet possible negative implications exist (Simpson, LaCava, & Graner, 2004). Raising hiring standards, while failing to increase compensation, may result in an actual shortage of skilled paraprofessionals. Thus, the human resources needed to execute services for students with Autism, regardless of their educational placement, may become limited.

Another main tenet of the No Child Left Behind act is the provision of educational practices based on scientifically based research defined as “research that involves the application of rigorous, systematic, and objective procedures to obtain reliable and valid knowledge relevant to education activities and programs” (NCLB, 2001). Studies have been conducted to determine which general education practices are based on scientifically based research. For example, the National
Reading Panel (National Institute of Child Health and Human Development, 2000) engaged in a meta-analysis of the literature to determine what constitutes evidence-based reading instruction practices. However, implementation of scientifically-based research practices with students with Autism may be impeded by the requirements of *No Child Left Behind*, as the rigorous and systematic methods specific to the research design are extremely difficult to implement with students with severe and low-incidence disabilities (Simpson, LaCava, & Graner, 2004). A complicating factor of special education research is that “… because of its complexity, may be the hardest of the hardest-to-do science. One feature of special education research that makes it more complex is the variability of the participants” (Odom, Brantlinger, Gersten, Horner, Thompson, & Harris, 2005).

Still, school administrators will be faced with increased inquiries and requests from parents of students with Autism regarding evidence-based practices, citing legislation to support such appeals. Before *No Child Left Behind*, specific methodology was not a required component of a student’s individualized education program. Rather, as backed by numerous court decisions, it was the district’s responsibility to provide the student with a free, appropriate public education that advanced the child toward meaningful and measurable goals and objectives, based on the child’s needs and ability (Yell & Drasgow, 2000). Parents were not allowed to dictate a specific program or methodology for their child’s educational program, but with *No Child Left Behind*’s requirement for scientifically-based programming, the special education waters may be further muddied and require clarification from the
courts to determine how incompatible tenets of the *Individuals with Disabilities Education Act* and *No Child Left Behind* will be interpreted in application.

It is not uncommon for programs or plans for students with Autism in the public schools to lack a scientific basis for implementation. An analysis of programs used with two hundred twenty-six students with Autism in Georgia revealed that the top five strategies lacked a scientifically based component (Hess, Morrier, Heflin, & Ivey, 2008). Due to a growing corpus of empirical support, however, four of the top five strategies were deemed to be propitious practices. The study helps to substantiate the need for additional training in best practices in Autism, as practitioners in the field need to learn more about scientifically-based programs and how to appropriately implement them in the public schools, especially as federal mandates and inquiring parents continue their propensity for increased pressures and demands.

School administrators may be ill-prepared to address special education matters within their schools, as typical administrator preparation programs tend to focus on building administration and instructional supervision training (Goor & Schwenn, 1997). As a result, knowledge of specific learner needs and instructional methodologies, paperwork and records, legislative mandates, district special education procedures, and other special education-specific policies and practices can be delegated to other individuals within the building or at the district level who may or may not possess the necessary training themselves to effectively implement best practices. The Lasky and Karge study (2006) revealed that the majority (46.2%)
of principals surveyed requested assistance from district office personnel when special education questions arose. Special education teachers at the school site (23.3%), psychologists (14.92%), and district program specialists (10.44%) were also heavily relied upon by principals.

An expansive study (Wakeman, Browder, Flowers, & Ahlgrim-Delzell, 2006) involving a random sample of 1,000 secondary principals from all fifty states and the District of Columbia revealed principals’ self-reported fundamental (professional practice, inclusive education practices, characteristics of disabilities, legislation and learning differences) and current issue (those which influence research, policy and practice) knowledge of special education. Principals’ reported a generally sound fundamental knowledge of special education, but they possessed limited understanding with current issues involving self-determination practices, functional behavior assessments, and universal design.

Despite limited resources and in-depth special education knowledge, paired with the complex dynamics of leading a school, principals can make a significant difference on special education practices within the building by providing meaningful professional development opportunities for all staff, assisting special educators with problem-solving and managing conflicts, and cultivating a school culture that promotes a supportive environment for all teachers (Gersten, Keating, Yovanoff, & Harniss, 2001). In a report prepared for the Center on Personnel Studies in Special Education, DiPaola and Walther-Thomas (2003) reiterate that effective principals tend to the needs of diverse learners by addressing the organization, curriculum and
instruction, professional development, climate, and student assessment in their buildings. Faced with a myriad of responsibilities, today’s school administrator must be prepared to obtain a certain level of expertise in both regular and special education matters.

The influence of the principal on inclusive educational practices is demonstrated in the Horrocks, White, and Roberts (2008) study in which principals were surveyed regarding placement decisions, specific inclusion attitudes, and general attitudes toward inclusion and special education. Results indicated that principals who believed students with Autism could be included in the general education setting tended to show positive attitudes toward inclusion and increased recommendations for more inclusive-type placements.

Collaborative instruction or co-teaching is a strategy that promotes general and special educators working together to plan, develop, modify and adapt curriculum and instruction for students with disabilities in the regular setting (Friend, 2007). In this model, regular and special education teachers are able to work with all students within the classroom, not just those identified with disabilities. Implementing co-teaching strategies is one way to support an inclusive educational environment, but it requires specific supports from school administration.

School administrators are critical contributors and shapers of the school’s culture and value system. Fullan (2004) stresses the importance of moral purpose in leadership. Moral purpose involves closing the learning gap for all students, being respectful in interactions with others, and changing the social environment to obtain
positive outcomes. By cultivating a strong moral purpose, school leaders can ensure that inclusive practices are valued for their benefit to all students and provide the requisite supports and resources for collaboration and planning time, professional dialogue and meaningful staff development. Higher education teacher preparation programs also impact the attitudes and confidence levels of teachers working in inclusive settings (Jung, 2007; Campbell, Gilmore, & Cuskelley, 2003).

Principals’ knowledge of instructional procedures with special education may be related to their beliefs about inclusion (Wakeman, Browder, Flowers, & Ahlgrim-Delzell, 2006). Also, principals who were knowledgeable about special education tended to reflect on and continue to learn from situations that arose in their buildings. Regular meetings with special education staff also assisted with relationship building while increasing their knowledge of disabilities and instructional strategies. Providing resources to support effective instructional practices and involvement in special education program decisions were also hallmarks of principals’ knowledge.

The process of evaluating and identifying students with Autism in the public schools is detailed and can be cumbersome, even for those specially trained in assessment and diagnosis. Meagher (2007) found that school psychologists were unable to provide strong support as to their grounding in appropriate therapies and evaluative tools.

Variances exist in language and criteria for diagnosis or eligibility between the Individuals with Disabilities Education Act (2004) and the Diagnostic and Statistical Manual-Fourth Edition (2000), as clinicians and educators use different identification
criteria. A student may have a clinical diagnosis but not an educational identification if the condition does not have a negative impact on educational performance (Safran, 2008). Conversely, a student may be educationally diagnosed with Autism and eligible for special education services but may not have a clinical diagnosis. Either way, a diagnosis alone does not determine a child’s need for special education services. There are students with higher functioning Autism who may not be identified until later in life or who may never identified due to average or above-average intellectual functioning, academic achievement, and communication skills that contribute to their “blending in” and going “unnoticed”. It would behoove school administrators to, at minimum, be aware of the complicated issues surrounding Autism criteria and eligibility, especially if the administrator has a primary involvement in special education matters in the school.

Meagher (2007) surveyed 332 school psychologists, employing a study designed to analyze the diagnostic instruments and treatment recommendations provided for diagnoses of Autism among school psychologists. Findings indicated that, while no assessments were rated as negative, no particular assessment tool was highly legitimated by the participants. Also, while multiple instruments exist, there were only two predominantly used assessments, and they were generally viewed as moderately effective. Meagher suggests that the scope and range of assessment instruments may have been limited due to school psychologists’ familiarity and experience with them, not because of the measured effectiveness of the tools. Meagher also found inconsistencies with intervention recommendations.
School psychologists tended to suggest a treatment that was ranked less effective than another treatment about which they were also more knowledgeable. The research proposes that parent-driven influences over methodology may pose a strong impact on IEP team decisions. Meagher states, “Thus, it is the parent who may influence the decisions about methodology and specific therapeutic interventions, rather than basing these decisions upon efficacy studies that the school psychologist may be aware of” (p. 68).

Whether building-level administrators are directly involved in the majority of special education proceedings in their buildings or whether they delegate the bulk of special education-related responsibilities, the principal is held accountable for what happens under his or her leadership. As dynamic social systems, public schools often invoke team-based approaches to planning, instruction, curriculum development, and a variety of student support services (Tincani, 2007). The successful implementation of interventions for students with Autism are contingent upon individual student variables, characteristics of the implementers, and the environment and context in which the plan will be effected. Building administrators must ensure that staff possesses the skills needed to implement and sustain plans as they are designed. To avoid student plans being rendered obsolete or even counterproductive, it is essential that administrators provide adequate staffing, planning and collaboration time, training, consultation, and supervision.
Chapter Summary

A review of current research pertaining to general educational and diagnostic issues related to Autism, purposes of literature reviews, and hermeneutic phenomenology as a research approach was provided in chapter two. More specifically, studies related to Autism parents' perspectives on familial and educational experiences provided a framework for understanding the unique circumstances and obstacles parents of children with Autism experience on the home and school fronts. Though limited research is available on multiple incidence Autism families, studies of parents with a child diagnosed with Autism present valuable insights. Finally, literature on some of the current challenges and issues facing school administrators, in relation to special education and Autism, was reviewed. A relatively recent increased focus on Autism, partially due to increases in incidence and prevalence rates, results in constant and new research in the field as researchers, parents, and educational practitioners grapple with understanding the complex phenomenon.

Parents in multiple incidence Autism families have experiences that are unique. Their narratives and lived experiences are worthy of study, because their stories may assist educators and administrators who may be struggling with understanding the intricacies that directly impact family life and educational planning and programmatic issues. The challenges of understanding and coping with Autism for parents may not be so disparate from those experienced by teachers and school leaders. Hence, if additional research about this phenomenon can help bridge a gap
of understanding, then perhaps there will be contributions that will result in a reciprocity of richer relationships and empathy amongst parents and educators. The intended goal of the research would be to benefit the students who are subject to the shared educational decision-making in which the parents and educators engage.

**Introduction of Chapter 3**

Chapter three will focus on the proposed methodology for this study. Research questions will be shared and strategies for obtaining data will be discussed, including procedures for site and sample selection. A theoretical framework, the conceptual structure for this study, will be explained and justified, and details regarding methods of data analysis will be provided. To conclude, chapter three will incorporate information pertaining to the study's research validity and reliability, the researcher's subjectivity statement to expose potential biases, procedures for maintaining stringent ethical conduct and strategies that respect the integrity of participants, and limitations of the study.
CHAPTER 3

METHODOLOGY

Research Design

The purpose of this phenomenological study is to better understand the essence of the experience of multiple incidence Autism families, at the home front and within the public educational realm. Exploring the perceptions of school administrators who have worked with these families also provides a perspective from a different angle and lens.

Face to face interviews with parents were initiated by posing a general question about the experience of the multiple incidence Autism family. Authentic open-ended questions permit the interviewee to determine which responses are most important (Patton, 2002). The open-ended question also allows the participant to describe their experiences with self-chosen words and to carve the direction of that which they choose to express and share with the researcher. The general interview format was informal and conversational. Subsequent probing questions were developed and only asked by the researcher contingent upon the responses of parents. Patton (2006) explains that probes are used to follow-up on interviewee responses, with the goal of inquiring deeper into original responses to deepen and enrich data.

School administrators were interviewed via face to face dialogue; however, these interviews followed a standardized, open-ended format to ensure that the same questions were asked of each administrator. This approach required the
construction of carefully worded questions prior to the interview and provided highly focused questions to establish priorities and ensure efficient use of time for administrators who had limited time to spare (Patton, 2007). The researcher’s questions for school administrators were derived from information and themes, specific to educational experiences, obtained from parent interviews. The intent was for administrators to reflect and provide their own perspectives of the educational experiences, based on their work with similar families and students with Autism.

**Research Questions**

A phenomenological approach “attempts to understand the hidden meanings and the essence of an experience together with how participants make sense of these” (Grbich, 2007). A discovery-oriented approach is used to detect lived meanings that emerge from the data (Giorgi, 2008). To achieve this aim, the following research questions will guide this study.

1) What are the experiences of parenting multiple children diagnosed with Autism and navigating the educational realm?

2) What are the perspectives of public school administrators who have worked with the children and parents of multiple incident Autism families?

In-depth parental responses to these questions enhanced the understanding of the phenomenon and yield rich, descriptive data that captured the essence of the experience. Additionally, the study examined school administrators’ reactions to specific data or themes that emerged from the parent interviews. In particular, administrative reactions to educationally-related experiences generated insights that
could either corroborate or contradict parental perceptions. Analysis of disparities and similarities in responses shed light on contextual, procedural, and relational aspects of the educational processes for multiple incidence Autism families and school personnel.

**Theoretical Framework, Design, and Rationale**

Phenomenology as a research approach involves the collection of data, obtained through direct conversations with participants and/or interactions with texts, to better understand the essence of a particular experience. Since the data are richly descriptive and derived from narrative information, phenomenology is qualitative. A qualitative approach is often applied when the participants are viewed as having the power and expertise on the subject of study (Grbich, 2007). Exploratory questions, an inductive approach, data in narrative form, and interpretive analysis through thematic approaches are often aspects of a qualitative study. Furthermore, qualitative studies are appropriate when a “complex, detailed understanding of the issue” is needed, when the contexts or settings in which the participants experience an issue are critical to understanding, and when the intent is to empower individuals to share their stories and have their voices heard (Creswell, 2007).

Quantitative research, more deductive and premise based, relies on theory testing, generalization, and predictability (Grbich, 2008). The study of the phenomenon of multiple incidence Autism families lends itself to a qualitative design. Phenomenology is atheoretical; it does not suggest a theoretical basis, begin with hypotheses, or test theories against empirical instances (Giorgi, 2008).
The descriptions come from persons in the Lifeworld which, from a phenomenological perspective, precede a scientific perspective. Yes, all descriptions are perspectival, but not all are theoretically chosen, and moreover, the phenomenological analysis can often tease out some of the assumptions that belong to the perspective from which the person describes the phenomenon. But such Lifeworld descriptions, while perspectival, are pre-theoretical: (p. 51).

While descriptions are not driven by theory, collective data and resulting essences could contribute to the body of literature on the topic and inform existing theory.

Since it is important for the researcher to bracket herself in order to fully engage in the participant’s recounts and descriptions, a qualitative approach is needed. Participants must feel free to share and explore experiences they identify as significant, not perceive that questions and interview direction were coerced or lack a malleability that can be determined by the participant, the one who is exposing vulnerability by sharing his or her story. The data should not be quantified or converted to numerical data, as meaning will be lost and the purpose for conducting a phenomenological study will become irrelevant. According to Moustakas, the phenomenological research question “is illuminated through careful, comprehensive descriptions, vivid and accurate renderings of the experience, rather than measurements, ratings, or scores” (Moustakas, 1994, p. 105).
This phenomenological study aims to better understand the experience of multiple incidence Autism families. Another goal of the study is to share school administrator perception, providing an administrative viewpoint that will assist with broadening the scope of the study’s perspective. Since phenomenological research is based on discoveries, not driven by pre-existing constructs (Giorgi, 2008), theory cannot drive this type of study. The researcher must engage in phenomenological reduction, which includes bracketing (Moustakas, 1994), “in which the focus of the research is placed in brackets, everything else is set aside so that the entire research process is rooted solely on the topic and question” (97). Giorgi (2008) clarifies that the goal of phenomenology is to obtain general knowledge of the phenomenon, not to follow an idiographic approach which aims to highlight and specify individual accounts. Rather, phenomenology assumes a nomothetic approach as it attempts to understand the phenomenon in a more comprehensive manner.

**Site Selection and Sample**

Purposeful sampling strategies, the selection of individuals and sites for study due to their potential to purposefully enhance the understanding of the phenomenon (Creswell, 2007), will be used. Patton (2002) states that the power of purposeful sampling is found in the selection of *information rich cases* which can greatly inform the issue being studied. The goal with this method is to obtain insights and comprehensive understandings from participants. Intensity sampling “consists of information-rich cases that manifest the phenomenon of interest intensely” (p. 234).
Parental participants were chosen by their willingness and capacity to provide rich narratives of their experiences in multiple incidence families, enhancing the intensity of understanding of the phenomenon studied.

North Carolina’s Research Triangle area, consisting of Raleigh, Durham and Chapel Hill, is home to many families of children with Autism due to the availability of diagnostic and treatment resources in the region. Specifically, the Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) Program, a division of the University of North Carolina’s Department of Psychiatry, provides extensive services, training, and research for individuals with Autism (TEACCH). Since many families move to the area to access TEACCH diagnostic services, intervention and therapy, the prevalence of multiple incidence Autism families in the region is elevated and access to potential participants meeting the criterion for this study was ample. In addition, through previous work as an exceptional children’s program coordinator with a local school system, the researcher had knowledge of several multiple incidence Autism families in the proximal geographic region.

Since phenomenological research aims to describe the structure of an experience, not characteristics of the participatory group, subjects were selected for their ability to inform the research through the provision of rich descriptions of their experiences. Unlike quantitative research, phenomenology is not designed to follow statistical sampling theory that is rooted in randomization and generalizability of results. Rather, subjects are selected to provide a broad range of descriptive
variations that will determine the essential structures of the phenomenon (Polkinghorne, 1989).

To initiate the study, the researcher contacted a particular parent, a key informant, with whom there have been many mutual encounters with the researcher through experiences with the school system to inquire about interest in participating in this study. Key informants can serve as valuable sources of information because of their personal knowledge and insights about subgroups relevant to a study to which the researcher may not have direct access (Patton, 2007). Snowball sampling, a process of identifying additional participants or sources of information from individuals who possess personal knowledge of information-rich cases (Creswell, 2007), was initiated by obtaining potential participant information from the key informant. The key informant’s involvement in Autism support groups and networks placed her in a prime position to inform the researcher about other information-rich cases. Additional parent participants provided information about other families that met the study criteria and that may have been interested in participating. The researcher used this information to initiate participation inquiries and to determine additional suitable families for the study. The criterion for selection required that participants have experienced the phenomenon being studied, possessed a genuine and enthusiastic interest in understanding the phenomenon, and were willing to engage in potentially lengthy interviews and follow-up interviews (Moustakas, 1994).
The study’s criteria required participants to be biological parents of the children and to have maintained custody and direct responsibilities for child-rearing. Participants meeting this criterion were deemed more likely to share more in-depth and accurate pre-natal and early childhood experiences than non-biological parents who may not have acquired custody until a child’s later years. The researcher requested that participants share reflections from the earliest familial and educational experiences up to present day.

Participants’ children must also have possessed current membership in public school. The rationale for this criterion was to ensure that relayed educational experiences, whether referring to initial evaluation and identification; relations or communications with school personnel; special education placement and service decisions; or interactions with administrators were current. The researcher aimed to obtain information that was related to current educational policies and practices. Analyses of possible implications of NCLB, IDEA, and inclusive practices were deemed more applicable to children and families in existing public school placements.

Interviews of selected participants occurred at locations that were convenient and chosen by the participants. For parents, interview sites at the home were chosen. School administrators preferred to be interviewed at their school sites.

The number of recommended participants in a phenomenological study depends upon the source. Polkinghorne (1989) suggests 5 to 25 individuals and Giorgio (2008) recommends at least 3 participants. For the purpose of this study, the
researcher interviewed multiple incidence Autism families until the data reached a level of richness and depth that produced meaningful units of information and structures, ultimately describing the essences of the phenomenon. Four families and four administrators were interviewed resulting in rich data that contributed to an enhanced understanding of the phenomenon. Transcripts from parent interviews provided thick descriptions, core to qualitative research (Patton, 2002). The four administrators provided perspectives from the elementary, middle, high school, and central office levels. Their experiences provided insights from a variety of educational levels and a diversity of interaction with students and families.

The names of all participants were changed to protect their identities and to adhere to confidentiality agreements detailed in the consent to participate forms for parents and administrators.

**Data Collection**

After the researcher contacted prospective participants and obtained information regarding participation interest, an informed consent form for parents (Appendix E) and a permission document form for administrators (Appendix F), were provided through email communication. All initial communication was established through email, though a telephone question guide (Appendix G) was developed in the case that participants did not respond through email and needed to be contacted by phone. The consent and permission documents contained information about the purpose of the study, potential risks and benefits, confidentiality and measures taken to protect participants’ confidentiality. An additional purpose of the forms was to
provide potential research subjects with information to assist them in making an informed decision about their participation. Additionally, potential participants were given information about procedures for data collection such as audio taping of interviews, transcription methods and means for securing data.

Once participants’ questions regarding the study were answered, the researcher contacted the families through telephone calls or email to schedule face-to-face interviews. Interviews occurred during times and at locations that were convenient for the participants. The parent interviews began with a general question that asked participants about their experiences of parenting in multiple incidence Autism families. More specific questions or probes were posed to participants, based upon the information shared. To address the research questions of the study, the researcher raised more specific probing questions (Appendix A), if needed, regarding parents’ educational and familial experiences if participant reflections and sharing necessitated discrete redirecting.

Probing questions for parents (Appendix A) were reviewed by the key informant for feedback on appropriateness of questions and to determine needed revisions or additions prior to the data collection phase. Several changes were made to the original document based on key informant feedback. In general, the interview questions were broad, allowing participants adequate opportunity to share comprehensively their perspectives (Giorgi, 1997). When asked the initial general interview question, it was feasible that some parents would either be uncomfortable talking about certain topics or that they might have required prompting questions to
share experiences in more detail. Giorgi explains the interview process in a phenomenological study:

What is sought is a concrete, detailed description of the subject's experience and actions, as faithful as possible to what happened as experienced by the subject...When a description and an interview are used together, the description usually comes first and is used as a basis for further elaboration during the interview. In general, descriptions are briefer but more organized; interviews are more rambling and disorganized but more spontaneous (Giorgi, 1997, p. 7).

Interpersonal engagement is the focus of a phenomenological interview, and through an open-ended and unstructured approach, participants are encouraged to share the details of their experience. Pre-formatted questionnaires were not utilized since such stimulus-response designs require the exact wording of questions in the same order and possibly limit spontaneity and authenticity of participant response. The discourse-style of interview associated with phenomenology promotes engagement and sharing. The researcher aims to obtain non-theoretical descriptions from subjects, absent interpretation (Polkinghorne, 1989). The interviewer must remain open to new information and avoids presenting questions that can be categorized into pre-existing schemata or interpretive structures.
Rather than seeking general opinions, the interview focuses on specific situations and action sequences that are instances of the theme under investigation so that the essence or structure of the theme will emerge and show itself. When the statements of an interviewer are ambiguous, it is the task of the interviewer to seek clarification. The interview is a temporal process, and descriptions may become richer and clearer in the latter portions of the interview (Polkinghorne, 1989, p. 49).

The researcher obtained permission from participants to audio tape all interviews so that interviews could be transcribed accurately for later review and analysis. To ensure quality recording, the researcher obtained a new tape recorder/transcribing machine. Acquisition of quality equipment and tapes, bringing extra tapes to interviews, and choosing a location during the interview that was quiet and as free from interruption as possible (Patton, 2002) were strategies followed by the researcher. Also, throughout the interview, the researcher checked for proper functioning of the recorder.

Transcription of audio recordings ensured that participants’ experiences and stories were documented with precision. During interviews, the researcher also wrote notes as participants shared their experiences to notate specific words, phrases or other descriptions of interest or curiosity. Note taking can assist the researcher to design and pose additional questions and prompt remarks to stimulate participant elaboration (Patton, 2002). Taking notes also facilitates later analysis by providing additional information or thoughts stimulated during interviews.
School administrators who have worked with multiple incidence Autism families were contacted via telephone or email for interviews as well. Administrators were not chosen based on their work with the families in this study, and confidentiality was maintained by not providing any identifiable information through interview dialogue or the questions. Only one administrative participant actually worked with one of the families interviewed, but neither group (administrators or parents) was aware of specific individuals who were interviewed.

Focused interview questions (Appendix B) were semi-structured, as administrators were presented with themes and reflections, specific to educational experiences, from the parental interviews and were asked to reflect on data. Prior to the actual interviews, the questions were provided to an administrator with multiple levels of administrative and special education experience who participated in the study for feedback on clarity and appropriateness. Open-ended questions were used as well, providing administrators with opportunities to share their opinions about working with multiple incidence Autism families and other educationally related issues, current experiences, and reflections from past interactions. Questions for administrators were also derived from the researcher’s anticipation of certain gaps that may have occurred in responses and the need for probing questions to obtain more specific data.

**Data Analysis**

After initial interviews were conducted, each recording in its entirety was transcribed by the researcher. A detailed transcript can provide the researcher with
verbatim interview data that, unless recorded and transcribed, would be difficult to reconstruct and accurately represent throughout a potentially lengthy research process (Seidman, 1998). The researcher examined the transcripts and determined if follow-up interviews were needed with individual subjects to further explore information shared during the initial meetings. Several follow-up interviews occurred with parents. All data within the transcripts were analyzed for potential themes and the researcher attempted to locate the essence of the experience and identify the elements within (Grbich, 2007).

Analysis of the data, however, did not commence until the researcher read through all of the data, taking a holistic approach (Giorgi, 1997). Careful and deliberate initial reading of transcripts resulted in the identification of “meaning units”, found not only in the conversation or textural descriptions, but also discovered through the researcher’s interaction and openness to permit the emergence of natural meanings. Giorgi further defines the term “meaning units”:

This is a purely descriptive term that signifies that a certain meaning, relevant for the study, and to be clarified further, is contained within the segregated unit. Operationally, the relevant meaning units are formed by a slower rereading of the description, and each time that the researcher experiences a transition in meaning in the description, he or she marks the place and continues to read until the next meaning unit is discriminated, and so on (p. 8).

Meaning units were identified and analyzed before being transformed to
determine which were deemed essential to the phenomenon (Giorgi, 1997). Imaginative Variation is a phenomenological process which requires the researcher to employ divergent perspectives in order to determine structural descriptions of an experience (Moustakas, 1994). During this stage of data analysis “the world disappears, existence is no longer central, anything whatever becomes possible” (Moustakas, 1994, p. 98). It is within the Imaginative Variation process that the researcher’s intuition and imagination are required as she searches for meanings and essences. Giorgi (1997) explains that structures represent measures of central tendency, expressing “how the phenomenon being investigated coheres or converges” (p. 9).

The final stage of data analysis involved synthesis of textural and structural meanings and determination of essences. By integrating the essential textural and structural descriptions into a cohesive conclusion of the experience of the phenomenon, the essence is described as more of a universal quality or condition (Moustakas, 1997) rather than merely as personal accounts from individuals.

Transcripts from interviews with building administrators were compiled and analyzed for accuracy and possible thematic conceptualizations that emerged from the data. The use of a different type of interview process and question format, along with the involvement of participants other than the families, contributed to data and methods triangulation. Using multiple sources of evidence can contribute to a more accurate study and can promote the exploration of a broader scope of perspectives (Yin, 2003).
Validity and Reliability

While validity addresses the extent to which a concept or topic of study being measured is really being measured, often by a particular scale, reliability refers to how well a scale is truly evaluating that which it is designed to evaluate (Sirkin, 2006). Giorgi (2002) writes about the predominance of validity and reliability issues in test situations and experiments, where tests assume a symbolic nature in order to depict life situations. However, the tests, or measures, can only sample the individual or some portion of the world in attempts to describe the whole. Giorgi (2002) elaborates on the complexities of traditional empirical measures with phenomenological studies:

If the phenomenological approach did come up with genuine insights with respect to judgments and rating processes, it would utilize such knowledge in situational analyses. That is, phenomenologists would seek situations as faithful as possible to the situations the research is trying to understand and come up with structures that would tell us how the performers actually lived through their tasks. In other words, there would be no issue of the “validity” of a testing situation in relation to the actual lived situation (p. 10).

There are numerous perspectives regarding validity and reliability in qualitative research. As a result, alternative terms and models have been constructed in order to apply validity and reliability concepts which may be more quantitatively applicable to qualitative research (Creswell, 2007). Validation
strategies to address the accuracy of qualitative studies may be more appropriate. The researcher’s ability to develop a well grounded and well supported study that involves descriptions that truly reflect the participant’s actual experience; accurate transcription; comprehensive conclusions by the researcher; identified alternative conclusions; and general structural descriptions that may be more generally applied to other situational experiences (Polkinghorne, 1989). The textural descriptions describe the what of the experience, while the structural descriptions depict the how. Conclusions in phenomenological research are represented by the essences.

Creswell (2004) delineates standards to assess the quality of a phenomenological study. They include the researcher’s conveyance of an understanding of phenomenological beliefs and practices; a concise communication of a clear “phenomenon”; use of recommended data analysis procedures specific to phenomenology; conveyance of an overall essence and the inclusion of a description that depicts the experience and the context; and reflexive author practices.

Application of the Creswell (2004) and Polkinghorne (1989) standards for a quality phenomenological research were applied to this study. Measures of validity took on a more general perspective and are evident through the provision of persuasively presented findings that are accurate (Polkinghorne, 1989). The use of Atlas.ti software assisted the researcher to adhere to the principles of validity and reliability espoused by Creswell and Polkinghorne with as much accuracy as possible. Atlas.ti allowed the researcher to analyze large amounts of textual data
using a systematic approach to explore meanings in the data (Muhr, 2004). All interview transcripts were input into the program, codes were selected and applied to the narratives and were then analyzed by content and connections with other similar codes. Parent and administrator interviews were separated into two hermeneutic groups, or families, since the format of the interviews and data collection methods differed. Common themes for each data family were developed and analyzed.

**Ethical Issues**

In order to uphold the integrity and ethical standards of the research and to maintain confidentiality and protection of all individuals participating in this study, the researcher complied with all policies, rules and regulations set forth by the North Carolina State University Institutional Review Board. All research procedures minimized risks to subjects, informed consent was obtained prior to eliciting participant participation, and participants were provided with detailed information regarding the study so they could engage in an informed decision regarding their involvement.

Since participants, asked to share their experiences and reflections of parenting in multiple incidence Autism families, may have found themselves in a sensitive and precarious position as they divulged deeply personal information to the researcher, the researcher assumed a genuinely responsive and perceptive role to parents, so they felt that they were embarking on a safe and comfortable journey of reflection and sharing. Advice for interviewing, provided by Seidman (1998), was
followed to ensure a comfortable environment for participants. In particular, listening more and talking less, following up on participant responses, asking questions for clarification, requesting to hear more about an event or topic, exploring laughter and tolerating silence were strategies that contributed to a safe environment.

It was also important for the researcher to create a non-judgmental environment for school administrators as they reflected on practices and on confidentiality-maintained, thematic data from parental interviews. Sharing of parental thematic data was designed to stimulate administrative reflections from an educational perspective, thus providing a broader scope to the study. Administrators could have been put in a position of defensiveness had they perceived the need to counter possible negative parental data. It was the researcher’s responsibility to ensure that administrators did not feel confronted by data, but rather that they viewed them as integral components of a study that is attempting to understand a phenomenon shared by so few. This was accomplished by applying the strategies used in the parent interviews (Seidman, 1998). Establishing rapport by conveying empathy and understanding without judgment and maintaining neutrality through provision of objective reactions to responses were also key to creating a safe and comfortable interview environment (Patton, 2002).

**Limitations of the Study**

This study was limited to a select number of parent and administrative participants who reside in a limited geographic region. The abundance of Autism-related resources available to the public and private domains in the area may
contribute to which services are available and how those services are accessed by families. This availability may result in experiences that are different from those with limited resources. The influence of a high quantity and quality of resources also has bears influence on educational practices for students with Autism. Since many parents receive TEACCH evaluations or services, interventions suggested and used in the schools may be abundant. This may not be the case for other regions of the country where resources may be extremely scarce or distant. To address this limitation, the researcher obtained rich data from lengthy parent interviews. In addition, parent data reflected experiences that occurred outside of the region of this study, as well as stories about limited access to resources, despite the perceived abundance in the region.

Also, since the administrators all work within the same region as the parents in the study, their level of candidness about certain issues may have been restricted. Possible apprehensions with information shared being connected back to the individual administrator could have influenced forthrightness of some responses. The researcher addressed potential apprehensions by ensuring confidentiality and promoting a safe interview environment. Along with reinforcing confidentiality before and after the interviews, all participants understood that the study was approved by Institutional Review Board of North Carolina State University, thus ensuring an acceptable level of professionalism and ethics.

Some of the administrators’ lack of training and limited experience with direct involvement with special education programming and instruction, especially specific
to Autism, may have limited their depth of insight they were able to provide. Participant experience and knowledge of Autism in this study was varied, and any varying depths of insights may result in interesting implications for further studies.

Furthermore, a limitation to this study may be that the administrators interviewed, though spanning various grade levels and possessing a great deal of collective experience as determined by years of administrative experience, did not represent a full continuum of services for students with Autism. Practicing building administrators all currently had programs for high functioning students in their respective buildings. One participant did possess direct supervisory experience with self-contained programming for students with Autism, providing a wider range of perspective for the collective administrative participants.

In addition, the participant sample was extremely homogeneous since all parents and administrators were middle class and Caucasian, thus limiting participant diversity. The researcher defined criteria for each sample group based on certain indicators that did not include socio-economic, cultural or ethnic factors. Unexpectedly, the defined criteria resulted in a homogenous participant sample.

**Chapter Summary**

Chapter 3 provided a detailed description of the study’s methodology. In particular, the research design and rationale for the study were explored. Data collection and analysis methods were discussed. In addition, issues of validity and reliability were addressed, and alternative applications, more specific to qualitative research, that were employed in this study.
In this chapter, the researcher also discussed methods and practices for ensuring exceptional ethical standards. Detailed information regarding the study and protections for participants were shared with all subjects, and procedures for withdrawing from the study without repercussion were detailed through consent for participation documents. Since participants were asked to divulge deeply personal information, the researcher was committed to caution and thoughtfulness at all stages of the study in order to create a safe, trusting environment. Concluding chapter 3 is a description of anticipated study limitations.

**Introduction of Chapter 4**

Chapter 4 addresses the findings from the interviews with parents and school administrators. Descriptions of the essence of multiple incidence Autism families, along with themes from administrative reflections, are shared in detail.
Chapter 4

Findings

Introduction

This phenomenological study was designed to collect data in attempts to construct an understanding of the multiple incidence Autism family experience, illustrating the derived meanings expressed by parents. An equally significant and desired outcome was to obtain information from principals who have worked with multiple incidence families. As indicated by a review of existing literature, there are limited studies of multiple incidence Autism families and school administrative perspectives. Though the number of multiples with Autism within a family is on the rise, studies mostly focus on identifying and explaining etiological issues, resulting in a paucity of information concerning the authentic and experiential reality of parents and school administrators.

Analysis of administrative perspectives, in conjunction with examination of parental narratives, resulted in a conglomeration of multi-dimensional data aimed at answering the following research questions:

1) What are the experiences of parenting multiple children diagnosed with Autism and navigating the educational realm?

2) What are the perspectives of public school administrators who have worked with the children and parents of multiple incident Autism families?
Semi-structured interviews with school principals were designed to elicit targeted information regarding their involvement with multiple incidence families in an administrative capacity. Specifically, principals’ experiences with diagnostic and evaluative situations for special education eligibility, programs and services for students with Autism, special education leadership practices, and interactions and communication with parents were explored.

Parents were asked open-ended questions that addressed the familial and educational realms of their experiences. These interviews were designed to provide parents with maximum autonomy to share information and to determine the direction of the interviews. Probing questions were prepared and available to the researcher as a resource to be used if interviews entered a stagnant stage or if parents appeared uncomfortable or hesitant to share.

The Participants

Initial contacts with school administrators were made through email communication. Principals were selected based on their range of experiences at different levels (elementary, middle, high school and central office), their direct involvement with multiple incident Autism families, and their accessibility for interviews. General information about the study was provided in the body of each individualized email and the administrative consent form was attached, offering more detailed information about the study and principal involvement. Access to the study’s approval from the North Carolina State University Institutional Review Board (IRB) was offered, though no principals opted to review the document. All participants
agreed to participate in the study. After each principal indicated an interest in participating, an interview time and location was determined. Two paper copies of the consent form were brought by the researcher to the interviews. After reviewing the documents, the principals and the researcher signed both copies. One copy was given to the principal and one was maintained for the researcher's records.

Principals were informed that several of the interview questions were constructed based on themes or topics from the parent interviews. In order to avoid limiting responses or topics, administrators were also encouraged to share any experiences or perspectives that were not reflected in the questions asked by the research. Confidentiality of families was protected, as no information about specific families was provided by the researcher. Principals did not inquire about specific families, nor did they use names of families or students in their responses. The following table provides a brief description of each administrative participant. The names were changed to maintain confidentiality.

**Table 1: Administrative Participants**

<table>
<thead>
<tr>
<th>Principal</th>
<th>Teaching &amp; Administrative Experience</th>
<th>Current Role</th>
<th>Autism-Specific Experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Janet Duncan</td>
<td>• HST</td>
<td>• ESP</td>
<td>• HI/NP</td>
</tr>
<tr>
<td></td>
<td>• SBM</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mr. Mark Cook</td>
<td>• MST</td>
<td>• HSP</td>
<td>• DPHFAU at MS and at current HS assignment.</td>
</tr>
<tr>
<td></td>
<td>• HST</td>
<td></td>
<td>• SCAU</td>
</tr>
<tr>
<td></td>
<td>• MSAP</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• ESP</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• MSP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dr. Ann Wagner</td>
<td>• MST</td>
<td>• MSP</td>
<td>• DPHFAU</td>
</tr>
<tr>
<td></td>
<td>• MSAP</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• HSAP</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
A key parent informant was first contacted by the researcher through email communication. Through previous district-level employment, the researcher had established a positive relationship with this particular parent, the mother of three school-aged boys with Autism. The key information provided several names of families who met the study’s parent participant criteria and who would possibly be interested in participating. Through established relationships, networking and involvement in various local, state, and national Autism advocacy and support groups, the key informant was familiar with numerous families that were likely to be amenable to participation.

The researcher then emailed each parent, individually, asking if they would be interested in participating in the study. As with administrators, the same information about the study was provided in each email. Parents all responded and indicated interest. Interviews were then scheduled, according to parent needs and
preferences. Upon meeting with each family, the researcher presented two paper copies of the consent agreement, providing each family with a signed copy for their records and keeping a copy for the researcher’s documentation.

After interviews were transcribed, the researcher emailed each participant a copy of the transcript to review for accuracy of recorded information and to provide participants with an opportunity to suggest any revisions to their original interviews. One parent chose to make comments, offering additional details or elaboration on original narrative. No administrators responded with requested revisions.

The following table depicts the number of children in each family, each child’s age and current grade placement, and whether or not the child is diagnosed with Autism.

**Table 2: Parental Participants**

<table>
<thead>
<tr>
<th>Parent</th>
<th>Child</th>
<th>Age</th>
<th>Grade</th>
<th>Diagnosed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patty &amp; Robert Neal</td>
<td>Sam</td>
<td>10</td>
<td>5</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Joe</td>
<td>11</td>
<td>6</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Ian</td>
<td>13</td>
<td>8</td>
<td>Yes</td>
</tr>
<tr>
<td>Karen &amp; Paul Roberts</td>
<td>Ben</td>
<td>3</td>
<td>PK</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Tommy</td>
<td>5</td>
<td>PK</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Taylor</td>
<td>6</td>
<td>K</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Lee</td>
<td>7 ½</td>
<td>2</td>
<td>Yes</td>
</tr>
<tr>
<td>Laura Thomas</td>
<td>Perry</td>
<td>15</td>
<td>9</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Aaron</td>
<td>17</td>
<td>11</td>
<td>Yes</td>
</tr>
<tr>
<td>Carol &amp; Frank Larson</td>
<td>Farron</td>
<td>12</td>
<td>6</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Cory</td>
<td>15</td>
<td>8</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Amy</td>
<td>18</td>
<td>12</td>
<td>No</td>
</tr>
</tbody>
</table>
All administrative and parent interviews were recorded, transcribed by the researcher, and coded using Atlas.ti software, after thorough re-readings of each transcript were conducted. The names of all participants were changed to protect identities and to maintain confidentiality. Common topics from parent interviews were organized and analyzed thematically through the development of a customized term chart and several non-linguistic representation models developed by the researcher. Once common topics were determined from the parent data, an outline (represented in the Table of Contents under Chapter 4) was developed for findings. Similarly, administrative data were charted for organization of topics and to facilitate the reporting of these findings.

Since parent interviews were conducted before the administrative interviews and some of those data were used to develop administrative questions, these findings are reported first. While parents were given great latitude in determining the direction of the interviews and conversations, there were common topics or themes that were prevalent throughout many of the interviews. Thus, the findings are reported by identified theme and then by personal quotes from parents, as they relate to the general topic. Using the language of the parents to add further description of the themes is intended to deepen and fortify the meanings, since the phenomenon of multiple incidence families is such a personalized experience.
Parent Interviews

Early Signs

“Something is definitely up with this kid.” –Patty Neal

All parents involved in this study began sharing about their experiences of having multiple children diagnosed with Autism by talking about early signs, observations about their children’s behavior. For three of the parents, their first born was the first child diagnosed, so there were no other siblings to compare behavior and developmental milestones. Several parents spoke of having a limited frame of reference to identify behaviors that were atypical. Patty talked about her first son.

Ian spoke a lot. He repeated things, but he was my first baby. He repeated phrases and words a lot but I didn’t think that was strange. He was my first baby and I had no experience really with babies and toddlers. My second son spoke really early and then stopped speaking.

Patty and her husband did have initial concerns, noting that Ian experienced very long temper tantrums that could not be quelled. She had asked a friend, a special education teacher, to observe Ian because the tantrums and impulse control problems were concerning. “We knew something was wrong,” Patty shared during the interview.

“I’m seeing some red flags.” –Patty Neal

Joe, Patty’s middle child, began speaking early but then stopped speaking. When he was in a private pre-school, the teacher contacted Patty and told her that she was “seeing red flags.” Though the teacher mentioned possible testing for Joe,
Patty refused to allow the conversation to go any further, because it was at that very time that Ian and her youngest son, Sam, had just completed a battery of tests as part of the pre-diagnostic process. Sam’s self-injurious behaviors set him apart from his other siblings. According to Patty, he was “a head banger, face slapper, and a chest puncher.”

Laura Thomas’ eldest, Aaron, was born when the family was living in London, England, and, in retrospect, she identifies what could have been initial concerns when listening to other mothers during meetings of an American women’s group talk about their children. While other mothers talked about their child’s enjoyment playing with cars and engaging in other developmentally appropriate activities, Laura reflected how Aaron would be content repetitiously spinning the wheels on the cars. Nonetheless, Laura did not have concerns and rationalized, “Maybe her kid’s weird.” She never questioned whether or not Aaron was normal or not, adoringly sharing, “He was just perfect to me.”

Upon returning to the United States, Laura started noticing differences, observing, “it took a while for this retreating into himself to happen.” She took the initiative and had Aaron seen by their pediatrician, to obtain a different frame of reference regarding Aaron’s behaviors. Laura’s concern was conveyed to the pediatrician as she shared observations.

He was not playing with toys normal, you know toys at all normally. He was taking combs and flipping them in front of his eyes. He was staring down the
sides of things, you know, all these things you see in classic Autism. And so, I was really starting to get worried.

Perry, Laura’s youngest son, did not meet many of the developmental milestones. Laura and her husband had joked that, due to all the attention required to meet the needs of Aaron, Perry could end up having Autism because he was ignored during these times. These parents noticed that Perry did not meet many of the developmental milestones, and Laura reported, “He didn’t sit up, he didn’t roll over, he didn’t walk forever. You know, he was just this little ball of Jell-O…we thought he was retarded. We just thought, something is definitely up with this kid.”

“He behaves strangely.” –Carol Larson

The Larson’s first child was Amy, and she was always a neuro-typical child, never diagnosed with Autism. When Cory, their second child, came along differences or oddities in behavior were pointed out by visiting friends. Carol’s mother, who was staying with the family for support through an illness, stated that Cory “behaves strangely.” Carol shared, “He’d walk around the house, going back and forth, back and forth, kind of wild and shake his head, but he still had no words.”

During visits to the doctor with Cory, Carol would share that Cory was picking up some words. The doctor surmised that Cory’s behaviors were not too concerning, stating “well, your daughter was very precocious, you know, and he’s a boy.” Comparisons to the typically-developing eldest child did not yield any immediate acknowledgements by Carol or her doctor that Cory may have needed to be evaluated.
Farron, the youngest, did not start talking until about five years of age. Carol talked about early signs with Farron and her appraisal of the situation.

Farron is bizarre. He was a bizarre kid. He would get angry and throw socks down the stairs every time I would do laundry. He’d just throw them down, just angry. I didn’t know what his deal was. I didn’t even think Autism. It was just, he was just an odd sort.

Even while Cory was being treated and receiving services, Carol held tightly to the thought that Farron was simply “bizarre”. Comparisons to the typical and eldest child did not instigate action to address the concerns that were there with Farron. A professor who was supervising a university program for speech therapists, through which Cory was receiving services, mentioned to Carol that Farron should be evaluated, too. The professor had opportunities to observe Farron, since Carol was bringing him to Cory’s therapy appointments.

“He was just a shell.” –Karen Roberts

Karen and Paul Roberts are the parents of four young boys, three of whom are identified with high functioning Autism. They first noticed concerns with Lee, the eldest, around the age of two. Karen, the mother, had taught in a pre-school for children with developmental delays, so she had some level of exposure and knowledge about traits associated with Autism. Karen provided insight about early signs with Lee.

He was non-verbal, he had no eye contact, high sensory issues. He was the type of kid, too, that if you would put him out in the sandbox, he would just
pick up the sand and just watch it fall, but not actually put it in the bucket. A lot of his sensory issues were with clothing. Seams that touched his body…too itchy, too scratchy. Complete meltdown. He would have sleepless night terrors where he would just wake up during the night screaming and you would have to put him on the floor and let him work it out. You couldn’t do anything to help. He just would scream.

Lee’s early development did involve the acquisition of some words, but then he became non-verbal. He also was not walking and was difficult to reason with, quickly becoming angry and unable to express himself. Karen remembers Lee after the age of two.

Totally gone. But you could tell he was just in his, he was just a shell. You could get a hug or smile out of him once in a while, but he was just this little boy that was nothing, he was a body.

The Robertses also noticed atypical behaviors in the next two sons, Taylor and Tommy. There were safety and boundary concerns with Taylor who would “just walk out in front of oncoming cars” and “jump off a couch onto a table”, according to Karen. Taylor also experienced eating issues. It was difficult to get Taylor to eat much of anything, and this was complicated by his sensitive gag reflex.

When Ben, the youngest, was around two years old, Karen also developed concerns for him. She reported, “I couldn’t tell if it was just mimicking brothers or if there was truly a speech delay or if there was just some sensory going on.” After having three boys identified with Autism, Karen and her husband, Paul, were
convinced that the youngest would also be diagnosed. When the evaluation results came back that Ben did not meet eligibility criteria for Autism or speech, Karen was shocked and shared, “I had no clue what to do. It took me a month to figure out what I was going to do now.”

Interestingly, two of the four parents mentioned certain movies or media as frames of reference when they were first learning of their children’s difficulties and diagnoses. Patty talked about *Rain Man* and how that depiction of a person with Autism created anxiety in her as she wondered if Ian would eventually need to be institutionalized like the main character, Raymond, in the film. Carol made reference to a television show from the 1970’s. She remembered the show involved a character who spun plates.

**Evaluation Process & Diagnosis**

“*A long process with a lot of paperwork.*” –Patty Neal

While parents came to acknowledge and accept oddities or concerns, early signs, in their children’s behaviors, all parents talked about the evaluation process as a starting point toward diagnosis and services to follow. Since most of the children were quite young when early signs were identified, they were all evaluated outside of the school system. All parents accessed the Children’s Developmental Services Agency (CDSA), a North Carolina State agency specializing in early diagnosis and intervention. The CDSA was formerly known as the Developmental Evaluation Centers (DEC) and is designed to provide services for children, ages birth to three, as mandated by a section of the *Individuals with Disabilities Education*
Parents also accessed evaluation services through the University of North Carolina’s (UNC) program, Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH). The Thomas’s accessed the Center for Development and Learning (CDL) through UNC.

Patty’s oldest boy, Ian, was evaluated through the school system. She recalls that it was “a long, long process with lots of paperwork” as she traveled to and from home and the evaluation site for Ian to complete the battery of tests. Joe, because he was still two years old, was evaluated at the CDSA, then the DEC. The evaluation process for Joe stood out in Patty’s memory.

He was given all the tests, I mean all of them. Everything. Even the hearing because we wanted to rule out hearing. I had attempted to take him to an audiologist, but he couldn’t even test him because he could not tolerate being tested regularly. It was really wild. So they were able to do it at the DEC with the special machines. They have to be tested by people who have the equipment to test kids who cannot test normally.

At the DEC, Patty noticed that the physical environment was daunting. They were in a pediatric waiting room with many parents and their children with developmental issues, so there was no escaping the gravity of the situation. She shared, “Developmentally, something is wrong with all these babies and kids. And you just go, wow, this is my son. This is my son.” For Patty, the DEC experience was different than the one with the public school, where Ian’s evaluation was conducted.
They were even better than the public school. This is what these people do all day long. They were fabulous and the facility was really, really good and they had the right toys to do the testing with. It was not like a crowded room...like the testings in 1999 for Ian were done in a closet I think. I mean it was crazy. You have this kid climbing the walls, literally. DEC was a different experience. In some ways scarier but on other ways, more professional.

While Sam, the youngest, was also evaluated through the DEC, Patty’s middle son, Joe, was evaluated through the collaborative efforts of TEACCH and the public school system. Later, TEACCH was also involved in further evaluations for Ian and Sam.

For Laura, Carol, and Karen and Paul, not a great deal of interview focus was on the evaluation process, though they all talked about it to some degree.

With the Larson’s, The Kluge Center, part of the University of Virginia, was involved in part of Cory’s evaluation. Carol described that team as a group of “serious diagnosticians” that included a developmental pediatrician. Regarding Cory’s testing, Carol shared, “Bless his heart. I mean he had a screening for hearing. They knocked him out. They did developmental tests. I mean that poor kid was put through the ringer. He had brain scans and all that.”

From Laura’s memory, the Thomas’s experience for Aaron with the CDL also seemed like a drawn out experience.

It was many months before he got a diagnosis. It was just after his second birthday, so this whole process was like a six to eight month period, but it
seemed like six to eight years. Because every day I was seeing him, what I thought, getting worse and worse, and nobody had any answers for us.

The multi-disciplinary team included a developmental pediatrician, speech therapist, occupational therapist, physical therapist and other professionals who had a role in Aaron’s initial evaluation. Perry was also evaluated through the CDSA.

“I thought if I said it, it would be true.” –Laura Thomas

Some of the parents had stronger inclinations than others about a possible diagnosis when early signs were observed and through the evaluation phase. Additionally, all parents dealt with a range of experiences and emotions when officially learning about the diagnosis. Delivery of the Autism diagnosis seemed to be one of the most prominent and detailed memories for these parents.

Laura began seeing concerns from Aaron at an early age and took him to a psychologist who never mentioned the word ‘Autism’. As she reflected back, Laura wondered why he never suggested Autism. With a background in nursing, ‘Autism’ was reluctantly hovering in the back of her mind. When asked by the researcher if she had ever mentioned possible Autism to anyone, Laura admitted, “I never did, because I didn’t want it to be true. I thought that if I said it, it would be true.”

Delays in the evaluation process, based on input from the psychologist and pediatrician, resulted in wasted months, according to Laura. “Basically at the CDL, they took one look at him (Aaron) and said he has Autism. And so we had an answer. We had a name for it.”
“It was like somebody had taken the air out of my lungs.” –Patty Neal

Patty’s experience with Ian’s diagnosis was upsetting. The school psychologist had contacted Patty on the telephone to address some of the evaluation pieces, “just to get it done” was how Patty perceived the encounter. Before the conclusion of the phone call, the psychologist said, “I want you to know that we feel that Ian has Autism.” Information had not been shared through typical protocol and procedures, after the evaluation was complete and the multi-disciplinary team had a chance to come together to make a diagnostic determination. Patty, still seemingly devastated by the encounter when recalling this memory, shared, “It was like somebody had taken the air out of my lungs, because I was like, ‘Autism’?” When Patty asked the school psychologist what Autism was, she was told,

It’s a neurological disorder of the brain of which there is no cure. It’s a lifelong illness. But I don’t want you to worry. Don’t go on the internet and look things up. You’ll just get upset. Just wait till we get finished.

Patty learned of her eldest’s Autism diagnosis over the phone, with no preparation or opportunity for dialogue to ask questions or to seek resources. She then shared the news, still stunned, with her husband. While the process for the delivery of this information was quite disturbing, Patty shared this experience without bitterness or contempt, but the emotions from that day were quickly exhumed as if the event had just recently occurred.
“Welcome to the world of Autism.” –Paul Roberts

After Lee’s diagnosis, the Robertses began to notice oddities with Taylor’s behaviors, and they “kind of had an idea that we were going along the same lines. That he was going to be somewhere in the spectrum.”

The Robertses, who had Lee and Taylor evaluated through the CDSA, recalled learning about the diagnoses.

They come in and tell you, yes, your child is Autistic. They give you a folder and they say, hi, welcome to the world of Autism. All the information is in there. Go ahead and start making your phone calls. Any questions?

Though generally pleased with the process and services they were able to access through the CDSA, the Roberts’ desire to have been informed about the diagnoses in a more humane and gentler way apparent.

Carol’s son, Cory, first received an unofficial diagnosis by her best friend, a special education teacher, during a visit to her home in Mississippi. Her friend suggested that Cory may have some symptoms and shared some textbooks with Carol for additional information. The official diagnosis came after Cory’s evaluation.

Some nice ladies came in and by that time, I had started reading more. And the lady called me and she said, we think your son might have something called PDD-NOS. And I’m like, oh, that’s just your nice way of breaking it to me that he’s Autistic.
Her friend’s earlier attempts to educate Carol and encourage her to consider Autistic symptoms that seemed apparent in Cory prompted her to further educate herself, eventually resulting in some level of preparation when the diagnosis was delivered.

Farron’s diagnosis came through the TEACCH team. Carol was surprised by when the team suggested that Farron was Autistic, since Farron was so different than his older diagnosed brother. Even moments up to the diagnosis delivery, sitting in the TEACCH office, Carol was sure that the results would indicate that Farron was not Autistic.

“Walking away devastated but hopeful.” –Laura Thomas

Parents expressed a continuum of responses when dealing with the Autism diagnoses of their children. For some parents who had observed oddities, often times extreme, in their children’s behavior from a very young age, finally having a diagnosis provided some type of relief, an answer. When Laura’s son, Aaron, was diagnosed, she recalled, “We walked away devastated but hopeful that at least now there’s…we can call it something.”

“I was in denial. He was going to be my typical child, the middle child.” –Patty Neal

All the parents expressed some degree of denial, from first observations of early signs and behaviors to the evaluation and even after the diagnosis.

Patty and her husband admitted denial from the time they received that first phone call from the school psychologist. Upon learning the news, Robert, Patty’s husband, said that the psychologist was “full of shit.” He pointed out, from an
observation during a prior meeting with the psychologist, that she had no fingernails because she was a nail biter. Patty elaborated and said, “Why would you trust anybody’s opinion who has no fingernails?” Though, while recalling this memory, she laughed about this conversation with her husband, Patty offered that this was simply a way to justify dismissal of the diagnosis.

When her youngest was getting ready to be evaluated by the CDSA, Patty was in denial and took measures to try to avoid the looming reality of a diagnosis.

I remember dressing him up in the smartest, cutest little outfit I could possibly find for him to take him to these evaluations. He wore a trench coat. I mean, he wore the designer clothes and a little trench coat…I just did not want him to be mentally retarded, or, you know.

Sam’s behaviors, the most extreme and atypical of Patty’s three boys, did not thwart her attempts at hoping that he would be ‘normal.’ And when Joe’s pre-school teacher had called Patty to talk about some ‘red flags’ she was seeing, Patty attempted to hold on to hope that one of her children would escape the diagnosis of Autism. She tried to explain to the teacher that Joe may be copying behaviors of his other special needs brothers and provided justification for any behaviors of concern the teacher shared. Patty’s denial persisted and hope reigned. She shared that Joe “was going to be my typical child, the middle child. He was going to be my one normal child.”
“My kid isn’t Autistic. I can fix him.” –Karen Roberts

With Lee, the Robertses denied the consideration of Autism, even though his behaviors were often extreme and kept the family from leaving the house because Lee would “freak out” and “go crazy.” Even though Karen had some experience with children with Autism at the center where she worked, she initially kept telling herself, “My kid isn’t Autistic. I can fix him.” Paul also reflected on the denial.

The hardest part in the beginning was denial, getting over the denial. It is the hardest thing in the world, because everybody kept telling you, well, the boys are late bloomers. Don’t worry about it. It was just getting over that denial and then all of a sudden you’re like, oh my God, we’re so far behind. Waiting, while in denial that something could be wrong with their child, put the Robertses in a position of perceived catch up due to lost time. Initially thinking that she could ‘fix’ Lee, Karen “denied it for eight months. And then push came to shove” and she had to “start making phone calls to get him services.”

Even though Carol translated Cory’s diagnosis of PDD-NOS to Autism and prior to the Kluge Center evaluation, she realized she was battling some denial.

But back then, I didn’t really realize the severity of Autism. I was always one of those people, if it’s broke, I’ll just fix it. Don’t worry, I can deal with this, you know. That’s just the way I’ve always been.

Like Karen, Carol also felt that there was a way to avoid acknowledging or accepting the notion that something was amiss with their children. They both used the language of ‘fixing’ what might be broken.
The Robertses accepted the diagnoses, but they never accepted the notion that Autism would limit possibilities for their children.

There is no Autism in her family or in my family. None. I said, you know what, I’m not going to accept this. There are so many people out there who have said to me, it's hereditary, this is your life. Deal with it. I'm like, you know what? I'm sorry, that is not the attitude I have.

Paul talked about the importance of focusing on what his son could do, not on the limitations often associated with Autism.

We were told, when we had them evaluated, Lee had a certain skill set and because we did get some of the intervention through the school...they kept saying to us, like, Lee’s mild to moderate Autistic. But, these are the strengths we see. Well, if he's got those strengths...this is where I learned, if you got 1% good, I'm gonna take 100% and focus on that. I'm not going to focus on the negative.

Creating and relentlessly pursuing a path of endless possibilities has been draining, emotionally and financially, but the Robertses decided early on that no doors would be closed. Chasing all leads on strategies or interventions was important to the Robertses, because as Karen said, “we didn’t turn any service away, because we were so afraid. What if we turn that one service away and it could have helped our kids?”
Early Intervention

“Life just became like a blur.” –Carol Larson

Where do parents go after the news is given to them that their child has Autism? How do they know what steps to take next to provide early intervention? For some parents, getting started was a struggle because, at the time, resources were either limited or there was little knowledge given or accessed to those diagnosing that would help steer parents in the right direction.

Ten years ago, when Ian was diagnosed, Patty was given very little information, not only about the disability, but also about resources to access and explore.

Please, God, ten years in the making, they have to be a little bit more savvy about how this information is shared with the family. You know, how it’s communicated. What kind of supports are offered or even information about providing further support because it was very sketchy.

TEACCH was a resource that was suggested to Patty, but she was also told that there was a waiting list for years. Eventually, Patty was able to access TEACCH resources earlier than expected due to a cancellation that opened up a slot for her and her children.

Laura also struggled with developing a plan before and after Aaron’s diagnosis. She talked about the frustrations of not knowing where to go to begin therapies and intervention, but she also mentioned that the system is much improved now, providing a wider range of more systematic supports and services for
families in a timelier manner. Now, she reports, pediatricians and other
diagnosticians send families to the CDSA, but Laura and her husband did not know
that service existed at the time. She shared that “Nobody steered us in that
direction.”

After Cory’s diagnosis, Carol was told to talk to the school system about
providing therapies. Being a mother to three children and managing the schedule of
therapies for Cory was a logistical nightmare.

I had to drive out to Roanoke during the summer. That was hellish. I had
Farron in a stroller and Amy who was 4 or 5 and Cory in the heat. It was really
hot that year. I just remember life became like a blur. I was just kind of going
through the motions. Doing everything I needed to do.

Parental narratives about the efforts and energies required to access, organize, and
manage early intervention services told stories of persistence and determination on
the part of parents to ensure their children got what they needed.

“If you believe it’s going to help, then you need to keep doing it.” –Paul
Roberts

Three of the families talked about acquiring in-home supports for their
children. The Community Alternatives Program (CAP), through Medicaid, provides
comprehensive services to qualified individuals within the community. Parents talked
about allowing people in the home and entrusting individuals with their children.
Carol expressed positive experiences with Cory’s support people and shared how the assigned workers assist him with routines and daily living skills within the home and local community.

For Patty and Robert, after being advised to get help, bringing people into the home was difficult, especially for Robert. Patty said, “To have strangers in your house all this time, other people who aren’t your family, even if they’re not strangers, that was really hard for my husband.” Yet, Patty knew that this level of support was necessary to provide appropriate intervention for her three identified children. She understood that she could not do it on her own.

The Robertses described their home as a “therapy house” with a “reversing door,” explaining how speech, occupational, behavioral/play therapists and other service providers were coming in and of the house to work with the boys. Karen talked about the challenges of maintaining a hectic schedule.

I was always making appointments the month ahead. So had this month going, and I’d have next month going, too. I wasn’t willing to miss anything. If somebody said try it, or we found out about it, we were doing it.

In addition to having people in and out of the house, the Robertses have involved their boys in a variety of activities such as sports, going to movies, museums, church groups, social groups, and more. Paul recalled some advice they were given early on. They were told, “It’s going to be the hardest thing you’ve ever done, but you have to understand you’ve got to keep doing it. And you’ve got to change your life. You’ve got to constantly do change.” Ever since the counsel, the Robertses have
been constantly involving the boys and the entire family in change, and the payoff has been increased flexibility and participation by the boys. The advice from one therapist was, “If you believe it’s going to help, then you need to keep doing it” and the Robertses have taken this to heart.

Carol and her husband shared a similar philosophy as the Roberts’. Farron is involved in many activities to keep him busy, to give him practice in social situations, and to establish consistent changes to his world that will better prepare him to acclimate to the ‘real world.’ Even though Farron resisted certain activities and showed a keen disapproval of his involvement, Carol talked about the progress he made over time with soccer.

There are a lot of things he hates, but it’s too bad. I used to take him when he was little and didn’t like being around kids. So, I would go with him early and kick the ball and maybe one or two little children would come…he didn’t do games or anything like that, and that was cool. And every year, you know, he’d stay longer.

The same held true with swimming and basketball. Carol admits to “forcing” Farron to participate in activities he would not choose to do on his own. And even though Farron can dramatically resist, at times drawing stares and consternation from disapproving onlookers who are likely misinterpreting the situation, Carol and her husband persist with this type of intervention.

Laura talked about creating a social group for her child. Laura started a social group for kids with Autism, for her youngest son, and it continues to meet Friday
afternoons. Many of the same children are still participating. She reported, “They all have Autism so they have their own social issues, but at least he feels comfortable being around other kids and I think it has helped him.”

Alternative interventions have been pursued by some of the families. For the Robertses, an idea for treating the Autism came while Paul was watching an episode of *Extreme Eaters* on the Animal Planet network. As Paul recalled, the show was about an exotic bird that would eat toxic fruits and seeds and survive. The show further explained how the bird ate clay to neutralize the toxins in its body. Paul was inspired with an idea he explored after watching the show, and researched the potential effects of clay. An article suggested that clay baths would rid the body of years of toxins, so this intervention was implemented with the boys. Paul and Karen were amazed at the results after one bath, explaining how Taylor and Tommy started talking, stringing five words into sentences the next day. Eating issues also saw a dramatic change, as the boys began requesting foods they would never have eaten before. Changes were more subtle with Lee, but academic improvements were noticed and reflected on his report card at the end of the marking period.

Other interventions the Robertses have implemented with their boys include the administration of B6 vitamins, magnesium, and fish oil. Dimethylglycine (DMG), a metabolic enhancer, is another pill that is part of the boys’ alternative treatment regimen. The Robertses believe that their boys’ early vaccinations are the cause of their Autism, and their treatments are chosen by their effectiveness in treating, not only the symptoms, but the cause.
The Neals have also pursued alternative interventions with their boys. Patty spoke of the myriad of pills the boys have to take each day. At the time of the interview, all three of the Neal boys had been biomedically treated for about two years.

They see a pediatric neuro-developmental specialist knowledgeable about the DAN! (Defeat Autism Now) protocol. Hair, urine, blood, and stool samples are periodically done that show markers and create metabolic profiles that have indicated gut dysbiosis, fungal overgrowth, autoimmune disorder associated with strep, chronic viral infection, and heavy metal intoxication. A combination of diet rotation, exclusion of all gluten for 2 of them, over the counter supplements, and prescribed medicines have all improved the healing of their gut (no more GE Reflux), a healthy expansion of their diet to include adding new foods, reducing toxic metal overloads, and the diminishing of many observed symptoms of autism by also addressing autoimmune issues in their bodies.

Karen explained that, since she was Rh negative, she received Rogam shots while she was pregnant with the boys and after she delivered. She elaborated, “There were large amounts of mercury containing preservative themerasol in the Rogram shots for Rh negative moms.” Her boys also received vaccinations through the age of five. Karen’s treatment interventions are directly related to what she perceives as the causes of Autism in her children—the Rogam shots and the vaccinations.
Besides certain dietary restrictions for their boys, the Larsons mentioned that Farron started taking Depakote, a prescribed medication, after a pattern of concerning behaviors had been noticed at home and at school. Farron also receives craniosacral therapy, a non-invasive, hands-on treatment that seeks to restore the natural rhythmic movement between the bones of the skull. When asked her beliefs about the causes of Autism with her boys, Carol laughed, “We got a lot of weird people on both our sides.” Along with the genetic component, Carol believes that there are certain individuals who are more susceptible to environmental toxins, mentioning the rise in auto-immune disorders she and Frank have observed with friends and acquaintances.

Laura mentioned, when searching for reasons that might explain Aaron’s behaviors, the possibility of lead poisoning from living in an old house in London or from “walking around at exhaust pipe level” at a time when unleaded gas was not used. They had Aaron tested for heavy metal poisoning and the results came back negative. During the interview, Laura did not cite any other possible causes for the Autism in her children, and the interventions she discussed all had a therapy or educational base.

“We had people on our side guiding us to where we needed to be.” – Paul Roberts

A common, recurring theme in all of the parent interviews was the emphasis on individuals who helped each family at different times along the journey. Though some stories involved people who hindered more than helped, the bulk of people
references remained on those who were supportive and helped families find their footing to make next steps.

Several parents had friends involved in early diagnostic conversations. All who had this support, sought out the advice and insights of their friends, and perhaps, it was easier to begin to digest the reality of Autism when heard from those who are close and trusted. Specific school personnel and services providers were often mentioned by parents.

It was never the process but always the people that remained the focus and reason as to why a situation was progressing or regressing. Karen shared, “I felt like we had people on our side guiding us to where we needed to be.” Though not explicitly stated by the other parents, all made many references to individuals who made the difference.

Family & Relationships

“They turned their backs on us.” –Paul Roberts

The Robertses were dealt a traumatic blow when some family and friends refused to be involved in their lives because the children had Autism. Paul described the experience as a “rude awakening” when Karen’ brother and father indicated that they would not be involved with the family.

It was amazing because we had family that totally turned their backs on us. We had friends turn their backs on us...you get to a point where you’re so guarded. And you’re like, we can’t even set up a friendship or a relationship because we don’t even know if you’re going to accept our children.
Karen and Paul also recalled a time when they were at a party, about two months after Lee’s diagnosis. Lee was still having tantrums at the time, and he became upset in the playroom. It was also during a time when they thought that Taylor was also on the Autism spectrum but did not have verification yet. Karen told the story of a mother who asked if their children were Autistic. Karen confirmed and the mother “grabbed her kids and said, we cannot be in this room with you because this is contagious. We’ve got to get out of here.” These experiences caused the Robertses to ‘close their walls.’

Patty also reported that there were certain family members who simply did not understand the diagnosis.

That’s a very lonely place to be. Here they’re telling me this and they’re going, oh, they’re not right. You know what these kids need is a good spanking or something. It’s your parenting. You’re crappy parents, or the inference or whatever. It’s a big thing to be told that.

The impact of such rejection and admonition from family and friends was resounding for the Neal and Roberts families.

“You’re under this microscope. Everybody’s analyzing.” –Paul Roberts

Carol reported that her sister still has some reservations about the boys’ diagnoses and talked about her is uncomfortable telling others that her nephews have Autism, believing that the information is private. Carol offered her beliefs, stating, “That’s who they are, and I don’t want them to be ashamed of it.” Despite her sister’s opinion that such family matters are private, Carol pulls no punches in telling
others. A gentleman in the neighborhood once told Carol’s sister that the Larson house was ‘disenfranchised’. Though Carol and her sister remain uncertain as to the intended meaning behind the statement, there is an implied negative connotation.

The Roberts’ experienced a lack of understanding from family and friends, but they have received unsolicited criticisms from others as well. Paul felt the pressures and related the experience to being “under this microscope” where “everybody’s analyzing.” As with Patty, certain folks felt compelled to offer advice to the Roberts’.

It was amazing how many people had an opinion, how many people told us what we were doing wrong and what we needed to do. And it’s like, you know, we have a handle on this. You might want to read about it first. You might want to actually understand it before you give us advice.

Dealing with the insinuations, and sometimes outright accusations, that there was an error in mothering or parenting has been challenging for the several of the families. The impact on family and social relationships has had some damaging effects.

“It’s impossible to do it yourself if you have multiples.” –Patty Neal

A common thread for all four of the families has been the unity of their marital relationships with their partners, despite powerful stressors and sometimes overwhelming obstacles.

Patty and Robert had to divvy up responsibilities, because there was so much to manage and organize on a constant basis. Patty assumed primary responsibilities for attending IEP meetings and working with in-home and community services, while Robert continued to work seven nights a week to provide financial stability. Robert
has also played an integral role in helping with homework and serving as a sounding board for many decisions which Patty carries out. Of Robert, Patty stated, “I always bounce everything off of him because he’s fabulous. Every time I write an email to a teacher or anybody, he helps me word it.” The ability and desire to stay together was a passionate topic for Patty.

It’s impossible to do it yourself if you have multiples. Impossible. I think, for Robert and I, we’ve always had a good marriage. When this happened with the kids and we started going to the outside, the external world, for help with our children, it divided us in some ways but it strengthened us in others. It’s almost like maybe we were just stubborn. Or maybe there’s a lot of grace in our lives...you either have it or you don’t. And if you don’t, you better get it, because you will not survive.

Patty also talked about statistics related to the divorce rate for parents with children who have disabilities. She theorized, based on her experiences in her own life and through networking with other similar families, that parents of multiples have a higher rate of remaining together, simply because the job of raising the children cannot be done without the support of a partner.

The Robertses echoed Patty’s sentiment about the need to stay together. Though they admitted that they hit a rough spot this year and almost separated, accessing supports helped them realize that they needed to work it out. Karen talked about the recent challenges.
It’s been hard. And I guess you just have to know deep inside, do you want it or not? And I think you know that clearly, but it’s hard to reach it at times because you are just so consumed with other things that you do forget. But I knew I couldn’t leave because that’s not what these kids need. They need both parents to survive in this world, and you need your spouse to survive in this world. You can’t do it on your own.

The resounding theme with the Neals and the Robertses when it comes to their marriages and having multiples was that ‘you cannot do it on your own.’ Carol and Laura did not talk about their relationships with their spouses, but they are both still married to their children’s father. The absence of conversation about this topic does not imply a lack of significance. The topic was simply not initiated by two of the interviewees.

**School Experiences**

“We just didn’t have the energy to fight an entire methodology.” —Carol Larson

All the parents interviewed talked about school experiences, both positive and negative, but none of the parents talked about wanting a certain methodology for their children. Rather, the focus revolved more around having and being involved in choices for appropriate placements.

Though Carol and Frank actually moved to the area specifically for TEACCH methodology, Cory’s educational placements always included TEACCH strategies
because the resource is located in a nearby community. Hence, many of the local schools have adopted TEACCH methodology with students with Autism.

However, before coming to the area, Cory attended preschool and kindergarten in Virginia. When discussing the transition to the public school kindergarten, the preschool teacher told Carol, “Good luck. This is going to suck for you.” Carol went on to explain that the school system provided services around a total inclusion philosophy. The troubles ensued for Cory, who despite supports from an instructional assistant in the regular kindergarten classroom, experienced some pretty extreme difficulties in a class of 20-30 children in an open classroom concept. In fact, Cory went through nine aides, one per month, because “nobody could keep up with him.” Carol reported that Cory “basically became the class mascot, and some of the children really looked at him with disdain and aggression, even.”

In the full inclusion environment, supports for Cory were inadequate and ineffective.

Every single day he would be out in the hallways screaming and pounding on this big rubber banana they had to let his aggressions out. He’d go into the EC room. I mean it was ridiculous. The kid wasn’t learning anything. They would call me, trying to get me to pick him up. So I just didn’t answer the phone. And when I did, I’d say, from this time to this time, he’s your problem, not mine.

After that year, Carol and Frank moved the family to North Carolina. Carol confided, “And when we left, they said, you know, we’ve never had anybody this severe before
come through our system. And I said, you know, you better get ready, because they’re coming.” At the time, the special education world was relatively new to the Larsons, and they were unable to muster the energy to “fight an entire methodology,” referring to full inclusion.

“These children deserve better.” Patty Neal

Patty’s experiences with the public school system have been varied. She sang the praises of certain individuals who were instrumental in providing information or services and for those who served as advocates for the students. One experience that stood out was when the district moved the location of the separate Autism programs at the children’s base school to another school in the district. Patty, and the other impacted parents, were asked to visit the new school site. She remembered “the urine stained basement room” where the classes would be located and being unable to hold back her response of screaming and jumping up and down outside the school in protest. “These children deserve better,” Patty recalled saying. She insisted that Sam would not be attending that school. Instead, Sam remained at his base school and Patty advocated and received appropriate supports for her youngest.

Patty seems to have taken it all in stride. Even as Ian transitioned from elementary to middle school, the district did not notify her of where the Autism program would be for Ian until she received an email over the summer months. And despite a lost educational file, no teacher and no room to start the year in the new school, Patty could still reflect with humor on the experience. The Autism classroom
was eventually assigned a location. “They painted a trailer. Yeah, it’s the EC and the ESL students out in the trailer. Next door to each other. I was like, it’s ‘Shanty Town’!”

As the children become older, Patty’s advocacy foci tend to have shifted more heavily to academics, especially for Ian, her child who seems to struggle the most. She referred to Ian’s dysgraphia, dyslexia and ADHD as predominant contributors to his academic struggles.

At this point, his literacy is so crucial to his ever having a chance of doing anything he wants. He can still have the Autism and do anything. There’re a lot of interesting, socially not doing well, people who are brilliant and who could make tons of money designing computer programs and stuff. Ian’s last dream, his vision for himself is to be a video game designer.

The earlier struggles of battling placement issues for her children are hopefully in the distant past, but Patty expressed some concern about Ian’s coming transition to high school. With his academic struggles and the district’s past communication glitches concerning the provision of programs and supports, Patty does not leave anything to chance.

“All the big guns in place.” –Paul Roberts

Karen and Paul have also undergone a grab bag of both encouraging and disheartening experiences with the school system, mostly with Lee, their first born. Their first preschool experience with Lee was positive, until they were informed by the district that Lee would need to attend a different program at another school
because he no longer needed the level of support provided by the current preschool program. Paul explained, “He did so well that they said they couldn’t serve him. They wanted to put him in the inclusive classroom.” Not given a choice in the decisions about Lee’s placement, the Robertses chose to fight, as Paul stated, “That’s not how it works. There’s a placement meeting, IEP meeting, not just dictation. And that, unfortunately, set the tone of what kind of fighting we’re going to have to do.” The Robertses removed Lee from public pre-school to pursue other private options.

Eventually, they returned to the public school to complete Lee’s pre-school years, and the experience was positive. Karen and Paul were impressed with the pre-school and kindergarten teachers who ensured that Lee’s needs were met.

We had a great kindergarten teacher. She was outstanding. We loved her. The first grade teacher, that was such a different experience. It was really hard because the kindergarten teacher was open to everything. She came to our house and said, what can we do to make your situation better? How can we make his year better?

The first grade experience for Lee and the Roberts family was tainted with turmoil. The Roberts’ recall a first grade teacher who was hands-off with Lee, relegating him to the perimeter of instruction and classroom activity to work with an assistant in the room for much of the time. For a child who was fully included and mainstreamed in kindergarten, the Robertses were outraged by the first grade teacher who appeared to make limited attempts to include Lee in the classroom community. Karen remembered the teacher leaving Lee on the computer all day, and Paul talked about
the teacher “feeding the disability,” providing no redirection and destroying what independence had been established through pre-k and kindergarten.

A standout experience for the Robertses was when they received Lee’s report card for the first marking period. While no parent-teacher conferences had occurred up to this point in the year to discuss positives or concerns, Karen and Paul received a report card that reflected negative progress. A number system (1-3) was used for all the students to reflect below, at, or above grade performance. This teacher placed a negative symbol before all of Lee’s numbers. Paul shared that this information about Lee’s progress, or lack thereof, was in direct contradiction to what had been reported over the last two years. His recount of the story reflected some of the anger and shock from that experience.

I said, you know what, Karen, she’s setting us up. Trying to put us back into the separate classroom, AU (Autism) setting. In the beginning he kind of had a hard time adjusting, transitioning, and basically she said he was a behavioral kid. And we had to fight. After we got that report card, it just blew up.

For fear that Lee was being corralled into a more restrictive environment, after all the progress he had made, the Roberts’ contacted the State Department to report concerns. They also began having multiple meetings with representatives from the district’s central office in attendance. Paul said, “As soon as I had all my big guns in place, I had all my ammunition, they were just kissing my butt, so to speak.”
Parent expectations for Lee were high, and they were not going to allow school or district personnel to pigeon-hole their son into a placement that was not appropriate. The Roberts’ transitioned Lee to a different school for his second grade year and were pleased with the response to their son. Paul shared, “What a different school it was, because they’re so structured and organized and have a routine. They have the whole team.”

“I’ve always gotten more than I’ve asked for.”—Laura Thomas

Laura reflected on positive school experiences for her children. She talked about her advocacy for her children and how the relationships with school personnel were collaborative.

I’ve always gotten more than I asked for. I’ve always had a good relationship with the resource people and the LEA system, so I have no complaints about any of that. And whenever I’ve approached them, like what are we going to do about high school? What do I need to do? It has always been collaborative. I’ve always been welcomed. Whatever I want to do, nobody’s ever said, you’re crazy.

Aaron and Perry’s experiences in school, from pre-school to current grades, have been positive. Laura’s one regret was placing Perry in a demonstration preschool. She had figured that the small student to teacher ratio and the regular involvement of therapists and service providers would provide the delivery of best practices to enhance Perry’s early education. In retrospect, she stated that the lack of exposure to typical children may have hindered Perry’s growth and reinforced some bad
habits. Laura reported that “He was the only child that was verbal in the preschool.” To counteract the potential negative effects of this placement, Laura involved Perry in a couple of different regular pre-schools for a couple of hours a day each week.

In planning for kindergarten for Perry, the director at TEACCH had suggested that he be placed in a regular kindergarten classroom. Laura declared, “It just never occurred to us that the public schools could accommodate him.” Aaron was in a school that had Autism classrooms and support, but the level of intervention he needed was minimal. The Autism teachers were able to consult with the general education staff, and the special education resource teacher worked with Aaron when needed. Both Perry and Aaron’s strong academic skills facilitated their school success. Though Perry still receives consultation services, Aaron was exited from special education services in 9th grade and takes several advanced courses.

There was only one adverse educational situation that Laura recalled, an IEP meeting when Perry was in the 6th grade.

We had the big team thing. And it was after the transition, so he was already at this school. The speech therapist was there. And she said, I don’t remember how she put it, but it was something like, ‘Perry doesn’t have a language problem.’ And I said, ‘Well he can’t talk very much. I consider that a language problem.’ She says, ‘Well, you know, Autism is a communication problem.’ I said, ‘Language is part of communication.’ We have this like going around in circles and what it came down to, but she would not admit, is once they get past pronouncing their words correctly…
From Laura’s perspective, she did not feel that most speech therapists in the schools necessarily knew how to work with pragmatic speech needs for children with Autism, but she also did not assign blame. Instead, Laura addressed Perry’s needs through the social group she developed. Since she realized that the speech therapist was not going to be able to help her son, Laura agreed with the dismissal from speech, bothered more by the approach of the therapist than the actual decision. Laura divulged how she was feeling at the time, “If you’re going to approach my child with this kind of an attitude, I’d rather you didn’t work with him.”

“There are always people who whine and moan.” –Carol Larson

Despite being faced with different levels of adversity with their children’s schooling, all the parents told stories about how they trudged forward, determined to provide what their children needed and deserved. They were all thankful for the positive experiences, and there were more of those than the negative ones. Carol put things in perspective, stating, “There are still people who gripe, because there are people who just whine and whine and whine. But I don’t see them doing anything about it.” Whether it is preparing to fight by dusting off the big guns, getting involved in school and district decisions, politicking, or gently collaborating, all the parents interviewed developed strategies to use when they met adversity.

Carol became involved in a Special Needs Advisory Council (SNAC) which provides parental representation at each school. Student transition needs from high school are a current focus of the group. Additionally, she and her husband have learned to collaborate with school personnel in order to obtain information and to
help mold the direction of upcoming IEP meetings. They talk with folks outside the meetings, addressing goals and other IEP items before scheduled meetings. Frank said, “We convince the underlings before the meeting what needs to be done” and they “play the game.” Carol talked about another strategy that has been successful for the Larsons.

If you go and present it in such a way that’s not adversarial and you basically come across in a way that is really saying, ‘Let’s help Cory. I want you to help my child. I need your help. I think people take you differently. It’s a lot different than saying, ‘I want you to do this, this, and that. Cory really needs this. I can see such a benefit he gets from this and I know that you’re the person who can do this for him. And that just goes so much farther. It’s nicely asking somebody to help my child.

Similarly, Patty makes all attempts to work with school personnel. She has taken well-prepared information and has helped to facilitate meetings. On occasion, she has equipped the IEP teams with fresh coffee and snacks for the meetings. But Patty has also climbed the hierarchical ladder to share her thoughts and wishes with school board members, the superintendent and other central office players. For one board meeting, Patty and a group of parents had prepared a booklet summarizing Autism research and resources and provided each administrator and board member with a copy. After experiencing her own difficulties finding resources and direction when her own children were identified, Patty wondered, “Who’s giving these parents
a flashlight?”. Putting procedures and resources in place would help other parents to avoid some of the struggles she faced.

Patty has had numerous meetings with the district Exceptional Children’s Program Director and other high-ranking school officials to advocate, not only for the needs of her children, but for all students with Autism.

Advocacy is now embedded in Patty’s being. She created a brochure to “sell” Ian during a transition to middle school meeting, and she has developed other materials over the years to help others understand her children. Laura has done the same for her youngest, starting when he was in the third grade.

I made a book for Perry first about his Autism. The first year, we just shared his little book that I wrote for him. Then the next year we did that. Then in 5th grade, we shared it with all the 5th graders in school because they were all going to go to middle school together. So we figured, the more kids that knew why he was weird, the better off he would be.

Carol also remembered talking to Cory’s classmates when he was younger, attempting to educate them about Cory and his Autism.

Parents were not apologetic about their advocacy or confrontations with the schools. Rather, they tended to focus on the proactive strategies instead of situations where they had to be reactive. Laura described herself as, “kind of pushy. I mean, I don’t think I’m one of those moms that they cringe when they see her, but they know who I am. And I think, for the most part, it’s been a very positive thing.”
School Administration

“She wanted to find out anything and everything about Autism.” Patty Neal

When reflecting on their children’s school experiences, parents tended to be more focused on personnel directly involved with their children. Though principals must assume responsibility for all occurrences and practices in their buildings, these parents were not critical. In fact, empathy, more than any other emotion, seemed to be expressed by parents.

When a new principal started at her children’s elementary school, Patty made an appointment with her to talk about her children and Autism. The principal not only listened attentively, but she followed up the meeting with a phone call to TEACCH to seek more information for understanding. Patty beamed when she reported, “She wanted to find out anything and everything about Autism.” This was a novel approach by a principal, from Patty’s experiences, as she was normally the person who had to provide information and to encourage understanding.

The new principal reached out in ways that made a difference to Patty. An avid knitter, Patty began a knitting group at her children’s school. The principal joined the group.

She would knit after school because she needed it, and I needed it. Also, she’s a faith-filled woman. She’s a woman who has faith. Not that that’s a requirement to do a good job, but I think somebody who believes in something, anything, will help.
For Patty, certain special education facilitators, individuals who assist with organizing and managing IEP meetings, were most helpful with the IEP processes. She defined them as “the glue between your school site and downtown.”

“It’s a tough job. I wouldn’t want to do it.”—Carol Larson

Patty, like several other parents interviewed, did not necessarily expect principals to attend their IEP meetings. Understanding the demands of the job, Patty acknowledged, “I don’t think a principal has time to go to all the IEP meetings…not unless there’s something extra that has to be asked for.” Empathically, she also shared, “I can’t imagine what it would be like to be a principal.”

Despite some of the adversity that arises when there are clashes between opposing parent and school expectations, there was a pervasive understanding of the administrative role. Referring the district’s special education director, Carol confided:

I know people will criticize her. I had my share of moments where I didn’t think she was all that swift, but at the same time, she’s holding the purse strings and she has to allocate resources to a lot of needy people who want the best for their kids.

Carol, like all of the other parents, did not seem to harbor any resentment for administrators, knowing that they are the ultimate decision makers within the buildings and the district. There was an appreciation for the work with which administrators are faced. “You know, it’s a tough job. I wouldn’t want to do it”, Carol articulated.
Parents did not express concern about principals not attending many of the meetings; there was an acceptance that the principal’s role was bigger than issues related just to special education. Paul said of one principal, “He focuses on the main issues of the school.” The Robertses also pinpointed the special education facilitator as a key player whose job it is to focus on exceptional children issues and lead the team.

“Unless they know what they’re dealing with…”—Patty Neal

Based on their educational experiences with their children, some of the parents offered some suggestions for school personnel.

Professional development is crucial in Patty’s eyes. Over the course of her children’s educational careers, Patty has frequently asked for all administrators and general education staff to be Autism trained. Her advocacy in this arena is strong and persistent.

When I’m looking at Autism compared to other categories for eligibility, I will tell you that Autism is a different animal. It’s a very nebulous kind of thing, but it is a pervasive developmental disorder and because of that it affects every single area of an individual’s life. It’s also a really, really broad spectrum. That’s what makes it so nebulous. We’re also dealing with two gauges. You have an Autism gauge and you have a cognitive gauge. And anybody can be on those two gauges, anywhere—the same person.

School personnel who better understand the complexity of Autism will be better prepared to work with students and families, according to Patty. The pervasive
effects of the disability impact families in a broad way. Planning for services and an inclusive model cannot be feasibly accomplished “unless they know what they’re dealing with,” Patty professes. This requires “thinking outside of the box” for some students, as long as it is appropriate.

Carol’s suggestions focused more on transitional issues for students with Autism. Inadequacies with Vocational Rehabilitation services, coupled with insufficient resources and planning by the public schools, leaves many students like Cory at a disadvantage when it is time to leave high school. Options for students with more severe needs seem limited post high school, according to Carol.

You have this little kid and he’s so cute and he needs help with speech and he needs—you know, you’ve got teachers and it’s easy to just totally gravitate towards and help these kids along, but all of a sudden they become awkward teenagers—some of them ugly and some of them with more problems—emotional and all that. And then they’re off and nobody seems to know just off to where.

Providing more residential and supported living options for individuals like Cory is an area of much needed attention, according to Carol. She continues to work with the school system to make advances in this area.

Though both of Laura’s children are high functioning, academically and cognitively, she knows they will need support to transition to the next level and to the workforce. Since both boys have required little support from school, with most of the supports coming from home, Laura knows that there will not be many services
available to them. She has some concerns for Aaron adjusting to dorm living in college, but the bulk of her concerns lie with her youngest, Perry.

So I am a little more concerned for his future in terms of him being independent. But, I think we kind of decided a long time ago that Perry is going to be with us a while. And not that he isn’t going to ever be capable of living on his own, but I just, he’s so immature. It’s going to take longer.

Expanding transition services and options for a wider range of students with Autism, as they matriculate from high school is one of Laura’s hopes.

**Coping & Stress**

*“You could just go crazy being angry all the time.”—Patty Neal*

The frequency and intensity of stressors with multiple Autism families can be paramount to the daily functioning of the family, but all parents talked about coping strategies they used to deal with the pressures. Strategies, all agreed, were essential to individual survival and the perpetuation of the family as a healthy unit.

For Patty, talking with her husband about shared responsibility was a key strategy. They could not both go to all the meetings and appointments, work, and maintain the family, so they agreed who would have primary responsibilities in each arena. She also “did nothing but eat, breathe, and sleep Autism” at first because she “had to”. She immersed herself in Autism to learn and to develop a plan, stating, “That’s how I personally deal. Other people deal in different ways. For me to remain functional, I have to have a plan. It’s a control issue.” Knowledge was power, and Patty tried to get as much as possible.
Maintaining a sense of humor through it all also helped Patty cope. “You could just go crazy being angry all the time,” Patty revealed.

Carol and Frank find comfort in spending time with friends, going out regularly to socialize. “It’s a good thing. I know some people who get totally in to the whole Autism world. All their friends are only people whose children have Autism.” Creating momentary chasms between the pervasiveness of the Autism world and social and personal life is also important to Laura. She started running when the boys were younger, starting with small races and working up to marathons.

That’s something that gives me goals, personal goals, things to, you know, I can’t go back to school with the kids. I needed something that was short term, goals that I could meet.

Her book club is also important to Laura and provides an opportunity for her to “let her hair down.” Spending time with parents who have typical children is also important to Linda, and the book club provides that sanctuary for her.

There are people who are different from me and they don’t have children with disabilities, and I think it’s important. Because it seems like when you have a child with problems, you tend to gravitate towards other, that you find each other.

Laura also admits that seeking a reprieve from the Autism world is a change that has occurred over time. When she was first introduced to Autism through her children’s diagnoses, Laura actively sought out parents in similar situations. She would follow any lead, just to talk to others who could relate and to find out more information.
“We’re on an island here, all by ourselves.” Paul Roberts

The Roberts’ coping began when they were rejected by family and friends who were ignorant and fearful of their boys’ Autism. They felt isolated and left to deal with everything on their own. Eventually, the couple sought therapy to deal with stressors that were tearing the family apart. Even when their youngest child escaped the Autism label and they found a peaceful and collaborative school environment for Lee, they were at a loss. “You’re so used to fighting, so used to being guarded, and it’s like how do you take a step back and relax?” Paul explained.

When Lee was first diagnosed, Karen and Paul made some clear decisions. To provide financially and maintain benefits, Paul was to continue working and the kids became the focus, to the detriment of their marriage. “Karen and I made the decision, the kids are the focus. Everything else is second. Our marriage was second, and that caused a problem this year”, Paul stated. Working overtime to pay for the bills and the therapies and needed supports while Karen was absorbed with managing the two calendars and household activities set the couple in different directions with massive negative impacts on the children.

Problems with his health and a slowly crumbling family unit drove Paul to seek help from a doctor. Prescribed medicine helped him to start sleeping, eating, and feeling better. The rest of the family’s health also began to follow suit. Religion was also a significant factor in getting Paul back to where he needed to be, mentally and spiritually.
What brought me out of the first round of depression, or whatever you want to call it, is I had to get back in touch with Jesus. I had to get back in touch with my religion. I couldn’t do it myself. I keep telling myself that God has a plan for us, and I have to work His plan. It’s in His hands. I’m not in control. And that takes a lot of pressure off.

The stressors of parenting multiple children with Autism were unavoidable for these families, and they all employ different coping strategies, many of which have changed over time. Carol expressed concern, saying, “You’ve got some parents who are pretty devastated. I’ve had some friends who have suffered some pretty severe depression and they’re having to take pills for it.”

All of the parents have had, or currently have, some involvement in Autism support or advocacy groups. For Karen and Paul, their participation changed over time, as the boys grew and continued to make progress. The division between the Roberts boys’ cognition and adaptive skills and other children in the support group widened over time, leaving Karen and Paul with a decision to make. Ensuring their sons’ exposure to typically developing peers was important for the Robertses. Paul talked about the difficulty, but the reasons for, leaving a group that has shown so much support for the family, especially during their initial entrance into the world of Autism.

You don’t want to leave it, but unfortunately you have to because that’s the direction we’re going. We’re trying to get them to model regular kids, regular
peers. It's heartbreaking because you gotta leave one group to go to another group.

The Robertses also became disconnected with the support group, because they perceived conversations to be repetitively negative.

As parents, you've heard all the negatives before. Once you knew you entered the Autism world, you were already hit with 50 negatives. So you are trying to dig really hard to find the positive in all this mess. It would make me sick at times, because I was thinking, Paul, is this the best it's going to get, because look at so and so. And I know our kids can do better. So, you kind of get caught.

Seeking a more positive, proactive direction for their family as they faced the challenges of Autism prompted Karen and Paul to distance themselves from the support group.

Outcomes & Celebrations

“You start seeing the world differently.” Carol Larson

The resiliency of the families is astounding, despite the challenges with personal and social relationships, advocacy, stressors and coping, accessing services, and navigating educational processes. Perhaps the resiliency exists because of these things rather than in spite of them. All parents did not hesitate to recall positive outcomes and blessings they have derived from their experiences in multiple incidence Autism families.
Carol readily offers that she has learned to be a lot more patient and tolerant of other people. She recalled a recent experience when she and her husband were out with friends.

There was a lady who started talking to me and she was just really drunk. She started complaining about her kids. Well, her husband is a Ph.D. and she’s like, ‘Why can’t my kids be Ph.Ds?’ I guess one of the sons is a welder and the other guy is a cook or something. And so I said, ‘Well, I happen to have two boys with Autism. I’d be thrilled if one of mine could do that. Stuff like that really gets to me. I think I can count my blessings more than other people can.

The ability and desire to pay more attention to the world around her is another outcome for Carol. She has a keen sensibility for a wide range of individuals and groups who are disadvantaged or misunderstood. Insightfully she offered, “You start seeing the world differently, I think. You start being a little more tolerant towards people and not so tolerant towards other people.”

“What other families might take for granted, gives us so much to celebrate.”—Patty Neal

Celebrations were common to all the families interviewed. When their children found success, in whatever arena and to whichever degree, the parents took time to recognize the magnitude and to celebrate.
When challenges are met, goals are mastered or something is learned, they take time to rejoice. In Patty’s family, they capitalize on opportunities to acknowledge accomplishments.

What other families might take for granted…gives us so much to celebrate. Sam said this word and we broke out the ginger ale and made long distance phone calls to all the family members. Where something that is so difficult for a child to do naturally, when the child does do it. It’s just so huge, the celebration and the gratitude and the thankfulness, the feeling of joy. When somebody does something that other families just take for granted, that’s a biggie for Robert and I.

For Cory to sit through an entire movie at a theater is a cause for celebration for the Larsons. When this occurred for the first time, Carol and Frank were excited, actually applauding Cory at the end of the movie. “He actually made it!” Carol said. “You go to a movie with your kid. You go to countless movies with your kids. What’s the big deal? You go to a movie with Cory, he actually sits through it.” Most parents, in Carol’s opinion, would take this success for granted, not understanding the implications for a child like Cory.

With both of her children identified with Autism, Laura frames her situation as beneficial. She said, “I’m sure my life would be very different if had another child who was typically developing.” Laura elaborated, “But then on the other hand, it’s kind of good having both of them with disabilities because the one, the normal one, which
there isn’t one, doesn’t feel like oh, I’m gonna have to take care of the other.”

Normalcy, for this parent, is having two boys with Autism, and it works.

The richly descriptive data from parents provided stories from multiple angles, detailing how the pervasiveness of Autism saturates all aspects of their lives, often in profound ways. Data from administrative interviews allow insights into how school administrators have experienced working with multiple incidence families. Their backgrounds, interactions with families and students, special education leadership, strategies for creating an environment of acceptance, and thoughts on administrative preparation contribute to a better understanding of the administrative perspective.

**Administrative Interviews**

**Administrator Backgrounds & Autism Experiences**

Mr. Cook began his career in education as a middle school teacher before becoming a teacher at the high school level. His administrative experience began with an appointment as an assistant principal at a middle school. Mr. Cook’s first principalship was at an elementary, next at a middle school, and currently he is in the role of high school principal at Standish High School, a rural grade 9-12 public school with an enrollment of approximately 1650. Mr. Cook’s administrative experience with Autism spans the levels of his different assignments. When he was principal at the elementary school, there were two self contained Autism programs located in the building. Students with Autism from the district would be assigned to these classrooms, based on their needs for a more restrictive and specialized program. The middle school and his current high school both have high-functioning
Autism classrooms, designed as resource supports for students whose instructional
time is mostly in the general education setting.

Mr. Cook’s experiences with Autism families at the elementary school
prepared him for interactions at the middle school, where there were numerous
students with high-functioning Autism in the general student population. Since all of
his administrative experience has been within the same school district, Mr. Cook has
been able to work with many of the same families as their children have advanced
through the grades. Some of the students who attended the elementary at which he
was principal later came through his high school.

Reflecting on some of the families with whom he has worked, Mr. Cook
recalled one family with two children identified with Autism. The girl, according to Mr.
Cook:

Came in very high functioning, very intelligent, but also had all the oddities
that go along with Autism. They were exaggerated in her. And it took a month
or so for the kids here to really accept her. But when they did, she thrived.

In the afternoons, Mr. Cook often was witness to the frustrations that built up over
the course of the day with the student. On several occasions, she attacked her
mother in the parking lot during pick-up. Mr. Cook reported that the girl was a
National Merit Scholar, graduated and is now attending a college designed to
accommodate students with Autism.

Dr. Duncan’s career in education began as a history teacher at the high
school level. Through her training, she received a bachelor’s degree in history, a
master’s in American Studies, and a doctorate in Educational Administration. She also has the unique experience of having served as a school board member for the school system with which she currently works, before receiving the appointment as principal of Spring Valley elementary school. At the time of the interview, it was Dr. Duncan’s fourth year at her current assignment.

Spring Valley’s enrollment is approximately 750 students and there is a significant population of students diagnosed with high-functioning Autism and Asperger’s Disorder, and others who are identified “on the broader spectrum of high functioning.” There were two self-contained classes for students with Autism the year before Dr. Duncan came to Spring Valley.

Dr. Duncan’s greatest challenges in dealing with Autism families at Spring Valley has included attempts at “providing a traditional regular education program” along with a “pull-out setting for EC services” to meet the requests of certain parents who seem to want the entire continuum services to provided at Spring Valley. Dr. Duncan stated, “Without any sort of self-contained setting here, it has been really interesting to watch those two settings within one work for individual kids with Autism.”

Before becoming principal at Chadwick Middle School, her current assignment, Dr. Wagner was assistant principal at the middle and high school levels. Classroom experience involved being a middle school language arts and social studies teacher. Dr. Wagner has been at Chadwick, a school with an enrollment of over 1,000 students, for about 4 ½ years.
Chadwick houses a high-functioning Autism classroom for students in grades 6-8 across the district. Similar to Mr. Cook’s high school program, Dr. Wagner’s program is designed to be a resource for students whose days are spent mostly in the regular education setting. Under the direction of the Autism teacher, a couple of teacher assistants are also used to help students with transition needs, coping strategies, and instructional supports when needed.

Dr. Wagner talked about the status of the program when she arrived at Chadwick. Eligibility criteria for assignment to the classroom was not clearly defined by the district, so students who needed more intensive supports were placed in the program, requiring a great deal more time and energy from the teacher and assistants. Dr. Wagner stated that the class eventually morphed into more of a self-contained program than a resource for students who required limited support. The program’s reputation and strong teacher resulted in a blurring of the boundaries for placement decisions. When the teacher retired, the boundaries were redefined; some students were moved to placements in other schools, some went to a different separate program at Chadwick, and some remained placed in the high-functioning classroom.

Ms. Barbour started off in education as a teacher at the elementary level before choosing the field of special education for a focal change. She served as an assistant principal at a middle school before becoming principal at an elementary school. Eventually returning to a position that would tap more directly into her special education interests and knowledge base, Ms. Barbour was appointed as Executive
Director for Special Education for the district. Her current position is with the state department of education where she leads state teams to provide support to identified struggling schools throughout the state.

Ms. Barbour's experience in working with families of children with Autism is varied. As principal of the elementary school, she was responsible for two self-contained Autism programs in her building. As the executive director at the district level, Ms. Barbour worked with all of the programs and parents with identified children across the continuum of service delivery. Currently, her role takes on more of a consultative nature with the public schools, so her special education background and experiences will be beneficial, but there are no direct responsibilities or involvement with programs and students.

**Parents: Characteristics & Observations**

When talking about the parents of one of his identified students, Mr. Cook described them as “everyday normal Standish High School people out in this community” that struggled with making sense of and dealing with the social issues related to their children’s Autism. The parents were “totally perplexed as to what to do.” Mr. Cook suggested that some of the some of the parents’ difficulties coping could have been due to their own issues. He suggested that “both parents also have strong Autistic tendencies. So, it’s in the entire family.” In his experience, Mr. Cook has seen many cases in which the parents seem to have similar communication and social difficulties as their children with Autism. “We’ve had several situations where
the parents, because they’re very defensive in many cases. Not really, I think
overprotective maybe instead of defensive.”

Stories and memories of individual students and particular families was
common to all principals. Mr. Cook revealed, “You deal with some peculiar folks
when you see these families and a lot of families that have multiple incidences of
Autism.” He recalled one family that was visiting the area. While in town, the parents
perceived that their Autistic child no longer exhibited severe tendencies, so the
family concluded that the ‘cure’ was related to ‘something in the air.’ As a result, the
parents sold their belongings and moved to the area. Mr. Cook worked with the
family when he was principal at the elementary school. The parents confided in Mr.
Cook that they believed “with all their heart that when he reached puberty, that it
would be over, that all of this would go away.”

Mr. Cook also recalled a young mother who had a son with Autism who
pursued an alternative treatment.

She would go and spend two nights over there on the weekends, and it was
expensive. She would go and sleep in that thing with him. She was kind of
claustrophobic and it would freak her out, but she would do it for her son. And
they would sleep in this thing, and supposedly he would get better for a short
period of time.

Mr. Cook briefly mentioned kelation as an alternative treatment, too, with some
families. “it’s a bizarre disease or condition,” he said.
Dr. Duncan shared insights about characteristics unique to multiple incidence Autism families, based on her experiences working with one family in particular. After thoughtful contemplation, Dr. Duncan talked about what she felt may be differences between a family who may have a typically developing child and a child with Autism as opposed to a family in which all the children are identified with Autism.

I think, in a sense, there is actually a greater sense of grief in a family where one child has a diagnosis and another does not, because that family can see the gulf between a child who must cope with Autism and one who does not. And, in the family to which I was referring a moment ago, in which there are three students, three children with that diagnosis, I think that is the norm for that family. Clearly there’s grief in the sense of knowing the challenges that face those children, but I think because they’re all in the same boat, the parental experience was really quite different and there was a greater level of acceptance up front.

Insights on how families differ in their emotional reception of initial diagnoses were also shared by Dr. Duncan. As an elementary principal, Dr. Duncan has had multiple experiences with early identification through the school system. “There’s almost no center position. I think parents are either relieved to obtain, privately, a diagnosis of Autism, so now they have an explanation of behaviors that they have seen for years,” she shared. There is a range of parental responses, based on Dr. Duncan’s observations.
With Autism, I think it dawns on families slowly because, as you know, most of us raise children somewhat in isolation and we don’t know what’s typical. You could read books, but if you don’t have a wide spectrum of kids your child’s age to compare you child with, you don’t know if it’s a phase or if this behavior is something that’s going to be lifelong. And so, I think for most people, it’s a gradual acknowledgement that something is not the norm with their child. Either the diagnosis is relief or it’s a source of grief.

Dealing with a diagnosis for the first time is very difficult for parents, Dr. Duncan reflected. However, according to Dr. Duncan, diagnoses that are provided when children are so young can also be viewed as “more malleable than if you were dealing with an 18 year old and you got the same information at that point in that child’s life.” Perhaps the hope that Autism diagnoses may have some pliability for young children impacts how parents receive and deal with the information, Dr. Duncan considered.

Being charged with sharing initial evaluation results with parents is not an uncommon experience for Dr. Duncan, but how it is handled is critical. She thinks, “the approach, generally, is the same. Once you know which of those camps the parents are in, in terms of their reaction, then you know whether to, you know how to respond emotionally better to them or to offer the type of support they need.”

Dr. Wagner observed that Autism parents’ communication with the school can be sporadic. She indicated that, “They can be turned off for months, and then all of a sudden get worked up over an issue.” Overall, the parents tend to be more involved,
communicate more, and express their desires for their children more than other special needs students or the general population, according to this principal.

An increase in the number of diagnoses and references in the media makes Autism “kind of a buzz word,” at least in this geographic region, according to Wagner. In her estimation, some parents may rely on the label or diagnosis to explain their child’s behaviors.

It becomes a reason why my child is doing this. So, it’s an answer to a problem. And so they all of a sudden have an answer to something, even if it’s not the real, right answer. My child has been misbehaving or doesn’t socialize well, or I’ve been having trouble with whatever piece of the puzzle and now I have an answer for it.

As did Mr. Cook, Dr. Wagner believes that many parents of children with Autism have autistic tendencies. She sometimes sees “communication problems…the impulsivity or the compulsive, routine kinds of pieces of Autistic children” in the parents of identified students.

Dr. Wagner recalled one parent who “would hear things that were simply not said” due to “her own processing.” Recording the audio of the conference was a strategy for both parties, to help clarify and recall information that was shared.

Even at the middle school, Dr. Wagner and her team have been involved in evaluating and initial diagnoses, whether through the school or delivered by a private agency. For higher functioning students who may have been successful in elementary school, middle school and the advent of adolescence poses different
challenges and expectations which may result in academic, organizational or social struggles which become more apparent.

Dr. Wagner has not had to deal with parent requests for specific methodologies, mostly because of the nature of the high-functioning program as a resource. Parents have requested more assistance with organization, for example, but “they’re pretty basic needs”, according to Dr. Wagner. Several parents have asked for certain reading programs, Dr. Wagner shared, recalling one vocal parent who involved an advocate.

Parents of students with Autism are very vocal and demonstrate strong advocacy for their children, Dr. Wagner purported. They are often very knowledgeable about special education policies and procedures.

Parents of children with Autism appear to be very passionate for their children, according to Ms. Barbour, “at a different level than parents of children with other disabilities.” She suggests that one reason for this heightened passion and interest may be partially due to the nebulousness of the disability. Parents may also be compelled to seek as much information as possible on their own, because what is handed to them is often limited in scope. Ms. Barbour also felt that these parents tend to seek others in similar situations as they look for commonness.

Ms. Barbour shared a story of a mother with whom she worked when she was at the central office. The daughter’s difficulties began with sensory and OT issues, and later she was diagnosed with Autism. Through collaborating with the mother and having open conversations to problem-solve, Ms. Barbour and the parent were able
to identify struggles with the younger son, pursue an evaluation, and access early intervention due to similar concerns. The parent, who eventually had multiple children identified, was able to use information and experiences from her first born’s situation to intervene earlier with the second child.

**An Environment of Acceptance**

Mr. Cook expressed pride when talking about the High-Functioning Autism program at his school. “I asked for the program to be here. Just, I love it. You know, it’s a great bunch of kids, and we have had great success with them,” Mr. Cook asserted. He describes the classroom as beautiful and “very active” and conveys a strong show of support for the teacher and the assistants who work with the students.

Being ‘open’ and ‘transparent’ about what they are doing in the classroom has helped develop an environment of trust with parents. “We have the best and they’re gonna get the best while they’re here. And I think our parents really feel that,” says Mr. Cook. Making efforts to be “overly accepting” with parents has been a successful strategy at Standish.

There have been some situations in which Mr. Cook has had specific methodology requests from parents, but they have been limited. He talked about the importance of being proactive and transparent with plans. “We stay pretty much on the cutting edge,” he offered. At the time of the interview, Mr. Cook reported that there was a group who wanted to come into the school to provide music therapy. Understanding the potential benefit for some students, Mr. Cook said, “It’s a good
way to draw them out.” The problem involved planning the delivery of the therapy during the school day while ensuring that the students maintained their core classes.

Creating a welcoming environment that involves parents is important to Mr. Cook. In fact, when they were recruiting and interviewing for the Autism teacher position a couple of years ago, Mr. Cook invited several of the parents to meet and speak with the candidates. Though the final decision on final hiring was Mr. Cook’s, he seized an opportunity to fortify a partnership with parents and to access their knowledge and perceptions. “They certainly have great questions. They know it better than anyone else”, he believes.

Dr. Duncan’s understanding parents results in an environment that is respectful of parents and families. She did not hesitate to reveal that she is parent-friendly and in touch with the struggles experienced by many of the parents of children with Autism.

No parent knows where their child is going, but when you’re the parent of an Autistic child, that ignorance is even greater, because you don’t know what your child is going to be able to do and what kind of support he’ll need and what it is going to mean for you or your lifetime. And if you’re not here, who's going to help and just how independent your child’s going to be. It’s just magnified from the parent of a typically developing kid.

To support the varied needs of parents, Dr. Duncan’s chief approach is to simply listen and plan the most effective delivery of educational services possible and make revisions to the plan when needed by following the lead of the child. She recognizes
that the expressed anger or grief is “not the point”, but “that's an expression of their concern for what their child needs.”

Listening and learning are important for Dr. Duncan, and she expects this from her staff. She cautions her teachers about being defensive about their practice and spending more energy constructing retorts to parent comments than on listening and gaining knowledge. Dr. Duncan expects teachers to:

Enter a conference to actually learn something from a parent, even though you may be the educational expert in the situation, you can gain insight about your student from very anecdotal things that the parent will share. So you need to have your antennae up for those. And when you hear those, then you've just gained something that may make you more effective in working with that child.

Parents are often seeing the same things at home, probably even more acutely than teachers observe in the classroom, says Dr. Duncan. Teachers who can “learn something they didn't know before they walked in there” are better equipped to help the students and to mold positive working relationships with families.

Having students with Autism in her building has been a learning experience for the entire school community. Dr. Duncan felt that, when strategies are working and parents and teachers are working in concert and when identified students are comfortable for what has been put in place for them, the typically developing children benefit, as well. For those students “to see that there are kids whose gifts differ from
their own and who struggle with things they may not struggle with, I think all around, it’s very humanizing,” Dr. Duncan affirmed.

Fostering a culture that recognizes and understands that all children have different needs, regardless of disability, socioeconomic status or any other factor, is one strategy that promotes positive relationships and trust between parents and school staff at Chadwick. Dr. Wagner asserted,

You have to meet them where they are and bring them along. From a value system as a school, you have to create that atmosphere that we love all kids, we want all kids to learn. We want no special need, whatever it is, to get in the way of their education.

IEP meetings are another opportunity for Dr. Wagner and her staff to show parents they and their children are valued. The team tries to be “warmer” and “solution-oriented” by placing value on parent concerns and avoiding the negation of frustrations. “It’s more like an attitude than actual typical procedure”, Dr. Wagner claimed.

**Leadership for Special Education**

Standish High School has not had Autism-specific training for the faculty. Professional development in this area is handled more on an as-needed basis. The Autism teacher will approach Mr. Cook about certain programs and workshops, and Mr. Cook says that he “can usually provide the assistance to get her to those programs.” The teacher collaborates with general education to address individual student needs.
Mr. Cook talks about “laying down expectations” to the student body about tolerance and understanding for students with differences. During national Autism week each year, the school paper publishes articles about Autism during this time. Educating the student body is important to Mr. Cook and his staff “because we do have a number of kids that are a little, they’re different. And our kids just see them that way and they embrace them.”

Like many principals, charged with managing and leading all aspects of the school, Mr. Cook does not participate in all IEP meetings, but there are certain meetings he does attend.

I have a facilitator and I have some assistant principals that do a lot of those, but if there’s a contentious issue, a lot of IEPs with the Autistic kids, I’ll go into those meetings because I know the parents and I have taken a special interest in them.

Mr. Cook acknowledges and embraces his ultimate responsibility for all of the meetings, consequently stating, “You better believe I’m involved.”

When it comes to helping parents access resources in the community, Mr. Cook notices a difference in willingness to take advantage of existing resources based on the socio-economic status of the family.

I think if you have parents that are in touch and have resources and good jobs and money, those parents know about those things. It’s when you have a parent that lives in the projects and lives in a situation where there’s not much money around. It really depends on the level of economics for the family. It’s
really difficult with families you try to offer assistance to and they don’t see the connection with what they’re going to need once they’re out of here.

While the area is rich in resources for families with Autism, only certain families seem to either have the desire or ability to seek out and access such supports, according to Mr. Cook.

His passion for ensuring that students with special needs are properly taken care of, along with his desire to remain out of “trouble” from procedural violations and wanting things “done correctly” inspires Mr. Cook to run his “whole school around a couple of issues or scenarios…one being that group of kids that are EC.” Mr. Cook ensures that students with special needs are scheduled first and that “all the procedures consider EC first.”

At Spring Valley, with a high incidence of students with Autism, professional development is predominantly addressed with individual teachers who work with identified children in the classroom. Dr. Duncan feels that she has a strong EC staff that is good at communicating with classroom teachers and providing, sometimes demonstrating, strategies within the classroom environment. The principal shared that they have had “smatterings of whole faculty information about Autism” but they have not engaged in “an in-depth book study or in-service on Autism itself.”

When asked what, if anything, could or should be done to improve faculty knowledge and skills in working with students with Autism, Dr. Duncan admitted that she did not have that answer. Rather, she felt that the question would need to be
addressed to the faculty to see if they felt they had sufficient support or if they needed more information or training.

One practice Dr. Duncan believes is critical to the students’ success is to include special area teachers (i.e., art, music, p.e., science) in instructional planning so these teachers are familiar with needed modifications or accommodations. Special classes can pose either significant challenges or they can serve as a stage to highlight student strengths or interests. Dr. Duncan provided an example, “Music can be an Autistic child’s most dreaded special area because of all the sounds and everything that there is to process. Or in other cases, it can be the child’s most cherished part of the week.” Individualizing and including key players provides strategies for the child to cope and succeed.

Dr. Duncan also takes careful steps when considering scheduling for students with Autism, attempting to balance the amount of time a child spends in one location for services and the number of transitions during a given day. Flexibility is also key. Dr. Duncan commented, “Sometimes you put something in place and then you follow the lead of the child, and if it doesn’t work, you realize you’re too tight or you’re too loose.” The child’s response to the intervention or support dictates the details of the plan for that child.

IEP meetings and conferences with parents consume much of Dr. Duncan’s time. She always attends at the request of a parent, teacher, or counselor. Sometimes, Dr. Duncan asks to attend if she notices that the schedule involves a
parent with whom she has had a recent conversation or a student with whom she has had recent or on-going involvement. She sees her involvement as “fluid”.

To face, head on, the challenges of parents who demand a wide continuum of services within the Spring Valley environment, Dr. Duncan takes a personal interest in each child and family case. On occasion, parent requests are not appropriate, and the educational team may feel that the child needs a more specialized placement that may exist in another school. Accepting this recommendation can be difficult for some parents who push to have their children remain in a traditional setting for as long as possible.

Dr. Duncan embraces the magnitude of early intervention during children’s formative years, when opportunities to influence brain and behavioral development are crucial. In order to help parents understand that a different placement and level of service may be necessary, Dr. Duncan has taken certain steps. She has visited other placement options within the system, so that when talking to parents, she can speak from experience and direct observation. Personalized, one-on-one conversations with parents, outside the often arena-like atmosphere of an IEP meeting is another strategy. Dr. Duncan recognizes that IEP meetings can be intimidating, with many people who have agendas that may differ. Ultimately, the parent “has to be willing to make the leap”, according to Dr. Duncan, but creating a culture of trust and respect assists with building the bridge between resistance and acceptance.
Dr. Wagner attends “a select few” IEP meetings. Mostly, she will be involved when a parent or teacher asks her to attend. There may also be potentially contentious meetings which require her attendance and leadership. Dr. Wagner’s knowledge of special education law may require her to participate in meetings that may be “sticky”. She stated, “I’d rather be in there from the early stages versus cleaning it up later... I’d rather make a parent very happy in the beginning than to try to undo their fury and bring them back on.”

During her principalship at the elementary school, Ms. Barbour promoted Autism awareness and participation in the development of the IEP by the regular education staff. “Rather than the special education teacher developing the IEP alone and then bringing it to a meeting and everybody just kind of signs off, actually sitting down and participating in that.” She also capitalized on the expertise of the regular education teachers by having them observe children in the classroom and bring viable interventions to pre-referral meetings. Talking with teachers about a continuum of supports for both regular and special education helped Ms. Barbour and her faculty implement sound strategies and evaluate progress over time before making a referral for special education.

Due to the range of student behaviors, communication skills, and academic needs, general education teacher training involved collaboration between special and general educators. Whole staff training “was not as effective as case-by-case because Autism is such a spectrum” according to Ms. Barbour. A couple of videos were shown to staff, providing more of a global perspective on Autism. Still, Ms.
Barbour found individualized conversations and planning to be more beneficial. Specific student strengths and needs could be shared and effective strategies and interventions defined, resulting in a higher comfort level by a teacher who may have little to no experience in working with students with Autism.

Also, it eliminated the fear factor for regular ed. teachers, because there’s a stigma or a fear when you say ‘Autism’. And, when you say ‘separate’ (self contained), then automatically they’re going to rocking in the corner, screaming, grabbing things, not able to communicate…they have those stereotypical perceptions of what that means, so breaking through those was huge to get teachers to see the kid before they saw the disability.

Even in today’s educational community, the movie, *Rainman*, is a common reference point for many who lack the experience and knowledge about Autism, Ms. Barbour claims.

The basics of understanding children and families and building relationships are crucial to creating a trusting, collaborative environment, according to Ms. Barbour. “Recognizing that the family may come in with baggage and experiences that are negative in a school setting and breaking down those barriers and building that relationship with the family” is key. The current educational landscape presents challenges to teachers and administrators who face multiple pressures to meet standards and to follow policies and procedures. Ms. Barbour opined:

I think we get lost in test scores. We get lost in labels. We get lost in services. And in EC, we get lost in paperwork. Well, did we sign that? Well, did we pass
that form around? Did you put that in the minutes? All that is for naught—if we were serving kids, if we were focused on kids, we wouldn’t have lawsuits and we wouldn’t have the paperwork the way it is… and I think as an administrator, you have to communicate to your families, I’m here to do what’s right for kids. Sometimes, doing what is right for kids, means that conflicts will occur between teachers and administrators and with parents and administrators. Ms. Barbour believes that partnering with parents and fostering a culture of professionalism that involves understanding and skill sets with teachers helps to eliminate potential conflicts.

In her undergraduate and graduate training, Dr. Wagner took some general special education overview course. Additional informal training tended to focus more on policies and laws rather than specific disabilities or instruction and planning. Dr. Wagner claimed to have a definite interest in special education, and she had recently attended an inclusive school conference and served in two special education advisory roles for the system.

Dr. Wagner defined professional development with Autism at Chadwick as informal and based on that teacher’s needs. Most information-sharing is done through the Autism teacher to the general education teacher. At the district-level, all Autism teachers do meet periodically, but Dr. Wagner was uncertain about the format and content of the meetings when they do occur.

When asked what could or should be done to better prepare administrators to work with families of students with Autism, Dr. Wagner reported that it was not
realistic for every administrator to be an expert in Autism. A solid understanding of special education law and the different disabilities is important, though. “They definitely need to know typical kinds of stereotypical kinds of things we see from Autism so that, of course, when they see something, they could recognize it as something that may need to be looked into.” Dr. Wagner relies on a designated person in her building, someone with Autism knowledge, to answer teacher questions and to work with parents. Dr. Wagner felt that the challenges with providing extensive training to school administrators would not be effective “…because the research changes…I don’t necessarily think that we have to know Autism because it’s a special entity of its own…it’s too big for me to be the expert on. I need other people to support that.”

**Administrative Preparation**

Mr. Cook said that he did receive some training with special education issues, but most of his education came from on-the-job training. When he was an assistant principal at the middle school, Mr. Cook was in charge of the EC department at the school. Reflecting, he shared, “I took it very seriously and read a lot…and I feel like I know EC law pretty much now. Have good people that are doing that for me right now, but I do know what I’m talking about.”

When asked what could be done to better prepare administrators to understand and work with Autism families, Mr. Cook suggested that administrative preparation programs spend more time on special education issues. The focus, he suggested, should be on procedural and legal knowledge, because “EC issues take
up a lot of time, and potential of it bringing you down totally is great.” Mr. Cook expressed concerns with new principals who are unsure of themselves when it comes to special education legislation and what their responsibilities are. “When they’re unsure of all that is when mistakes happen and when you don’t do right by kids,” Mr. Cook shared.

Dr. Duncan described her preparation as “somewhat dated”, informing that her only exposure to special education during her coursework involved an abnormal psychology course. In retrospect, she thinks that there could have been education about specific disabilities.

There could have been some component, either within the class or in addition to that class, that dealt with exceptionalities and that probably had people who were well-versed in 5 or 6 of the most common exceptionalities come present or show slips of teachers working with students with those diagnoses.

Something so that when you got into a school, it wasn’t the first time you saw it.

Despite not having any formal training with Autism or other exceptionalities, Dr. Duncan has honed her skills working with parents and understanding challenging situations. She credits her abilities in this area with her prior classroom experience and her respect for parents. As a classroom teacher with a heterogeneous group of students, Dr. Duncan understood the need to differentiate for student differences.

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on policies and laws rather than specific disabilities or instruction and planning. Dr. Wagner claimed to have a definite interest in special education, and she had recently attended an inclusive school conference and served in two special education advisory roles for the system.

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Ms. Barbour entered administration with a very comprehensive background in special education, from the teaching level to the central office level. She claimed to have a biased opinion about what administrative training is needed to better prepare administrators to work with Autism families, deeming it invaluable.

I have been in the presence of principals who have no knowledge, and they can sit in an IEP meeting and look like an idiot. I didn’t have to be on the receiving end of that because I had the experience that I had and because I had the knowledge and passion for it. So, to me that’s something that’s priceless and everybody needs to have some level, but not every principal needs to be an expert necessarily.

Katherine feels strongly that failing to understand Autism, or any other disability, results in ineffective relationships with parents.

While the administrators interviewed tended to focus on the possession of EC procedural knowledge as an important tool, Ms. Barbour believed that more emphasis should be on understanding the disability, stating, “somebody can be taught the procedural piece. You can’t teach understanding for what a parent’s going through that’s just been told their third child also has Autism.” The ability to relate and connect with parents because of understanding and compassion is what allows schools to make mistakes and to avoid the “gotcha!” effect that prompts parents to seek legal action. Strong relationships, Ms. Barbour stated, have allowed her “to go to a parent and say, ‘Man, we fouled up. We gotta regroup and redo. Great, let’s talk
sit and talk about it.” Peaceful resolution and outcomes in the best interest of the child were often obtained.

The common threads in perspectives between administrators and parents, along with the different angles and lenses through which their worlds are viewed, begin to create a level of understanding of how Autism affects families and schools.

**Chapter Summary**

Chapter 4 summarized the findings from interviews with multiple incidence Autism families and school administrators who have had direct experience in working with similar families.

All interviews were recorded, transcribed, and copies were emailed to participants for review. All participants were offered the opportunity to make any revisions they felt necessary, in order to ensure their comfort with information they provided. The researcher then reviewed all transcripts several times to become familiar with the content and input the data into Atlas.ti, qualitative analysis software, for further analysis and coding of the data. The coding data were then organized into charts and visual representations to assist the researcher with identifying possible themes or common topics.

Identified themes and topics were used as the outline to present the findings in Chapter 4. Though some common themes were found, not all parental narratives addressed all topics, since the format of the interviews was open-ended, allowing parents to determine the content and direction of specific experiences they chose to share. Themes from administrative data had more commonality due to the more
structured nature of those interviews. Throughout the reporting of findings, direct quotes from participants were frequently used to represent their voices and to personalize the data.
Chapter 5

Discussion of Findings

Introduction

In Phenomenological research, the collection of data through individual participant interviews results in individual textural descriptions. For this study, the individual textural descriptions, detailed accounts from participants, were extracted from the transcripts. Individual structural descriptions, clear depictions of principal dynamics that involve themes and qualities for how feelings and thoughts are connected to the phenomenon studied, were then derived from the individual accounts through data coding and analysis.

Chapter 4, a report of the findings, incorporated individual and composite textural and structural descriptions. The composite textural descriptions are a compilation, from all participant data, of themes studied, and composite structural descriptions describe how participants, as a group, experienced what they did.

This chapter concludes with a synthesis of composite textural and structural data to identify ‘essences’ of the experience of parenting in a multiple incidence Autism family. Essences, also known as invariant structures, are aspects of the experience that are common to all participants. Analysis of administrative data and themes are then discussed in relation to the essences, and implications for educational practice and future research are discussed.

The themes, common topics of conversation pervasive throughout the narratives, were derived from the data coding process, after all parent interviews
were transcribed, read, and reread several times. They represent stories and discourses all parents shared about their experiences with multiple incidence Autism. From an in-depth analysis of individual and composite textural and structural descriptions, shared in Chapter 4, the essences of the experiences are derived. Synthesis of all levels of textural and structural descriptions resulted in identified essences, aspects of the experience that were common to all participants.

Though all of the parents experienced all of the processes, depicted by the themes, there existed significant variance in how these experiences were undergone and remembered. Phenomenology has a constructivist foundation which theorizes that individuals construct meaning from their interactions with the world. People and their interactions with the world are interdependent, both relying on one another to create meaning. Thus, there are no ultimate truths to be found with phenomenological research. The essences identified in this study represent common aspects of the multiple incidence Autism experience, as lived by the families that were interviewed. No assumptions or claims are to be made that the following essences would be universal to all similarly defined families.

The synthesis of textural and composite structures is organized by subheadings created by the researcher after analysis of all data. The subheadings are designed to capture and blend the identified commonalities of the parental experiences by using descriptors that conceptualize the group textural and composite structures, the *what* and *how* of their collective experiences.
Synthesis of Textural and Composite Structures

Tacit Resiliency

It is said an eastern monarch once charged his wise men to invent a sentence, to be ever in view, and which should be true and appropriate in all times and situations. They presented him with the words, 'And this, too, shall pass away.' How much it expresses! How chastening in the hour of pride! How consoling in the depths of affliction! (Abraham Lincoln, 1859).

There is a tacit resiliency possessed by the families. Despite constant adversity, the families demonstrate an incredible ability to adapt to changes, some which were pursued but most which were imposed without choice in the matter. Adversity and challenges are pervasive in all the narratives, from notice of early signs, through the evaluation and diagnostic processes, in locating and accessing interventions, and in relationships with family and friends. Oftentimes, progress involved a few step forwards, met with several steps backwards. Parents' resilience is tacit because it is implied and gently embedded within their narratives, never self-identified as a quality but demonstrated through their attitudes and actions.

President Lincoln’s words in the quote above represent the resilience of the families. Parents faced unexpected news or undesired results, not with acquiescence, but with an attitude of persistence. Obstacles were temporary, and solutions were to be explored and acquired, despite the presence of transitory emotional, social, and financial setbacks. Even in the “chastening hour of pride”, when successes were tightly embraced and deeply cherished, parents understood
that there were more struggles and victories in the near and distant futures of the family. Unknowns of what the following day, month, year, and remainders of parents’ and children’s lives will bring are always present, but their resilience is the driving force that compels them on with positive attitudes and expectations.

Resiliency was also reflected in all parents’ abilities to cope with stressors related to the Autism. For some, stressors crept in, invading lives like a silent intruder. For others, stressors were confronted along the way and strategies were put in place to keep them at bay so the blazing of paths could continue with limited interference. Whether proactively or reactively, all the parents learned to cope in ways that were meaningful and applicable to their personal and familial lives.

Denial was a factor for all, at some point along the journey, but there was no mention of anger or bargaining, stages of dealing with grief as defined by Kubler-Ross’ (1969) model. One parent admittedly faced depression, but still, for all, arriving at acceptance appeared to be expedited. Perhaps this occurred because there was no time to waste. Their children’s needs had to be met, and early intervention was crucial. Or, perhaps there is no need for anger or bargaining, because there was nothing about which to be angry and nothing that to be bartered. Parents accepted their children for who they were, and the Autism did not result in a loss of their expected child. Love was unconditional, so assigning blame or failing to accept what was simply was not an option.
Path Blazers

Henry Ward Beecher stated, “The difference between perseverance and obstinacy is that one comes from a strong will, and the other from a strong won't” (“Henry Ward Beecher Quotes”, n.d.).

Upon learning of their first child’s diagnosis, all parents had to figure out what to do next. Though resources and information were sometimes provided in small doses, parents were equipped with a compass and a map of uncharted territory. Finding direction for next steps was toughest in the beginning, but the challenges continue and will persist for the families as they plan for their children’s independence and adaptability to an ever-changing world. The comforts and securities discovered thus far, a better understanding of how to navigate educational processes and to acquire community-based services and therapies, are temporary, for there will always be next steps. The parents are path blazers, illuminating their own ways through the world of Autism.

Expecting and waiting for resources and services to be handed to them was, and is not, an option. Each family became more knowledgeable as their children were identified and developed. A trial and error approach was often their only option, and successes and failures occurred along their journeys. But, as Henry Ward Beecher stated, “a strong will” and a “strong won’t” serve as their torch. Differences in behaviors and in needs of their children, along with multiple paths from which to choose for treatment and intervention, are potent catalysts for parental
perseverance. They can clearly articulate what they will and what they will not accept as outcomes for their children and for their families.

Though a drastic rise in incidence of Autism has occurred over the years, there currently remains no definitive explanation for the cause. This elusive etiological basis for the disorder automatically places parents in a position of truth definers and solution seekers. There is usually some type of explanation for many other disorders, whether they are psychological, medical, or physical in nature. But with Autism, the jury is out, and this leaves parents to be the researchers of information and the judges of intervention decisions on many occasions as they blaze their own paths. They must filter out what is truth and what is fiction, and they do so with their children at the forefront of all decisions.

People Over Process

Carl Jung (1955) stated, “The meeting of two personalities is like the contact of two chemical substances: if there is any reaction, both are transformed” (p. 57).

The processes along the Autism journey are intricate and cumbersome, but it is not the processes that were the focus for parents. Though parents talked about the steps for acquiring evaluations and diagnoses and services, the people they encountered were central to the experience.

Individuals were remembered and discussed in terms of their ability to help or to hinder situations. Jung’s statement describes the reaction of personalities and the resulting transformations. The parents experienced affective responses to certain individuals whom they encountered, and never was the account related to
the person’s knowledge-base in any particular area. Rather, parental memories converged on how the individuals interacted and how they made them feel about an experience.

Parents spoke fondly of people who listened, cared, and understood. They were not hesitant to talk in detail about those who not only showed an interest in helping them, but who took actions to help and work with their children, whether it was their job to do so or because they simply took the initiative to become involved and be a part of the solution.

Those who rejected or were obstacles to the families were mentioned, but parent narratives were limited in detail and scope in such instances. The affiliations of such individuals bore no significance or differentiation in how they were discussed. Whether they were family members, service providers, or educational personnel, the parents described these individuals’ indifference, outright dismissal, or disconnectedness to their plight. Transformation of the parents came from those who were “on their side”, those who were supportive, compassionate and involved. The focus on what was good can also be attributed to parents’ resiliency and focus on blazing their paths. Efforts and negative energies on perceived barriers would only divert the families from their chosen paths.

**Preservation of Family Efficacy**

The great novelist, George Eliot, wrote in the novel *Adam Bede* (2001):

What greater thing is there for two human souls, than to feel that they are joined for life – to strengthen each other in all labour, to rest on each other in
all sorrow, to minister to each other in all pain, to be one with each other in silent unspeakable memories. (p.494)

Despite the challenges faced by individual children diagnosed with Autism, the family unit remains the core for the parent participants. Self-efficacy is replaced by the determination to preserve family efficacy, the family’s capacity and power to produce desired effects. Parents immersed themselves into the world of Autism, working determinedly to advocate for their children, to increase their own understanding of the disability, and to construct plans of interventions and services that seemed to undergo constant change. For those with typically developing children, there was no ignoring or placing aside the needs of those children either.

In Elliot’s words, the families embraced the concept of being “joined for life”. And memories of their experiences with adversity and successes are “silent” and “unspeakable” in many cases, because there is no time to rest and reflect on where they began, where they are, and where they are headed. Parents are too busy balancing and juggling, at a rate and pace that leaves little time for explicit discussion and deliberation about the current path and journeys ahead. Still, they manage to do all that needs to be done, keeping the entire family intact and functional.

**Altered View of the World**

Henry Miller (1964) said, “The moment one gives close attention to any thing, even a blade of grass it becomes a mysterious, awesome, indescribably magnificent world in itself.” (p.37)
The American novelist and painter, Henry Miller, provides an excellent description of the experiences of these multiple incidence Autism families. Having more than one child diagnosed with Autism submerges parents into a different world and, hence, a different way of defining and thinking about their world. Allocating massive amounts of time, energy and effort to take care of their children’s needs altered them as parents and as individuals. Paying “close attention” to the Autism and necessary interventions and supports resulted in parents who received and perceived the world around them in a different light.

Whether it was becoming more tolerant or intolerant of certain individuals or situations or learning to accept defeats or successes in a dissimilar manner than parents with typical children might, parents were deeply changed by the experience. Celebrations of successes, ones that may be taken for granted by parents of typical children, were treasured. A child’s ability to ride a horse, speak a word, tie one’s shoelaces, independently follow a schedule or sit through a movie in its entirety at a theatre were all major accomplishments that necessitated major celebration.

Acquisition of this different perspective was viewed in such a positive light by parents. They expressed no regrets, no misgivings about their situations and how their lives had been changed by the “close attention” to Autism that was demanded of them. Autism, their “blade of grass”, became “a mysterious, awesome, indescribably magnificent world in itself”. Consequently, there is no looking back on what could have been, only a future of seeing the world through a different lens that
others cannot truly and completely understand unless they have experienced it for themselves.

**The Essence**

The essence (Diagram 1 & Appendix H) that emerges from the collective experiences of these multiple incidence Autism families is the obligation to a spirit of resilience, because the need to be emotionally and spiritually strong as a family is required for survival. The search for services and interventions, the call for advocacy, mothering and fathering, managing varied schedules and calendars, and being a partner in a relationship are factors that demand constant attention and nurturing. Like cogs in a machine, they all must be oiled and cared for so the instrument can continue to function as intended.

With multiple incidence Autism families, the pervasiveness of the disorder is intensified. Autism impacts all aspects of a child’s life. The effects are not restricted only to home or to school or to community, but they are felt at all times, for the individual and for the family. Parents must focus on the wide-ranging needs of all their children at all times. The academic, sensory, eating, social, adaptive and communication needs can be so disparate between identified children within a family.

While this non-stop managing occurs for diagnosed children, parents who also have typically developing children are charged with a different type of focus. They must make certain that the typically developing children receive appropriate attention in suitable formats and doses. This may mean shifting focus in a
completely different direction, away from the apparent constrictions dictated by the Autism world. Typically developing children may acquire independence and self-sufficiency at earlier ages and, ultimately, to different degrees than diagnosed children. Therefore, parents must be continually cognizant, not only of the differences in needs between identified children, but of the needs of typically children whose seemingly accelerated development could be misconstrued as false independence and autonomy and result in an subconscious withdrawal of parental attention.

The survival of the family is contingent upon the parents’ abilities to construct and continually reinforce their resilience of spirit and attitude, patching holes and cracks in the foundation when necessary. Damages and disappointments will occur along the journey as families forge ahead, but they cannot and will not be thwarted by such nuisances. There is no time to rest when all or several of your children are diagnosed with Autism, because the demands require resiliency. Indifference and surrender are the only other options and the consequences of both would be devastating to the children and the family unit.
Findings & the Literature

Cashin (2004) found that the parents of children with Autism became transformed, experiencing a loss of self, and that there remained anxiety and exhaustion from the intense requirements of care for their children. A comparison of the results of Cashin’s study to those from this current study reveal some similarities and differences. Parental self-loss was not apparent in this study of the four families. Though they did describe experiences that were damaging, expressions of self-loss through the narratives, were never portrayed as life-enveloping but temporary set-
backs or losses of direction. The initial reactions to diagnoses and understandings that family life would be forever changed yielded a range of emotions from parents, but as they talked further in interviews about their experiences, there appeared to be an escalation of confidence and perseverance even in how they shared their stories.

Whether evaluations and diagnoses were handled through private or public agencies or through the school system, the parents in this study were generally accepting of the process. The immense amount of paperwork and time involved were mentioned by some, but the actual delivery of the diagnosis was mentioned in an almost surreal manner by most. Patty Neal’s memory of being informed over the phone that her child had Autism was an outlier experience, based on data from the interviewed families. Whaley (2007) found that parents often viewed professionals who delivered and discussed diagnostic information with them as realistic, compassionate, and careful listeners. Besides Patty Neal, the parents in this study did not focus on the professionals who provided them with information, though the emphasis on people over process permeated the remainder of the interviews. For those who received information from a compassionate diagnostic team, that experience may have been clouded by the intensity of emotions parents felt as they processed the evaluation results and the resulting diagnosis. After learning “what it was”, parents then needed to channel energies on what to do. These efforts to learn about interventions and services required communicating with individuals who could help through mutual dialogue. During the evaluation and diagnostic processes, communication was more one-sided as professionals obtained information from the
parents and child and then shared results with them. Events that are perceived as more procedural in nature may be alternatively filed in parental memories.

Parents in the Spann, Kohler, and Soenksen (2003) study rated their involvement in IEP meetings as moderate to high. The parents in this study were extremely involved in IEP meetings and all aspects of their children’s education, initiating conversations and meetings in many instances. There may be notable differences in the participation rate and level of contribution between parents of children with Autism and parents whose children as identified in other special education categories. Self-initiated research, parental networking, a sense of isolation from having limited supports and resources, and exploration of treatments and interventions may contribute to different levels and types of involvement in educational decision making for parents with children diagnosed with Autism. Future studies may choose to explore this notion and obtain data regarding the nature of advocacy with Autism parents.

Some conflicts between the parents in this study and school personnel were noted, but tensions were not a focal point of the narratives. Isolated events were shared, but the concentration was on progress and successes. The researcher expected narratives to include more stories of disagreement between parents and schools over educational services. In particular, programmatic issues were anticipated, since there are multiple competing methodologies related to Autism (Yell & Drasgow, 2000) and due process and legal action often result when parents and schools disagree. The absence of methodological disputes between parents and
school personnel in this study may be due to the geographic region and availability of information and services (i.e., TEACCH), as well as the higher functioning status of the majority of children. Since all of the children, with the exception of one, received their education in the general education setting, specific methodology was not needed because the children were highly responsive to the existing environment and general strategies provided. The child who was in a self-contained Autism program benefitted from the instructional methodologies and strategies implemented within.

Placements along the continuum of least restrictive environment also seemed to be an area of little concern for the parents in this study. Parents were realistic about appropriateness of placements. They evaluated the effectiveness and suitability of self-contained programs or inclusive practices based on their child’s needs. In support of some of the literature (Duhaney & Salend, 2000; Kasari, Freeman, Bauminger, & Alkin, 1999) on special education placement decisions and options, parents tend to perceive the benefits of educational settings in relation to what they believe their child truly needs. None of the parents in this study demanded an "all or nothing" extremist approach to placements. Rather, they seemed to value the input of the professionals who work with their children, while asserting their own insights about what would educationally benefit their children. The collaborative efforts were valued by all of the parents.

Kubler-Ross’ (1969) model of the grief cycle could have some application when analyzing data from parent interviews, but a more specific approach would
need to have been taken for this study to gather data that explicitly focused in on the stages. Feelings of denial and acceptance was common to all parents, but no assertions can be made regarding emotional states of anger, bargaining, or depression, even if a non-linear approach to the Kubler-Ross model is applied. Though Paul Roberts talked about his depression and the effects on the family, none of the other parents mentioned depression. Still, no assumptions can be made that the absence of dialogue about depression concludes that it was not a factor. The same applies to the stages of anger and bargaining. Specific questions about each stage of grief would have needed to be asked in order to further detail how parents coped and defined their experience.

Learning about their children’s diagnoses of Autism impacted parents’ belief systems, values, and perspectives of the world. The feelings derived from the diagnostic experience can impact all portions and moments of their lives and result in a loss of hope for the future due to modified expectations (G.A. King, Zwaigenbuam, S. King, Baxter, Rosenbaum, & Bates, 2006). The parents in this study, however, never expressed hopelessness. Determination for their children to reach their potential, regardless of the existing norms for development and growth for neuro-typical children, did not permit hope to be lost. Though the futures may not be what parents originally planned for their children, opportunities and successes remain imminent and expectations are realistic and individualized.

The question of whether or not the parents would define their selves as being transformed in such a manner that resulted in self-loss is interesting. How their
stories were shared, with an intense air of optimism and affirmation, suggests possible self-discovery. Perhaps there was some abandonment of the expected parental role, the one that would have been developed with typically developing children. But the transformation of self seemed to emerge as parents naturally assumed the roles needed to meet the needs of their children. The connections that were made between parent and child, for all families, echoed Cashin’s (2004) findings that extreme enjoyment was found when parent and child were able to recognize and celebrate successes.

Increased burdens and stressors impacting social relationships (Piven, Palmer, Landa, Santangelo, Jacobi, & Childress, 1997) for multiple incidence Autism parents was evident from data in this current study, still to differing degrees for each family. The non-negotiable changes in family structure and routine, for some, resulted in limited social relationships. For other parents, reactions from others to the Autism resulted in rejection, and the emotional consequences of such feedback continues to inform social connections to present day.

Strategies for coping and parents’ changed views of the world provide powerful contributions to how families evolve and deal with challenges associated with Autism. Gray (2006) discovered that coping strategies changed over time, as parents initially relied heavily upon service providers, family support, social withdrawal and individualism. The passage of time brings changes in perspectives and approach. Parents’ trial and error tactics with coping, increased understanding of Autism, consistent implementation of supports and services in the home and at
school, emotional and spiritual development, and efforts to maintain family efficacy may contribute to their evolving perspectives and coping strategies. While strategies for individuals were varied and changed over time, all parents were able to differentiate between successful and detrimental tactics.

Chosen interventions were contingent upon parents’ beliefs about the cause of Autism with their children. Again, the absence of definitive etiological explanations, leaves many parents to become researchers and interventionists. Mercer, Creighton, Holden and Lewis (2006) found that parents cited a range of possible causes for Autism, stressing the need to understand as a critical component to the coping process. Parents in this phenomenological study all reflected on perceived causes of Autism in their children, and they discussed the need for guidance and information following the diagnoses. Once the children become school-aged, parents are faced with new challenges as they familiarize themselves with educational policies and processes.

Parents’ willingness and desire to share their stories were evident from the onset of the study. They were eager to divulge personal information about their experiences, despite, or maybe because of, the emotionally and cognitively challenging phases undergone. The sharing of experiences can transform parents in a positive manner, serving as yet another form of coping (Fleischmann, 2004). Communicating their stories for others to read may be a catalyst for continued acclimation to the world of Autism and provide insights to other parents who share a similar journey.
Implications for Practice

Administrative Preparation and Training

Administrator interview data were relatively divergent, even though the interviews followed a standardized, open-ended format. Responses could be attributed to the type of school (elementary, middle, high school) and experience, the type of Autism program or supports available at the current school (high-functioning resource, separate, regular resource), administrative training, exceptional children’s background, district supports, and personal experiences with Autism. The Wakeman, Browder, Flowers, and Ahlgrim-Delzell study (2006) suggested relationships between principals’ special education knowledge and some of the demographic characteristics, training and practices. The data also indicated that principals’ personal experiences with an individual with a disability relates to knowledge of processes and advocacy levels, and special education licensure also contributes to understanding of special education issues. Further, the vast majority of principals reported not having special education licensure or certification and most had limited, if any, special education coursework at any level of their education and preparation programs. Participation in trainings or workshops related to special education issues over the previous two years was also minimal. Though principals reported taking advantage of their experiences to learn about special education issues, the implications for administrative preparation programs and continuous professional development are great.
Goor and Schwenn (1997) discussed administrator preparation programs and the previous focus on building administration and instructional supervision training. In light of the changing context of school leadership, Goldring and Schuermann (2009) address the need for alterations of the design and delivery of leadership preparation programs. Specific to Ed.D. programs, the authors claim that curriculum should “refine the judgment and enhance the decision-making capacity of school leaders” (p. 25). The development of new methodologies and pedagogy is critical to prepare school leaders who must successfully address accountability demands, changing leadership and learner foci, the need for increased analytical skills, and other factors which are rapidly changing the educational landscape. The need for formal training and coursework in the field of special education is perceived as critical to principals’ professional development (Lasky & Karge, 2006).

A new conceptual framework for a leadership assessment instrument is provided by Goldring, Porter, Murphy, Elliott, and Cravens (2009), centering on the leadership dimensions of core components, characteristics of schools, and key processes, behaviors of leaders. This proposal of leadership evaluation has some alignment with the North Carolina standards for school executives. The criteria and methods by which school leaders must be examined and assessed are evolving, but the question remains as to how leadership for special education will be reflected by theory and practice.

The North Carolina Department of Public Instruction outlines seven 21st century standards for school executives, previously identified as school
administrators. Though not directly addressed in the standards, there are implications and considerations for special education leadership within a building. The seven standards speak to the strategic, instructional, cultural, human resource, managerial, external development, and micro-political aspects of administrative leadership.

When considering implications for practice, based on this study, reflection will be given to aspects of the instructional and cultural leadership roles of the school administrator. There are specific portions of these two standards that have direct application to parental and administrative interview data.

**Special Education Knowledge and Leadership**

One practice related to effective instructional leadership is demonstrated when the school administrator:

- Focuses his or her own and others’ attention persistently and publicly on learning and teaching by initiating and guiding conversations about instruction and student learning that are oriented towards high expectations and concrete goals” (North Carolina Standards for School Administrators, 2006).

The standards are rooted in a distributed leadership philosophy, in which the school executive works with teachers in a manner that fosters “open, honest communication, which is focused on the use of data, teamwork, research-based best practices, and which uses modern tools to drive ethical and principled, goal-oriented action.” Assuring the application of research-based best practices related to Autism will require many school executives to increase their own knowledge of the disorder.
and related practices, as well as to ensure that the professionals they hire and consult with to be the experts are well-versed in research-based best practices. When system resources are inadequate or scarce, principals need to construct functional and effective structures within their buildings in order to appropriately address the pervasiveness of Autism in individual children.

The standards-based movement in education, as prescribed and detailed in *No Child Left Behind*, has resulted in more clearly defined learning standards for children in all grades. And, since one of the goals of *NCLB* is to ensure that all children appropriately access the general curriculum and are included in district and state accountability measures, states have developed a detailed curriculum that spans the grade levels. However, the provision of the most comprehensive and highest quality curriculum does not automatically lead to student achievement. Instructional practices are critical, and teachers must know their students as well as they know their curriculum. The learning profile of a student with Autism can be complex and necessitate a teacher’s application of multiple strategies for communication, academics, behavior, or social learning in the school environment.

Crisman (2008) provides pointers for inclusive programming and working with students with Autism. School administrators need to understand appropriate placements for students with Autism by first being familiar with the range of options along the least restrictive continuum. The selection of teachers (special and general education) and paraprosfessionals who work with students is critical, because the work is important and can be demanding in multiple arenas at times. Working
collaboratively with parents, oftentimes the Autism experts, benefits students, and administrators need to be able to set boundaries with parents who may inadvertently cross lines with their involvement. Establishing a vision and belief that all students can learn, establishing team approaches to planning and problems solving, as well as supporting and providing continuous professional learning are key factors to supporting students and families with Autism in the schools.

So, while the school administrator must be able to effectively dialogue with a range of audiences about “high expectations” and “concrete goals” for general student learning and instruction, she must also be to individualize such conversations and articulate how the needs of a diverse student population will be addressed, not just with students with Autism, but for all student differences and strengths.

Instructional leadership for the 21st century school executive also demands that he or she “systematically and frequently observes in classrooms and engages in conversation with students about their learning” (North Carolina Standards for School Administrators, 2006). Since many of the principals interviewed relied on special education facilitators or other designees within their buildings to handle the bulk of Autism-related issues or needs, it is important for administrators to be educated about Autism and other special education topics. Increased administrator knowledge can result in the facilitation of appropriate planning and decision-making, redirection of teams when needed, and promote the practice of effective instructional leadership for all special education matters.
Perhaps the practice of central office staff ‘experts’ serving as the primary observers in specialized exceptional children’s classrooms should change. Collaboration and consultation between experts and building principals and designees is encouraged, but school administrator understanding of Autism and best practices, paired with systematic and frequent observations in Autism classrooms, should contribute to improved programming for students. Principals who are not familiar with appropriate expectations and research-based best practices in Autism are not equipped to observe and provide feedback. Hence, allocating observational and feedback responsibilities to other experts may seem logical and efficient to principals who are providing leadership for an entire school, or this responsibility delegation may be dictated by central office policy and procedures.

Practicing principals admitted spending a great deal of time in special education meetings and conferences, sharing that this was a responsibility germane to their positions. Administrators mostly attended IEP meetings when parents or teachers requested their presence, if they were recently involved in a situation or conversation with the parents or child, or if there was a special interest based on prior interactions and relationships with the family. Data from the 2006 Lasky and Karge study indicated that the majority (40.7%) of principals’ time in meetings was viewed as “administrative” and less than a third (30.3%) reported a “facilitative” role. Only 8.9% of the principals reported that their role was that of “leader” at IEP meetings.
Administrative interview data for this study had a heavy focus on special education procedural and legal knowledge. Most principals perceived such a knowledge base as indispensable in their work. Yet, if administrative roles are shifting toward distributed or transformational leadership styles and collaborative organizational efforts, the need for principals to possess a greater breadth of knowledge of all issues of diversity is imminent. The capacity to assist special educators with instructional planning and data-based decision making and to facilitate conversations about programmatic feedback may necessitate administrator education that addresses analytic thinking, as well as disability-specific information.

Mastergeorge (2007) state the imperative for school administrators and educators to have an awareness of learning issues facing students with Autism and provides practitioners with four guidelines. She suggests that school personnel serve as “social engineers” for the children by facilitating social situations and interactions with typical peers. Secondly, clearness and consistency with routines is critical to address transition needs. Capitalizing on a student’s interest in a particular subject can promote social interactions and language skills. Finally, Mastergeorge encourages educators to embrace inclusive settings, because the opportunities for students with Autism and their typically developing peers provide important interaction and build acceptance of differences.

Inclusive practices in schools will demand a great deal of instructional leadership from principals. Providing leadership to address co-teaching methods, dialoguing with teachers about collaborative planning, and assisting special and
general educators with curriculum development, modification and adaptation (Friend, 2007) are skills school leaders will need to ensure effective instructional programming and delivery. The principal’s beliefs about inclusive practices greatly influence successful implementation within a school (Horrocks, White, & Roberts, 2008).

**School Culture and Professional Development**

Increased administrator understanding of Autism and involvement in classroom observations and feedback dialogue also addresses cultural leadership expectations, in which the administrator:

- Systematically develops and uses shared values, beliefs and a shared vision to establish a school identity that emphasizes a sense of community and cooperation to guide the disciplined thought and action of all staff and students (North Carolina Standards for School Administrators, 2006).

Efforts to create a culture that values all students are recognized by parents. All parents interviewed expressed desire for their children to be included and a part of the school community. Conflicts tended to arise when individual school personnel’s values and beliefs were allowed to be imposed, permitting them to do what was comfortable for them, not what was right for the children. Administrative ability to develop a culture of community and cooperation that dismisses no child or family reduces the occurrences of rogue faculty decisions and behaviors that deviate from core school values, beliefs and vision.
This study proposed that one critical factor for the parents in multiple incidence Autism families was the people they encountered—how they interacted, attempted to understand, and made efforts to help the family. When relationships and trust are not established, situations have great potential to turn litigious. The principal who “communicates strong ideals and beliefs about schooling, teaching, and professional learning communities with teachers, staff, parents, and students and then operates from those beliefs” (North Carolina Standards for School Administrators, 2006) makes important contributions to school culture.

A change, however, must occur with the scope of the ideals and beliefs. This researcher’s experience suggests that benefits may be derived from leaders who are able to qualify their beliefs about students with disabilities. Additionally, change could be initiated by leaders who are transparent with their beliefs about instructional practices, differentiated instruction, and accommodating all students, and who strategically plan how professional learning communities will involve an expansive team of professionals so that true multi-disciplinary thinking and actions are encouraged and practiced.

Though not an outcome of this particular study, the researcher believes that school administrators who *enough* knowledge about Autism to recognize student needs, plan for teacher training and resources, and to engage in dialogue with parents and practitioners about research-based best practices will provide practical and much needed leadership to decision-making. Still, much attention is needed
regarding discussion about what constitutes *enough* knowledge at the administrative level.

An administrator’s willingness and desire to learn about the dynamics of a multiple incidence Autism family may also yield critical benefits. This study revealed some of the complexities of parenting in a family with multiples. Like icebergs, with nearly 90% of their cores below the surface of the water, what we can actually observe with the children and families of Autism is limited. There are “silent, unspeakable memories” constantly under construction below the surface, and the mere attempt to understand the inner workings and the relationships can result in insights that cannot be derived from general special education courses and textbooks.

Although current building level administrators were able to share a story or two about a multiple incidence family with whom they had worked, the administrative focus is more global. As the executive leaders for their schools, principals are responsible for the education of the entire student body. Since they have to look intently at so many “blades of grass”, the world of their focus is naturally broadened. Student cultures, languages, socio-economic statuses, family dynamics, disabilities, abilities and numerous additional factors create a diverse student population principals must support and nurture. Families of children with Autism are a part of the population, and they are esteemed as equally important and as valued as any other family within the school communities.
Interestingly, all administrators provided commentary on their observations and perceptions of parents. Principals noticed differences in communication with parents of Autism, stating that there seemed to be Autistic tendencies, manifested by social and communication oddities. These observations relate to earlier research (Piven, Palmer, Landa, Santangelo, Jacobi, & Childress, 1997) that found personality and language characteristics between parents of children with Down Syndrome and multiple incidence Autism parents. Autism parents demonstrated higher rates of rigidity, aloofness, hypersensitivity to criticism, and anxiousness. Genetic and environmental factors could contribute to differences in communication and personality characteristics for some parents, so it is important for administrators is to understand possible differences and to determine how to best adjust to the parents’ needs so effective communication can occur.

Creating an accepting and trusting environment was important for the interviewed principals. They valued this type of culture for all of their families, not only multiple incidence Autism families. Even if they possess limited expertise in special education, principals have the ability to cultivate a school culture that is supportive for all constituents (Gersten, Keating, Yovanoff, & Harniss, 2001). One strategy for these participants was to be transparent with parents by talking to them up front about the details of the program and their plans for the children. There was an overall value, by administrators, on establishing expectations of understanding, empathy, child and family-focused practices that would result in building relationships and trust.
Parents’ descriptions of adverse situations with schools were few, and administrators were generally respected for their positions. Several parents acknowledged the challenges associated with the job, and they did not express disappointment with principals’ limited involvement in IEP meetings. Principals were perceived as busy and responsible for various functions of the school, and for the most part, their presence at IEP meetings was not expected unless there was the need for additional resource allocations or if there was some point of contention between the school and the parents. Thus, the need for an administrator at the IEP table is seen as conditional, by parents and administrators.

The perception that administrators are predominantly needed only at IEP meetings that are expected to be adversarial or have high probability for contention, stands in contradiction to the refined view of school leadership. Important decisions are made at IEP meetings. Student goals and objectives are established, resources are allocated, and accountability for learner outcomes is defined through data-collection methods. A great deal of IEP meetings would likely benefit from the strategic and instructional leadership from the principal. Since principals’ responsibilities are numerous, it is not realistic for them to attend all of the special education meetings. Distributed leadership practices should then empower the appropriate faculty to lead in the principal’s stead. For this to occur effectively, the leadership skills of the designees must also be refined. The mere delegation of responsibilities and decision-making authority does not result in leadership, so the process by which leadership is distributed is critical.
For parents, the system they are in seems to determine the obstacles they are bound to face as their children progress through their public educational experiences. The organization’s dedication to certain methodologies and attitudes towards students with Autism seems to greatly influence school practices and suggests a truer implementation over time and over settings. An organization’s absence of willingness or ability to articulate best practices may contribute to the inconsistencies from school to school and within the same school. Still educational leadership at the building level may be most influential in how students and families are treated and served. Fullan (2005) states, “When leaders and teachers as a group have the collective capacity to make improvements, they become more confident and proactive in seeking parent and community connections that support classroom and school work” (p. 60). School communities that collectively articulate and demonstrate best practices should not be burdened by fear of retaliation or conflict with parents.

Parents made conscious efforts to build relationships with building administrators and to advocate on individual levels regarding their children’s needs. A principal’s attitude and values concerning students with disabilities can be profound, as he or she has the ability to establish and enforce a culture of respect for all student differences. This impacts the student body and the faculty, in either a positive or destructive manner, from the perspective of the parents.

So, parents may be empathic of the school principal, despite adversarial situations that may arise, due to the relationships that have been forged and the
principal’s leadership handling the situation. Parents also seem to comprehend that there are systemic organizational issues over which the principal has limited control or influence. Another potential explanation for parental understanding of principals could be that they see the principals’ roles in IEP meetings and special education matters for their child as contingent upon controversial situations or requests that place the parent and educational team at odds. For parents who are pleased with placements and services for their children, they see no need for the principal to be involved in their meetings. Parents also perceive the influential players in their child’s education as the team that works with the child. Maintaining positive relationships and consistent communication with school personnel can contribute to successful outcomes to educational plans and interventions.

Professional development for general education teachers who work with identified students in the regular classroom has been delivered on an as-needed basis, under the leadership of the interviewed principals. The special education staff or Autism teachers consult with general teachers about student strengths, needs, and strategies. From a parent perspective, specialized training in Autism for teachers and administrators would be greatly welcomed. One of the parents in the study remains actively involved in advocating for such system-wide training, working diligently to educate central office personnel and school board members to help them better understand Autism.

Along the journey, many of the parents have perceived that the most feasible and meaningful training has been provided through their own efforts. Providing
strategies to individual teachers, requesting get-to-know-you meetings with principals, offering literature, creating student-specific brochures to be shared with personnel and peers, talking to classes about Autism, and coming to IEP meetings prepared with information on goals and needed services are some of the ways parents have served as the primary Autism educators. Still, there are much welcomed sighs of relief when parents find themselves in the passenger seat and school personnel come to the table organized, prepared, and knowledgeable about their children’s needs.

Implications for Further Research

Though the data obtained from this study was rich and meaningful, the size of this study was limited with four families and four administrator participants. A continuation of similar qualitative studies would be able to further address multiple incidence parents’ experiences and perspectives with family and school life. Probing questions regarding more detail of how parents experience effective and ineffective leadership at the building and district level could provide useful information for school leaders. It would be interesting to acquire more data about specific school executive practices and behaviors and how parents evaluate and categorize them.

Further research could also concentrate on particular portions of the Autism ‘spectrum’. For example, studies could attempt to determine if there are correlations between parent and administrative experiences based on the severity of the child’s Autism, as demonstrated by communication, cognitive, and adaptive behavior functioning, or through educational placement and intensity of services. Since there
can be wide ranges of Autistic characteristics and symptoms manifested between children within a particular family, a multiple incidence approach could still be maintained with relative ease. Interviews from administrators who have experience with a continuum of services could yield data specific to program or support type or level. Are there differences in parent and administrator experiences based on where the child falls on the Autism spectrum and where their educational programming falls on the least restrictive continuum?

In this study, all parental and administrative participants were Caucasian. Parents were from middle to upper middle class backgrounds, and all were native English speakers. Future studies that incorporate participants from different ethnic and cultural backgrounds may yield interesting contributions to the body of literature on multiple incidence Autism families and administrative perspectives. Do parents and administrators with different cultural or ethnic backgrounds have different experiences? For parents, do these differences affect their parenting, family functions, social experiences, beliefs, values, coping strategies, and advocacy? If so, how? Do administrators interact differently with parents, based on their own cultural and ethnic backgrounds? Future research that explores how parents and administrators from differing backgrounds perceive one another’s communication and beliefs would also be interesting.

From the educational leadership angle, further exploration of organizational leadership structures and processes could provide data regarding how leadership for special education is valued, articulated, and executed at the district level. Research
could also address how these organizational factors impact school executive leadership at the building level. Are principals who are directly involved in Autism programming and feedback dialogue more effective as evidenced through relationships with parents, students and teachers and improved student achievement? What other factors are used to assess administrative effectiveness with special education leadership?

A more in-depth analysis of the school executive standards in relationship to special education leadership at the building level would contribute to an interesting study, as well. Research might incorporate the dissection of each of the standards and an identification of correlations to special education leadership. Interviews with building principals could focus on self-reflections on how they practice leadership for each standard, as related to special education programming and instruction. A collection of artifacts, physical evidences, would enrich the data and highlight how leadership is manifested for each appropriate standard.

Further research may also address how administrative backgrounds, training and other personal and professional experiences influence their leadership for special education. Does a background in special education positively impact leadership skills? What other factors influence leadership for special education? Are there correlations between previous administrative or educational coursework and leadership vision and practices?
Conclusions

As an educator whose career has been dedicated to special education, my experiences collaborating with administrators, teachers, and parents lead me to conclude, at least thus far, that it is a mere fragment of our knowledge, combined with a enormous dose of our humanity, that ultimately determines our ability to closely connect with others. Additionally, it is that connection that is the foundation of leadership, regardless of how it is defined or theorized. We may be able to recite the standard course of study for grades kindergarten through twelve, summarize the 21st Century school administrator standards, or even dialogue with colleagues about the great educational philosophers from any century, but our inability to relate will be the factor that keeps us from being genuinely effective leaders. We can learn a great deal from simply listening to the stories of parents, students, educators and administrators. Through listening and reflecting, we can exert monumental changes on our practice. This study will not change the Autism world and education, but perhaps the data will resound with those who review them.

Parents in multiple incidence Autism families have unique circumstances and challenges presented to them. The parental participants in this study shared detailed narratives that reflect their obligation to a spirit of incredible resilience. What is required from them to raise their children and to constantly address the nebulosity of Autism demands a persistence and focus that places stressors on marriages, finances, the family unit, and their social lives. The administrators who work with these families are also faced with challenges, many of which they are not
adequately prepared to handle without the support of school personnel with specialized knowledge and training. Partnerships with parents are crucial, since the parents are self-educated experts on Autism and their children’s needs. Fusing school personnel’s educational expertise with the Autism expertise of parents can result in sound programming for individual students.

As administrators tailor their practices toward the 21st Century standards for school executives, there may need to be adaptations to thinking and practice for special education leadership. The foci on standards-based learning and accountability have changed the way special education is viewed in schools. No longer a separate branch of the educational system, special education has become an integral part of general education, and the reverse holds true, as well. Inclusive practices, professional learning communities, high quality curriculum, and accountability for all students change the way we think and plan for all learners. Students with Autism are in all schools and their numbers are increasing. Educators’ and administrators’ responses must reciprocate. The acquisition of knowledge and understanding is readily available through parental and community partnerships. Research must be shared with teacher and administrator preparation programs, and school systems must become the training grounds for implementation of research-based best practices for all students.
BIBLIOGRAPHY


regarding inclusion of children with Autism in Pennsylvania public schools.

*Journal of Autism & Developmental Disorders*, 38(8), 1462-1473.


strategies of brothers and sisters of children with autistic spectrum disorder.

*Journal of Intellectual & Developmental Disability, 31*(2), 77-86


APPENDICES
Multiple Incidence Autism Parents

1. Guiding Research Question: What is the meaning of the lived experience of parenting in a multiple incidence Autism family?

2. How old were your children when first diagnosed with Autism. Tell me about the experience of learning about the diagnosis. How did you learn about it? Who conducted the evaluation? Who was involved and how was the information communicated? What was the experience like?

3. Please tell me about your first experience with the educational process (after identification and initial placement if this was done through the school system). How did you navigate through the process? What type of relationships and communication did you have with school personnel? Who helped you?

4. How would you have liked to have experienced the diagnosis process?

5. Please tell me about the transition processes (toddler to pre-k, pre-k to elementary, elementary to secondary, secondary to adulthood/college)?

6. What other school experiences stand out for you?

7. What advice would you give school personnel in working with you and your children (as well others)?

8. What have experiences with building level and/or central office personnel been like for you?

9. How was family life altered after learning about your children's diagnoses?

10. How is your family life different from parents of “typical” children?

11. What are some of the challenges as a parent (home, school, community, etc.)?

12. What are some of the blessings/good things that have happened?

13. What strategies did/do you use to cope with the challenges?
14. If there are other non-diagnosed children in the family, how are those relationships with your identified children?

15. Tell me about the sibling relationships (diagnosed sibling or not).

16. What aspirations do you have for your children? Where do you see them 10/15 years down the road?

17. What are the major obstacles do you think your children will encounter as they pursue their goals?

18. Have the challenges/obstacles for you as a parent changed/shifted over time?

General Probe: Please describe that particular incident in more detail.
1. **Guiding Question/Probe**: My research with multiple incidence Autism parents resulted in some common themes or essences that define the experience. Since you have served as an administrator who has worked with multiple incidence Autism families, I am interested in your reactions to these findings. In particular, I would like to get your perspective on the educational components/findings.

2. Please describe your professional background and experiences (also related to Autism) and current administrative role.

3. What has been your training/education specific to EC? To Autism?

4. Parents indicated _____________________________________________. Please tell me, from your perspective, have you had the similar experiences or reactions?

   *This prompt will be repeated depending on the overall findings/themes that emerge.*

5. What, if anything, do you see as unique to these parents who have more than one child identified with Autism? Do you feel that their interactions and involvement with school is any different than any other parent with one child with a disability? Why or why not might that be?

6. What behaviors/beliefs of school personnel (teachers or administrators) contribute to positive relationships and programming when working with these families? What behaviors/beliefs contribute to undesired consequences?

7. What could better prepare administrators to work with families in such unique situations? Are there training or support implications? If so, please describe them.
# APPENDIX C

North Carolina State University
Institutional Review Board for the Use of Human Subjects in Research
SUBMISSION FOR NEW STUDIES

## GENERAL INFORMATION

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<table>
<thead>
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<tr>
<td>1. Date Submitted:</td>
<td><strong>November 7, 2008</strong></td>
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<tr>
<td>2. Title of Project:</td>
<td><em>Phenomenological Study of Multiple Incidence Autism Families and Educational Administrators’ Perspectives: Informing Practice</em></td>
</tr>
<tr>
<td>3. Principal Investigator:</td>
<td><strong>Kristin M. Bell</strong></td>
</tr>
<tr>
<td>4. Department:</td>
<td><strong>Educational Leadership</strong></td>
</tr>
<tr>
<td>5. Campus Box Number:</td>
<td><strong>None</strong></td>
</tr>
<tr>
<td>6. Email:</td>
<td><strong><a href="mailto:kbell@hillcenter.org">kbell@hillcenter.org</a></strong></td>
</tr>
<tr>
<td>7. Phone Number:</td>
<td><strong>919-489-7464</strong></td>
</tr>
<tr>
<td>8. Fax Number:</td>
<td><strong>919-489-7466</strong></td>
</tr>
<tr>
<td>9. Faculty Sponsor Name and Email Address if Student Submission:</td>
<td><strong>Dr. Kenneth H. Brinson, Jnr./ken_brinson@ncsu.edu</strong></td>
</tr>
<tr>
<td>10. Source of Funding? (required information):</td>
<td><strong>None</strong></td>
</tr>
<tr>
<td>11. Is this research receiving federal funding?:</td>
<td><strong>NO</strong></td>
</tr>
<tr>
<td>12. If Externally funded, include sponsor name and university account number:</td>
<td><strong>N/A</strong></td>
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<td>13. RANK:</td>
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<td>□ Student: □ Undergraduate; □ Masters; or □ PhD</td>
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<td>X Other (specify): <strong>Ed.D. Student</strong></td>
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As the principal investigator, my signature testifies that I have read and understood the University Policy and Procedures for the Use of Human Subjects in Research. I assure the Committee that all procedures performed under this project will be conducted exactly as outlined in the Proposal Narrative and that any modification to this protocol will be submitted to the Committee in the form of an amendment for its approval prior to implementation.

**Principal Investigator:**

**Kristin M. Bell**

_______________________________ * 11-07-08

(typed/printed name) (signature) (date)

As the faculty sponsor, my signature testifies that I have reviewed this application thoroughly and will oversee the research in its entirety. I hereby acknowledge my role as the principal investigator of record.

**Faculty Sponsor:**

_______________________________

(typed/printed name) (signature) (date)

*Electronic submissions to the IRB are considered signed via an electronic signature*
Please complete this application and email as an attachment to: joe_rabiega@ncsu.edu or send by mail to: Institutional Review Board, Box 7514, NCSU Campus (Administrative Services III). Please include consent forms and other study documents with your application and submit as one document.

For SPARCS office use only
Reviewer Decision (Expedited or Exempt Review)

☐ Exempt ☐ Approved ☐ Approved pending modifications ☐ Table

Expedited Review Category: ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8a ☐ 8b ☐ 8c
☐ 9

Reviewer Name ___________________________ Signature ___________________________ Date __________

North Carolina State University
Institutional Review Board for the Use of Human Subjects in Research

GUIDELINES FOR A PROPOSAL NARRATIVE

In your narrative, address each of the topics outlined below. Every application for IRB review must contain a proposal narrative, and failure to follow these directions will result in delays in reviewing/processing the protocol.

A. INTRODUCTION

1. Briefly describe in lay language the purpose of the proposed research and why it is important.

This study is being conducted to provide data to better understand how the experiences of parents in multiple incidence Autism families may better inform educational administrative decision making, as it pertains to programming and services for students with Autism Spectrum Disorder. Having more than one child with Autism poses familial and educational challenges, and the struggles may be intensified as parents learn to manage issues specific to the home and to the school. School administrators who have worked with multiple incidence Autism families/children will be interviewed to respond to the data collected from parent interviews. Research on this topic will add to the literature (currently there are few studies of multiple incidence Autism families) and possibly help bridge the gap of understanding between parents and educational leaders, potentially resulting in the reciprocity of richer relationships and empathy amongst parents and educators.

2. If student research, indicate whether for a course, thesis, dissertation, or independent research.

The study is a dissertation research project to satisfy the requirements for the Ed.D. Degree in Educational Leadership and Supervision for North Carolina State University.

B. SUBJECT POPULATION

1. How many subjects will be involved in the research?
2. Describe how subjects will be recruited. Please provide the IRB with any recruitment materials that will be used.

All of the subjects (parents and administrators) will be chosen purposefully due to their unique characteristics. Parent contacts will be initially identified through a key informant who meets the criteria for the study. The key information is a parent of multiple children with Autism. Through previous employment and associated responsibilities, the researcher worked with the parent in the school system which her children attended. The key informant’s involvement with similar families, on a local and national scale, along with relationships that have been built, put her in a position of knowing many families who may be interested in participating in the study. Snowball sampling methods will be used to recruit additional participants.

School administrators may be from elementary, middle, or high school levels. No other school personnel (i.e., teachers, assistants, counselors, psychologists) will be interviewed. Administrators will be chosen based on their experience working with multiple families over the course of their careers. Since administrators will be asked only to respond to broad themes obtained from the collective parent interviews and no child or family-specific information will be provided, administrators will have no knowledge of which families were interviewed. Interviews may be conducted with administrators who worked with some of the families interviewed, but since interview questions will not contain identifiable personal or family information, confidentiality will be maintained. Also, the interviewed administrators will have had worked with several multiple incidence Autism families over the course of their careers, so confidentiality of students and families are further protected. No information or artifacts specific to the children or families will be shared or used in interviews with school administrators.

3. List specific eligibility requirements for subjects (or describe screening procedures), including those criteria that would exclude otherwise acceptable subjects.

Parents must be biological and have more than one child identified with Autism, and the children must have current membership in a public school. Children may be officially diagnosed (clinically and/or educationally) with any Autism diagnosis (along the spectrum). Biological parents will be able to share experiences from the child’s birth up until present day. Public school membership is required so data can be obtained to analyze the potential influences of recent legislation and public school policy.

School administrators must be practicing public school leaders, pre-K through 12, who have worked directly with multiple incidence Autism families/children.

4. Explain any sampling procedure that might exclude specific populations.

None

5. Disclose any relationship between researcher and subjects - such as, teacher/student; employer/employee.

There will be no researcher/subject relationships.
6. Check any vulnerable populations included in study:

- [ ] minors (under age 18) - if so, have you included a line on the consent form for the parent/guardian signature
- [ ] fetuses
- [ ] pregnant women
- [ ] persons with mental, psychiatric or emotional disabilities
- [ ] persons with physical disabilities
- [ ] economically or educationally disadvantaged
- [ ] prisoners
- [ ] elderly
- [ ] students from a class taught by principal investigator
- [ ] other vulnerable population.

7. If any of the above are used, state the necessity for doing so. Please indicate the approximate age range of the minors to be involved.

C. PROCEDURES TO BE FOLLOWED

1. In lay language, describe completely all procedures to be followed during the course of the experimentation. Provide sufficient detail so that the Committee is able to assess potential risks to human subjects. In order for the IRB to completely understand the experience of the subjects in your project, please provide a detailed outline of everything subjects will experience as a result of participating in your project. Please be specific and include information on all aspects of the research, through subject recruitment and ending when the subject's role in the project is complete. All descriptions should include the informed consent process, interactions between the subjects and the researcher, and any tasks, tests, etc. that involve subjects. If the project involves more than one group of subjects (e.g., teachers and students, employees and supervisors), please make sure to provide descriptions for each subject group.

Participants will be contacted by telephone and/or email for initial inquiries regarding their participation in the study. Follow up meetings will occur, and information regarding the study will be provided (informed consent). The researcher will meet with each participant to further discuss the study and to answer any questions potential participants may have.

Parents may choose to provide personal information about their child (pictures, childhood memorabilia, personal items) for the researcher to review. Parents will not be asked to provide the researcher with originals or copies of documents that contain any identifying or confidential information about their children. Sharing of information from any documents will be voluntary on part of the parents and may be done orally or through the showing of specific documents (i.e., evaluations, IEPs, reports). The researcher will not collect any documents or artifacts that contain confidential information. All documents/artifacts will remain with the parents, and any
information from such documents will merely be recorded by the researcher. The researcher will ensure that all identifying personal information is not included in researcher notes. Parents will be informed of all measures to maintain confidentiality and secure data. No information from artifacts or documents specific to the children or families will be shared or used in interviews with school administrators.

Interviews with parents will begin with a general question regarding their experiences within a multiple incidence family. Additional probing questions may be asked by the researcher, depending upon levels and depths of parental sharing. School administrators will be asked more structured interview questions and to respond to the themes/data obtained from the collective parent interviews. Confidentiality will be maintained as parental data/themes will be presented as a whole, not individually or in a manner that will lead to administrators making conclusions or assumptions regarding specific families or names. All participants’ names will be altered to protect anonymity.

Parents will be provided an opportunity to review transcripts and all information obtained during the interview process, allowing them to determine whether or not they feel comfortable with certain information they provided being permitted in the study.

2. How much time will be required of each subject?

Interviews with parents may take between 2-3 hours. Should follow up interviews be needed, an additional 30 minutes to an hour may be required. School administrator interviews should not exceed 1-2 hours.

D. POTENTIAL RISKS

1. State the potential risks (physical, psychological, financial, social, legal or other) connected with the proposed procedures and explain the steps taken to minimize these risks.

All participants will have the option of participating or not in the research. Parents and administrators will be sharing personal perspectives/experiences and sensitive information, so the researcher will maintain appropriate interactions that are responsive (active listening, empathy) to the needs of each participant. All information (interview transcripts, recordings) will be secured to ensure confidentiality and to protect identities. The researcher possesses extensive professional experience in working with exceptional families and school administrators. The researcher’s administrative responsibilities have included facilitating individual and team conferences with parents and administrators, frequently to work toward resolution of problematic situations. In addition to professional experience which required expert facilitation and communication skills, the researcher is a licensed school administrator and has successfully completed higher education coursework and training specific to facilitated leadership. Since sensitive, personal information is being shared, participants may experience emotional responses when sharing information. Based on the researcher’s experience and training, her ability to provide a comfortable and trusting environment will help participants feel at ease. Additionally, the researcher will be able to intervene (i.e. ask participant if he/she would like a break or stop interviewing for the day, turn recorder off if needed or requested, redirect the dialogue) should signs of anxiety be seen or emotions begin to escalate.

The children in this study may be considered “third party subjects”. Private, identifiable information is collected about the children although they do not participate directly in the research. Any identifiable information about the children in this study will be altered to protect anonymity. If parents decide to provide the researcher documents for review, no identifiable information from such artifacts will be used or referred to in any of the research. All digital recordings of interviews and other physical documents or artifacts will be kept in a secured
Since all children in the study will be school-aged and under the direct care and supervision of their parents, they will not be provided informed consent. Rather, parents/guardians will be asked to advocate and act on behalf of their children.

2. **Will there be a request for information that subjects might consider to be personal or sensitive (e.g. private behavior, economic status, sexual issues, religious beliefs, or other matters that if made public might impair their self-esteem or reputation or could reasonably place the subjects at risk of criminal or civil liability)?**

Participants will not be asked to share any information that could be damaging in any way should it be made public.

   a. If yes, please describe and explain the steps taken to minimize these risks.

   b. Could any of the study procedures produce stress or anxiety, or be considered offensive, threatening, or degrading? If yes, please describe why they are important and what arrangements have been made for handling an emotional reaction from the subject.

   No.

3. **How will data be recorded and stored?**

   All research data will be digitally recorded then electronically transcribed for analysis. The researcher will secure all data in a location that is only accessible by the researcher. All information that may connect participants to schools and families will be removed or changed. The names of participants will be altered in the original data in order to maintain confidentiality.

   a. **How will identifiers be used in study notes and other materials?**

      All participants will be assigned pseudonyms.

   b. **How will reports will be written, in aggregate terms, or will individual responses be described?**

      Individual responses and aggregate terms will be used, but all participants’ names will be changed so no connections can be made between participant name and family/school/district.

4. **If audio or videotaping is done how will the tapes be stored and how/when will the tapes be destroyed at the conclusion of the study.**

   Audio recording will be done digitally and data will be transferred to the researcher's computer which is
password protected and secured within the researcher's domicile. All recordings will be properly deleted/destroyed after the completion of the dissertation project.

5. Is there any deception of the human subjects involved in this study? If yes, please describe why it is necessary and describe the debriefing procedures that have been arranged.

No deception shall occur.

E. POTENTIAL BENEFITS

This does not include any form of compensation for participation.

1. What, if any, direct benefit is to be gained by the subject? If no direct benefit is expected, but indirect benefit may be expected (knowledge may be gained that could help others), please explain.

No direct benefits are expected to be gained by the participants. However, findings may contribute to a better reciprocal understanding of the challenges and needs of school administrators and multiple incidence Autism families with ultimate potential benefit in the arena of student programming and services in the public schools.

F. COMPENSATION

1. Explain compensation provisions if the subject withdraws prior to completion of the study.

No compensation will be provided for subjects.

2. If class credit will be given, list the amount and alternative ways to earn the same amount of credit.

No class credit will be given.

G. COLLABORATORS

1. If you anticipate that additional investigators (other than those named on Cover Page) may be involved in this research, list them here indicating their institution, department and phone number.

There is no anticipation of additional investigators.

2. Will anyone besides the PI or the research team have access to the data (including completed surveys) from the moment they are collected until they are destroyed.

No.

H. CONFLICT OF INTEREST

1. Do you have a significant financial interest or other conflict of interest in the sponsor of this project?

NO
2. Does your current conflicts of interest management plan include this relationship and is it being properly followed? N/A

I. ADDITIONAL INFORMATION
1. If a questionnaire, survey or interview instrument is to be used, attach a copy to this proposal. (Interview questions attached).
2. Attach a copy of the informed consent form to this proposal.
3. Please provide any additional materials that may aid the IRB in making its decision.

J. HUMAN SUBJECT ETHICS TRAINING
*Please consider taking the Collaborative Institutional Training Initiative (CITI), a free, comprehensive ethics training program for researchers conducting research with human subjects. Just click on the underlined link.
APPENDIX D
Institutional Review Board Approval

North Carolina State University is a land-grant university and a constituent institution of The University of North Carolina

Office of Research and Graduate Studies

NC STATE UNIVERSITY

Sponsored Programs and Regulatory Compliance
Campus Box 7514
2701 Sullivan Drive
Raleigh, NC 27695-7514

919.515.2444
919.515.7721 (fax)

From: Joseph Rabiega, IRB Coordinator
North Carolina State University
Institutional Review Board

Date: December 19, 2008

Project Title: Phenomenological Study of Multiple Incidence Autism Families and Educational Administrators’ Perspectives: Informing Practice

IRB#: 626-08-12

Dear Kristin:

The project listed above has been reviewed by the NC State Institutional Review Board for the Use of Human Subjects in Research, and is approved for one year. This protocol expires on December 16, 2009, and will need continuing review before that date.

NOTE:

1. You must use the attached consent form which has the approval and expiration dates of your study.

2. This board complies with requirements found in Title 45 part 46 of The Code of Federal Regulations. For NCSU the Assurance Number is: FWA00003429.
3. Any changes to the attached protocol and supporting documents must be submitted and approved by the IRB prior to implementation.

4. If any unanticipated problems occur, they must be reported to the IRB office within 5 business days.

5. Your approval for this study lasts for one year from the review date. If your study extends beyond that time, including data analysis, you must obtain continuing review from the IRB.

Please forward a copy of this letter to your faculty sponsor.

Sincerely,

[Signature]

Joseph Rabiega
NCSU IRB
APPENDIX E

Informed Consent

Revised 06/2008

North Carolina State University
Institutional Review Board For The Use of Human Subjects in Research

GUIDELINES FOR PREPARATION OF INFORMED CONSENT FORM

PLEASE READ ALL OF THIS INFORMATION CAREFULLY
PRIOR TO COMPLETING THE CONSENT FORM

An Informed Consent Statement has two purposes: (1) to provide adequate information to potential research subjects to make an informed choice as to their participation in a study, and (2) to document their decision to participate. In order to make an informed choice, potential subjects must understand the study, how they are involved in the study, what sort of risks it poses to them and who they can contact if a problem arises (see informed consent checklist for a full listing of required elements of consent). Please note that the language used to describe these factors must be understandable to all potential subjects, which typically means an eighth grade reading level. The informed consent form is to be read and signed by each subject who participates in the study before they begin participation in the study. A duplicate copy is to be provided to each subject.

If subjects are minors (i.e. any subject under the age of 18) use the following guidelines for obtaining consent:

- 0-5 years old – requires signature of parent(s)/guardian/legal representative
- 6 – 10 years old - requires signature of parent(s)/guardian/legal representative and verbal assent from the minor. In this case a minor assent script should be prepared and submitted along with a parental consent form.
- 11 - 17 years old - requires signature of both minor and parent/guardian/legal representative

If the subject or legal representative is unable to read and/or understand the written consent form, it must be verbally presented in an understandable manner and witnessed (with signature of witness). If there is a good chance that your intended subjects will not be able to read and/or understand a written consent form, please contact the IRB office (919-515-7515 or 919-515-4514) for further instructions.

*For your convenience, attached find a sample consent form template that contains necessary information. In generating a form for a specific project, the principal investigator should complete the underlined areas of the form and replicate all of the text that is not
underlined, except for the compensation section where you should select the appropriate text to be used out of several different scenarios.

*This consent form template can also be adapted and used as an information sheet for subjects when signed informed consent is waived by the IRB. An information sheet is usually required even when signed informed consent is waived. The information sheet should typically include all of the elements included below minus the subject signature line; however it may be modified in consultation with the IRB.

North Carolina State University
INFORMED CONSENT FORM for RESEARCH

Title of Study: A Phenomenological Study of Multiple Incidence Autism Families and Educational Administrators’ Perspectives: Informing Practice

Principal Investigator: Kristin M. Bell
Faculty Sponsor: Dr. Kenneth H. Brinson, Jnr.

What are some general things you should know about research studies?
You are being asked to take part in a research study. Your participation in this study is voluntary. You have the right to be a part of this study, to choose not to participate or to stop participating at any time. The purpose of research studies is to gain a better understanding of a certain topic or issue. You are not guaranteed any personal benefits from being in a study. Research studies also may pose risks to those that participate. In this consent form you will find specific details about the research in which you are being asked to participate. If you do not understand something in this form it is your right to ask the researcher for clarification or more information. A copy of this consent form will be provided to you. If at any time you have questions about your participation, do not hesitate to contact the researcher(s) named above.

You are not guaranteed any personal benefits from being in a study. Research studies also may pose risks to those that participate. In this consent form you will find specific details about the research in which you are being asked to participate. If you do not understand something in this form it is your right to ask the researcher for clarification or more information. A copy of this consent form will be provided to you. If at any time you have questions about your participation, do not hesitate to contact the researcher(s) named above.

What is the purpose of this study?
The purpose of research study is to find out how parents who have more than one child diagnosed with Autism have experienced home and school situations and how school administrators who have worked with multiple incidence Autism families perceive their experiences. School administrators will also be asked to respond to themes, specific to educational experiences, that emerged from parent interviews. The study will examine how the experiences and challenges facing parents and administrators influence the educational process. Data collected from the study may help to inform educational leadership practices to improve programming and services for students with exceptional needs.
What will happen if you take part in the study?
If you agree to participate in this study, you will be asked to spend approximately 2-3 hours with the researcher in an interview. The interview will be digitally recorded then transcribed and submitted with the final report. To ensure accuracy of the transcripts, you will be given the opportunity to review your interview transcript before any information is used as research.

Risks
As a voluntary participant, there are minor risks associated with your involvement in this research. You will be asked to spend time, either individually or with your partner, with the researcher to address interview questions.

Benefits
The information that you provide may contribute to a better understanding of the relationships between multiple incidence Autism families and school leaders and practitioners, with potential benefits in the form of improved programming for students with exceptional needs.

Confidentiality
The information in the study records will be kept strictly confidential. Data will be stored securely in a digitally/electronically location that will be password protected, only accessible to the researcher. No reference will be made in oral or written reports which could link you to the study. You will NOT be asked to write your name on any study materials so that no one can match your identity to the answers that you provide.

Archival information about children will not be collected in order to further ensure confidentiality of student and parent information. The researcher will not be asking for copies or originals of any documents or artifacts that contain any personal or identifiable information.

Compensation
You will receive no compensation for participating.

What if you have questions about this study?
If you have questions at any time about the study or the procedures, you may contact the researcher, Kristin M. Bell, at kbell@hillcenter.org.

What if you have questions about your rights as a research participant?
If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Deb Paxton, Regulatory Compliance Administrator, Box 7514, NCSU Campus (919/515-4514), or Joe Rabiega, IRB Coordinator, Box 7514, NCSU Campus (919/515-7515).
Consent To Participate

“I have read and understand the above information. I have received a copy of this form. I agree to participate in this study with the understanding that I may withdraw at any time.”

Subject's signature_______________________________ Date _________________

Investigator's signature___________________________ Date _________________
APPENDIX F

LETTER REQUESTING PERMISSION TO PARTICIPATE IN RESEARCH STUDY

Date: __________________

Dear School Administrator:

I am requesting your participation in research for my dissertation. Your experience and expertise working with families who have multiple children identified with Autism can result in valuable contributions to my study, and I would be grateful for your insights. The following provides some information about the details of my study:

Purpose of the Study:
I am conducting a qualitative, phenomenological study of the lived experiences of multiple incidence Autism families and reflections of school administrators who have worked with such families. I will be interviewing families to better understand their familial and educational experiences. School administrators will then be interviewed and asked to share their experiences with such families and to reflect on themes derived from the parent interviews. The study will examine how the experiences and challenges facing parents and administrators influence the educational process. Data collected from the study may help to inform educational leadership practices to improve programming and services for students with exceptional needs.

Details of Your Participation:
Should you choose to participate, you will be asked to spend approximately 1-2 hours in an interview with me. I will ask you questions regarding your experiences with multiple incidence Autism families during your career and to reflect on themes from parent interviews. If you are a currently practicing administrator, interviews will be scheduled at times and locations that do not disrupt educational services for students. All interviews will be scheduled at times and locations that are convenient for you.

Confidentiality:
No identifiable information of individual students or families will be provided, and you will not be asked to provide any such information in your responses. In fact, identifiable information will be discouraged from being provided during the interviews in order to maintain confidentiality of all participants. The information in the study records will be kept strictly confidential. Data will be stored securely in a digitally/electronically location that will be password protected, only accessible to the researcher. No reference will be made in oral or written reports which could link you
to the study. You will NOT be asked to write your name on any study materials so that no one can match your identity to the answers that you provide.

**Risks:**
There are no risks associated with your participation in this study. Your participation is voluntary and can be revoked at any time. No students or other school personnel will be interviewed as part of this study.

**Benefits:**
The information that you provide may contribute to a better understanding of the relationships between multiple incidence Autism families and school leaders and practitioners, with potential benefits in the form of improved programming for students with exceptional needs.

**Compensation:**
You will receive no compensation for participating in this study.

**Questions About Your Rights As A Participant:**
If you have questions at any time about the study or the procedures, you may contact the researcher, Kristin M. Bell, at kbell@hillcenter.org or [919-632-8883].

**Questions about your rights as a research participant?**
If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Deb Paxton, Regulatory Compliance Administrator, Box 7514, NCSU Campus (919/515-4514), or Joe Rabiega, IRB Coordinator, Box 7514, NCSU Campus (919/515-7515).

**Consent To Participate**
"I have read and understand the above information. I have received a copy of this form. I agree to participate in this study with the understanding that I may withdraw at any time."

Administrator’s signature________________________ Date _________________

Researcher’s signature________________________ Date _________________
APPENDIX G

Recruitment Script
Talking Points

The script below may be used to contact potential participants by telephone. The talking points included may also be incorporated into electronic mail correspondences as initial contacts or for the provision of follow-up information.

I = Interviewer
P= Potential Participant

Script/Talking Points:

I = Hello. May I please speak to [potential participant]?

P = Hi. This is [potential participant]. How may I help you?

I = My name is Kristin Bell, and I am a doctoral student in the Educational Leadership program at North Carolina State University. I am conducting research on multiple incidence Autism families. [Key informant] suggested I contact you as a potential participant in my study. Is this a convenient time to give you further information about the study?

P = No thanks. I'm not interested. Good luck.

I = Would you mind if I leave you with my contact information should you change your mind?

P = Sure.

OR

P = Sure, this sounds interesting. Please provide me with more information.

I = Absolutely. Here are some key points about the study:

- Qualitative study with a focus on interviews (digitally recorded).
- Interviews of parents in multiple incidence Autism families (defined as having more than one child diagnoses with Autism).
• Interviews with school administrators who have worked with such families.

• Interviews would last about an hour – May need follow up interviews at a later date.

• Will schedule at times and locations that are convenient to participants.

• Involvement is voluntary, with no known risks to participants.

• Questions for parents: Focus on experiences raising the children and school experiences.

• Questions for administrators: Focus on reactions to themes from parent information/experiences.

• All data will be stored in a secured location, and all information will be kept confidential.

• You may decline to answer any questions at any point and choose to withdraw from the study at any time.

• If you have any questions about this study, you may contact me any time at the following number or email address.

• The study has been approved by the NCSU Institutional Review Board.

I - With your permission, I would like to mail or email you an information letter which has all of these details along with contact names and numbers on it to help assist you in making a decision regarding your participation in this study.

P – That would be great. Please send me the information.

I – Wonderful! To which address would you like the information sent (email or traditional mail)?

P- Either is fine. Here’s my information.

I - Thank you very much for your time. May I call you in a couple of days to see if you are interested in being interviewed?
P – Sure. You can call or email. Either is fine.

I – Thanks again. Please remember, if you have any questions or concerns please do not hesitate to contact me. Goodbye.

P – Goodbye.
Appendix H: Diagram 1: Synthesis of Textural and Structural Descriptions & The Essence of the Experience

- Altered View of the World
- Tacit Resiliency
- Preservation of Family Efficacy
- The Essence: Obligation to spirit of resilience in constant change
- Path Blazers
- People over Process