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# Walden University

College of Social and Behavioral Sciences

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# Antonia Klein

has been found to be complete and satisfactory in all respects, and that any and all revisions required by the review committee have been made.

# **Review Committee**

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Walden University 2015

#### Abstract

Professionals have found autism to be an enigmatic condition. While necessary biomedical research continues, a gap exists in the inclusion of parental opinions, knowledge, and experiences in educational planning for their autistic children. The purpose of this mixed methods study was to identify the factors that the parents felt contributed to the academic success of their autistic child in the public school classroom environment and ways in which their ideas might contribute to overall educational planning and classroom design in structure, curriculum development, and intervention strategies which might lead to reduced stress. Parental input was explored through semistructured personal interviews with 8 parents and the administration of a 32-question survey questionnaire to 109 parents of autistic children. A content analysis was done on the qualitative data, and an analysis of quantitative data reported the frequency and percentages of the participant responses. Findings from the data revealed multiple areas in need of improved educational services that include the classroom organization, educator training and knowledge about the autistic condition, educator support, effective communication, and behavioral management of the symptoms of autism. The social change impact from the study's findings have the potential to inform educational planning, foster collaboration, increase educator participation in autism training methods, secure necessary funding for evidence based autism educational programs, promote further research, and provide awareness of existing empirically based approaches designed to meet the needs of a vulnerable population.

# The Environmental Health of the Autistic Student in the Public School Classroom

by

# Antonia Klein

MS, Walden University, 2007 BS, Rocky Mountain College, 2004

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy
Health Psychology

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## Dedication

This research is dedicated to the memory of Fernand Deligny. We must keep the rafts afloat as they are finely fit and not meant to lie as severed, rotted pieces of wood at the bottom of a copious ocean.

To the memory of Dana Robert Blanchard (5/25/1953 - 4/29/2012): a man who will be remembered for his unconditional love and the twinkle in his eye when he made me laugh.

To the memory of Martin Dennis Ballhaus (3/16/1952-2/7/2013): a man who will fondly be remembered as a saving grace.

To my best friend, Jesus.

To my daughter, Danielle J. Lupinacci for being patient and encouraging throughout this adventure.

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"It is more than time for the French medical community to acknowledge that it is decades behind the rest of the world in understanding what autism is and in treating and educating autistic individuals in ways that will actually help them achieve all they can" Chew (2013).

To David Heurtevent and Sophie Robert for their perseverance in working towards international awareness of a tragic social injustice that affects all autistic individuals and their families.

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# Chapter 1: Introduction to the Study

The autistic condition is a complex disorder, requiring parents, family members, educators, and service providers to adapt in order to meet its multiple demands. The Centers for Disease Control (CDC; 2014) reported that 1 in 68 children carried a diagnosis on the autism spectrum disorders (ASD) and some school-aged children previously had an unrecognized diagnosis on the ASD (Blumberg et al, 2013). Families and educators reported a high level of stress due to the lack of support, resources, and training (Cherniss, 1988; Gupta & Singhal, 2004; Milkie &Warner, 2011). Families who have a child with the autistic condition suffer from increased stress and anxiety in their attempts to deal with all of the complex changes they undergo when they learn that their child has a lifelong condition (Gupta & Singhal, 2004). Educators and service provider professionals might view parental involvement in the educational planning of their autistic child negatively, and this is a potential barrier for parents and students (Spann, Kohler, & Soenksen, 2003).

Researchers have concentrated on the cause of autism. One of the primary purposes of this study was to examine the potential educational challenges and barriers that might be important to parents of children with the autistic condition, particularly within the public school classroom environment. The child with the autistic condition spends a large portion of his or her time in the public school classroom, making it imperative for school administrators to be aware of and implement evidence-based approaches to autism in order for the educators and staff to provide quality educational services for students. Educators might benefit from gaining the necessary skills in order

to communicate positively and effectively with parents, provide resources, coordinate efforts, assist with the implementation of evidence-based program models, provide classroom behavioral management, and provide the support and awareness training for the parents in order to improve the quality of life for students and their families. Gutpa and Singhal (2004) emphasized that due to the rise in those diagnosed with the autistic condition, it is necessary to develop services to meet the needs of the entire family. The voice of the parents is required in any attempts to establish environmentally beneficial educational programs for autistic students in the public school classroom (Arnini, 2007; ASA Advocate, 1994; Spann et al., 2003).

One of the challenges facing educators and families of a student with the autistic condition lies in the management of behavioral symptoms in the classroom and in the home. The Division for Early Childhood (DEC, 1998) examined interventions for those with behavioral challenges. Critical factors in intervention planning include the need for a team-based assessment, extensive interventions, knowledge of environmental factors contributing to behavior, and input from a disciplinary team approach that includes family members. Koenig, Bleiweiss, Brennan, Cohen, and Siegel (2009) viewed the classroom "to be a major vehicle for change for children with autism spectrum disorder (ASD)" (p. 7). The DEC emphasized that the familial impact of the known behavioral challenges is something that must be considered in any planning and implementation approaches.

Oftentimes, family members have strategies that might be helpful in the management of these behaviors. Communication and collaboration among the

educational services providers of students with the autistic condition appears to improve services as well as unique approaches to individuals in the classroom setting. These factors have the potential to provide a positive classroom environment that might contribute to increased academic success and reduced stress for educators and parents.

While autism researchers have examined the challenges that exist in the areas of education, nutrition, pharmacology, audiology, optometry, cognitive, biopsychosocial, communication, environmental, stress, and anxiety among educators, parents, autistic children, teacher training, and collaboration among stakeholders, there remains to be the emergence of a single, unified expert voice in autism. There is a need for an integrated and collaborative approach in the educational programs developed for the autistic student in the public school system classroom with the primary voice being that of the parents and all components driven by empirical research findings.

While the bulk of autism researchers have focused on the biological or genetic causes of the autistic disorder, a majority of any available funding has been designated for these investigations leaving any financial resources that might examine the interventions and treatments, such as applied behavioral analysis (ABA). Treatment and education of autistic and related communication handicapped children (TEACCH), structural organization, and sensory sensitive environments are underfunded (Mesibov, 2004). Autism researchers have provided insights into brain dysregulation, which is believed to cause sensory processing problems, immune dysregulation, and genetic abnormalities (Akshoomoff, Pierce, & Courchesne, 2002). Such research has made a positive impact on educational services for students with the autistic condition in the

classroom environment, its structure, and methods of dealing with the number of stimuli sensitivities that exist in the autistic student population. However, evidence-based approaches have yet to be implemented in the public school environment for autistic students (Callahan, Shukla-Mehta, Magee, & Wie, 2009).

There are many issues within the biological and genetic research that have a direct bearing on the academic success or failure of autistic children. Many disciplines are involved in a contribution of positive approaches. While some work towards an empirical standing, some of the contributions by others over the past several decades who have focused on an autistic child's environment are not as well known. Such examples include the work of Deligny, a special needs educator, and Itard, a physician, who worked with autistic children free from medications and minimal knowledge of biological and genetic components that contribute to the autistic condition. Itard succeeded in providing learning opportunities with positive outcomes, all of which were either documented in print, movie, and/or written word. While interventions and research into the autistic condition grows, some methods founded by Deligny and Itard have not been explored as they should be and applied to what is known about the condition. These researchers contributed knowledge about the autistic condition and much of their writings focused on the ability of an autistic child to succeed in academics when provided a healthy environment that fostered their growth and development.

The purpose of this study was to examine the effects upon the autistic child and their families when there is a lack of integrated and collaborative evidence-based approaches within the public school classroom environment. The opinions of the parents

and/or primary caregivers of a child with the autistic condition in the public school system were sought regarding the school classroom environment as the parental opinions should be the basis of any educational planning and service provision for autistic students (Arnini, 2007; ASA Advocate, 1994; Spann et al., 2003). The findings from this study might inform policy makers, administrators, educators, and parents in ways to improve the educational environment for students with the autistic condition.

# **Background of the Problem**

The autistic condition is a developmental disorder that affects social interaction and communication and is accompanied by repetitive behaviors and restricted interests.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5, APA, 2013), defined the essential features of autism spectrum disorder as

Persistent impairment in reciprocal social communication and social interaction (Criterion A), and restricted, repetitive patterns of behavior, interests, or activities (Criterion B). These symptoms are present from early childhood and limit or impair everyday functioning (Criterion C and D)

Manifestations of the disorder also vary greatly depending on the severity of the autistic condition, developmental level, and chronological age; hence, the term spectrum. Autism spectrum disorder encompasses disorders previously referred to as infantile autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Asperger's disorder. (53)

Mahatmya, Zobel, and Valdovinos (2008) stated the etiology of the autistic condition was unknown and currently being researched as well as debated. An accurate diagnosis of the autistic condition would benefit researchers in that the identification of specific biological processes might be treated, as well as other subgroups as targets for precise treatment (Corbett et al., 2007). There are no known biological markers for the autistic condition and the diagnosis is solely based on behavioral criteria (Goines, Schauer, Heuer, Ashwood, & Van de Water 2007; Rice, 2009). Research is currently underway in many areas which will ultimately lend to our understanding of a complex condition.

There is an ongoing research into the genetic and physiologic factors believed to play a role in the autistic condition. Schall (2002) discussed the lack of knowledge regarding the pathophysiology of the symptoms of the autistic condition. Reinberg (2009) stated that some scholars had revealed that mothers suffering from an autoimmune disorder such as Diabetes 1, rheumatoid arthritis, and celiac disease were 3 times more likely to produce offspring who had the autistic condition. Dietert and Dietert (2008) believed that environmental exposure to infections and many prenatal stress conditions were likely to alter the development of the fetal immune system. Dietert and Dietert had coined the potential exposure, developmental immunotoxicity (DIT), and stated that the condition occurs when the fetus undergoes an exposure that potentially alters the development of the immune system, which results in an adverse event.

Smoking cigarettes while pregnant is one such toxic exposure and is believed to likely be a risk factor in developing the autistic condition. Drugs may be another risk

factor via the gestation period or during lactation and might have the potential to produce changes that are called "immunotoxic" (Dietert & Dietert, 2008, p. 672). As research continues, it will provide insights into those areas of concern and will likely reveal ways the abnormalities might contribute to the development of the autistic condition.

Research into the immune system has revealed some areas of dysfunction. There is an abnormality in the immune system response that might lead to the autistic condition (Littman, 2010). Enstrom et al. (2008) suggested a link between immune system response dysfunction and autoimmune and inflammatory processes gone awry, resulting in the autistic condition. Cabanlit, Wills, Goines, Ashwood, and Van de Water (2007) stated that while ASD might be diagnosed from a behavioral perspective, there are immune system response abnormalities that might suggest that autoimmunity plays a role in the development of the autistic condition.

Proflammatory cytokines, a product of the immune system response (ISR), has the ability to induce behavioral symptoms associated with the autistic condition (Croonenberghs, Bosmans, Deboutte, Kenis, & Maes, 2002). When the production of proinflammatory cytokines is increased, the result is a contribution to the onset of pathophysiology resulting in the autistic condition. The behavioral symptoms believed to be affected include social withdrawal, sleep disturbances, and oppositional behaviors.

Ashwood and Van de Water (2004) suggested that the dysfunction in the immune system might lead to neuronal tissue disintegration within the central nervous system (CNS) and there is reduced neuronal and dendritic formation in "the amygdala, hippocampus, mammillary bodies, and medial septial nucleus" (p. 166.).

There are neurological aberrations from faulty neuron differentiation development within the brain. An increase in the abnormal levels of neuron development during the fetal period potentially leads to abnormalities in the serotonin, dopamine, noradrenaline, gamma-aminobutryic acid (GABA), glutamate, and neuropeptides, which are all implicated in contributing to the dysfunctional process. Enstrom et al. (2008) suggested that the brain-derived neurotrophic factor (BDNF) plays a role in the development of the autistic condition as it has been suggested it does play a role in the development of certain psychological disorders in children, such as schizophrenia, depression, and bipolar disorder. Krause, He, Gershwin, and Shoenenfeld (2002) stated that immune system abnormalities have been found in autistic children that were believed to be responsible for a dysfunction in neurological development. Licinio and Wong (2002) hypothesized that the local autoimmunity in the gastrointestinal tract might have led to neurological impairment through the failure of adequately detoxifying the gut's neurological by-products. The abnormalities in the multiple areas noted by the researchers pointed out the complexity of the autistic condition and the importance of multi-faceted methods of investigation.

The biomedical anomalies in the autistic condition potentially lend to the many behavioral symptoms associated with it. Bradstreet, Smith, Baral, and Rossignol (2010) stated that the diagnostic criteria for a diagnosis of the autistic condition are based solely upon behavioral criteria rather than any contributions from biomedical influences.

Bradstreet et al. stated that there are potential roles that the biomedical processes might play, such as an immune response dysregulation, development of autoantibodies, faulty

fetal brain development, intestinal mucosal dysregulation, and others. Bradstreet et al. pointed out that it was possible that these factors might be attributed to some of the behavioral symptoms apparent in the autistic condition. Further research can only lend to an understanding of the etiology of the behaviors and whether the biomedical processes might contribute.

The autistic condition is a lifelong condition with no cure, typically occurring around the age of 3 years and affecting males more than females; mental retardation and epilepsy might develop (Rice, 2009). Before the new classification of the ASD in the DSM-5, Scott and Dhillon (2007) described the autistic condition as a DSM-IV-TR classification that lies under the pervasive developmental disorders (PDD) and included conditions within the autism spectrum disorder.

PDD had been replaced with the ASD label (Head-Dylla, 2009) and it remained so with the DSM-5. Nicholson and Castellanos (2000) stated that there are currently no specific treatments available for PDD. Mahatmya, et al. (2008) stated that the social interaction impairments include an inability to establish peer relationships, a lack of a desire for social interaction, repetitive motor symptoms such as rocking and flapping, repetitive use of words, inability to begin a conversation, and the lack of spontaneous play with others. Self-injurious behavior (SIB), disruptive behaviors, agitation, anxiety, over activity, and preoccupation with objects are common and suggested that the SIB had features of obsessive compulsive disorder (OCD; Handen & Lubetsky, 2005; Mahatmya et al., 2008; Wang, 2006; West & Waldrup, 2006). The treatment for SIB is a behavioral approach, and modifications in the autistic child's environment are necessary in order to

prevent the episodes of SIB (Mahatmya et al., 2008). West and Waldrup (2006) stated that the autistic condition is "a biologically based, neurobehavioral, multidimensional disorder that affected verbal and nonverbal communication, physical and verbal interactions, and daily routines and activities" (p. 545). The challenges that lie with professional caregivers and families are often overwhelming due to the severity of the behavioral symptoms of the autistic condition, which are often barriers to a quality of life including social and educational factors.

Strides are currently being undertaken in the psychopharmacological treatment of the autistic condition. West and Waldrup (2006) reported that the autistic condition is primarily treated through psychopharmacology, and problems exist with this approach as some psychotropic medications are not yet approved for use in the autistic condition through the Food and Drug Administration (FDA). Schall (2002) suggested that the children and adolescents who suffer from the autistic condition are "a highly medicated group" (p. 230). Gringas (2000) stated that psychotropic medications are given to at least half of the individuals diagnosed with the condition. Aman, Lam, and Collier-Crespin (2003) stated that while some psychotropic medications had empirical support, others are being prescribed to the autistic population without empirical support and the potential exists for adverse and toxic side effects. Gringas pointed out the importance of the individual nature of prescribing medications for an autistic child and stated,

The fact that a child meets criteria for the autistic condition is not a sufficient indication for prescribing psychopharmacological agents. Children need to be

described in terms of their individual behavioral, communicative, and psychological profiles and not just by a diagnostic label. (Gringas, p. 232)

Esbensen, Greenberg, Seltzer, and Aman (2009) stated that the psychotropic medications commonly prescribed for the autistic condition include antidepressants, stimulants, and antipsychotics. While psychopharmacological methods may be helpful in treating the autistic condition, further research is necessary in order to provide medications that are specifically designed for each individual and to increase the empirical support for such pharmacological treatment.

I examined parental insights, knowledge, and experiences undertaken that might contribute to a beneficial learning environment for the autistic child in order to develop successful academic skills. Successful academic skills may transfer to life skills while leading to reduced stress for the child, the parents, and the educators.

### **Statement of the Problem**

Several researchers have examined the biological, immunological, medicinal, and genetic impacts on the ASD. The research studies into interventions, use of combined programs, and the environmental structure of the classroom are minimal. Much of the research with the population has been done with preschool autistic children, and those scholars stress the importance of early intervention. However, few qualitative and mixed methods approaches have been used to examine the opinions and personal experiences of the parents of autistic students in the public school classroom environment. This phenomenological study contributes to the gap in existing research regarding parental experiences with and opinions about educational services, including teacher training,

potential barriers and stressors for parents, the need for the educational environment to meet the unique needs of the students with the autistic condition, and the lack of communication and collaboration with educators.

While research into the areas of successful design, sensory issues, teacher training, stressors for parents, autistic students, and educators has contributed an awareness into existing problems, little has been done in the implementation of the needed environmental changes specific to autistic students in attendance in the public schools (Callahan et al., 2009). Much of the implementation has been based on what is required by school administrators through the Individuals with Disabilities Education Act (IDEA), federal and state guidelines, and minimal access to training opportunities and journals that afford the educators knowledge about evidence-based approaches that have been empirically tested with autistic children (Hess, Morrier, Heflin, & Ivey, 2008; Tutt, Powell, & Thornton, 2006). Other barriers lie in the lack of the educator's knowledge into evidence-based programs for autistic students leaving educators restricted to picking and choosing what they feel might work with specific students (Callahan et al., 2009; Dingfelder & Mandel, 2011). Collaboration with other service providers and parents is often approached negatively, and a lack of understanding of adverse environmental stimuli exacerbates the situation and creates negative environmental health for autistic students which, in turn, is often carried over to the child's home and continues the impact within the familial structure.

# **Research Questions**

The inclusion of opinions, feelings, knowledge, and experiences of parents with autistic children in the public school classroom will contribute to improved educational planning, inclusion of parental opinion, educator and staff training, and classroom structure (Chandler-Olcott & Kluth, 2009; Cooper-Swanson, 2005; Kidd & Kaczmarek, 2010; Milkie & Warner, 2011). The contributions made by parents of children with the autistic condition receiving educational services in the public school classroom environment are likely to result in the following: greater collaborative planning among educational service providers and other stakeholders; implementation of evidence-based models; comprehensive classroom organization to meet the autistic students' unique needs; improved educator, staff, and parental training; decreased stress for educators; parents, and the autistic student; and improved communication skills among educators and parents.

The objective of this study was to examine parental input on the environmental health of their autistic child participating in the school classroom. The following research questions were developed in order to gain parental responses that were explored in an indepth personal interview that pertained to their feelings on the many complex issues pointed out in the research facing their autistic child in the school environment:

1. What is the lived experience of the parents and the process they underwent regarding the adequacy of current educational services their child receives in the public classroom?

- 2. What is the opinion of the parents regarding the quality of the classroom structure for their child?
- 3. What is the parents' opinions regarding the current environmental health of the public classroom in its ability to afford their child the best learning experience?
- 4. What do parents think might be the environmental health barriers that exist in the public classroom, if any?

A survey yielded insights into level of satisfaction with the classroom organization and structure, presentation of educational materials, noise, light, management of children's behaviors in the classroom, amount of communication with the educator, any perceived barriers, and perceptions of the adequacy of the level of educator training and knowledge of the autistic condition. The survey questionnaire was formulated as follows:

From a scale of 1 to 10 what is your level of satisfaction with the following:

- Classroom organization
- Classroom structure
- Curriculum
- Effects of overhead lighting
- Behavioral management
- Noise management
- Communication with educator and educational staff
- Ability to contribute input in the development of IEP

- Educator training and knowledge about the autistic condition, and
- Level of support provided by the educators and school administration.

# **Purpose of the Study**

The purpose of this research is to investigate whether the parents of autistic students felt that the unique needs of their child are being met in the classroom environment. A mixed methods approach comprising of a phenomenological approach and survey research was used for this study. A phenomenological approach was used to examine the parent and/or primary caregivers' views through an in-depth, personal interview with eight to 10 participants. The interviews were followed up with a survey questionnaire as the quantitative portion of the study. The survey questionnaire was available for 30 to 90 days on Surveymonkey.com in order to gather responses from parents and/or primary caregivers of autistic children who were not participants in the personal interviews.

Numerous agencies that serve the needs of parents and/or primary caregivers of children with the autistic condition who are in the public schools were notified that the survey questionnaire is available. Walden University's Participant Pool was notified in order to let interested parties know about the opportunity to participate in the personal interview and online survey questionnaire. The phenomenological portion of the study included personal interviews with the parents and/or primary caregivers examining whether they felt that educators had regard for their knowledge and experience in raising an autistic child. Parents and/or primary caregivers were asked what barriers they felt might exist in the public school classroom that potentially impedes their child's academic

progress and reduces their environmental health in the public classroom. This study included an examination of the parents and/or primary caregivers' opinions of the sensory supports, classroom structure and organization, IEP and curriculum development, lighting, behavioral management, educator knowledge about the autistic condition, educator communication with parents, parental input, parental training and support, and collaboration.

A qualitative study consisting of a phenomenological approach was chosen in order to explore parental and/or primary caregiver input through semistructured personal interviews and through the administration of a survey questionnaire. Common themes were expected to emerge regarding some parental and/or primary caregiver opinions and were anticipated from the interview data; member checking was employed, and then triangulated with any common themes that emerged with the results of the survey questionnaire and findings from the literature review. The outcome of this research might be used to remove educational barriers for autistic students; improve educator training; improve communication and collaboration; foster an understanding about a complex disorder; provide the parents a voice; reduce stress for educators, families, and autistic students; contribute to educational policy development regarding autistic students and their families; and initiate appropriate individual education plans that might improve the academic success for autistic students.

### **Theoretical Framework**

A foundation for the theoretical framework in the development of autism approaches appears to be developing in the research. There is more than one point of

view involved in working with individuals with the autistic condition. Differences in opinion might have been a barrier in establishing this framework; however, as more research is generated on the variables being examined, it can only lead to a greater understanding of the condition. The etiology of the autistic condition is related to other factors, particularly in the ability to learn.

The research into the autistic condition within the neural cognitive development and the genetic makeup in this population contributed to knowledge about how the condition might affect the autistic student's learning ability and what factors must be addressed in order to meet the unique needs of the autistic child in the classroom environment. For purposes of this study, brain development anomalies, genetic contributory factors, autistic intelligence, and behavioral challenges were discussed in the literature review as ways to theorize about the ASD in order to provide an understanding of the condition. Other research topics included the risk factors for the development of autism; the need for environmental structure; beneficial educational services through teacher training; parent training and support; collaboration of service providers and educators with parents; stress level of parents, educators and autistic children; and sensory processing and support issues in autism. Further understanding in these areas is likely to contribute to ways that might reduce the stress levels of parents and educators and improve academic success for those with an ASD.

The theory of mind (TOM) appeared the most often in the literature review as providing guidance on developmental topics, such as language acquisition, and social differences in those on the ASD. Communication and social interaction led some

researchers to believe that, due to deficits in these areas, the autistic child failed to establish a theory of mind when compared to other children (Yirmiya, Shaked, & Solomonica-Levi, 1998). The TOM was developed from the sociocultural child development theories of Vygotsky, who maintained an interest in the special education needs of developmentally and intellectually challenged children.

The TOM includes the ability to apply mental states to self and to others (Baron-Cohen, Leslie, & Frith, 1985). Baron-Cohen (2008) referred to the lack of an autistic child's ability to form a TOM as "mindblindness." (p. 112). Vygotsky's framework of the sociocultural theory of development was based on four principles: (a) children develop constructs for knowledge, (b) the social context plays a predominant role in development, (c) learning leads to development, and (d) language is at the heart of the child's mental development (Vygotsky, 1978). Vygotsky's research subjects were visually impaired and/or blind, intellectually challenged, deaf, and speech and/or language impaired children (Vygotsky, 1978). Vygotsky suggested that development was cultural-specific in that the child's culture provided tools that assisted him or her in the formation of his or her world view and that the psychological development of children began with the "interpsychological" or between individuals, making it a social level, and next, the "intrapsychological" or within the child (Vygotsky, 1978, p. 86).

Vygotsky (1995) viewed a child's disability as abnormal only when brought into the social context and emphasized that any child with a handicap was affected by the social implications of the condition. The teacher was likely left to deal not so much with the biological factors of that child's condition but with the social consequences it might

have (Vygotsky, 1995). Vygotsky's research on the social implications and its effects on psychological development have contributed a great deal to an understanding of children, particularly those in special education.

The acquisition of the TOM was believed to emerge when a child understood the separation of self from others or gained an understanding that his or her thoughts were different from his or her peers and was able to engage in socially appropriate behavior with their peers. Symons (2004) stated that an understanding of TOM grew through Vygotsky's theory of internalization. Internalization is the process in which a child gained a reasoning ability, likely in social play where the child is able to express him or herself and is able to understand the emotions of their peers (Symons, 2004). Vygotsky's sociocultural theory discussed the element of the zone of proximal development (ZPD). Vygotsky offered three different contexts within which ZPD could be adapted:

(a) identification of the way in which psychological functioning occurs, (b) an alternative to the standard testing, and (c) the role of ZPD in the synergy between daily and scientific thoughts (as cited in Kozulin, 2004).

The classroom environment for special needs children should "be a specially designed setting where the entire staff exclusively served the individual needs of the handicapped child. Their classroom environment should be a special system that employed specific methods due to the fact that handicapped students required modified and alternative educational methods" (Grindis, 1999, p. 79). Vygotsky suggested that a child should be viewed in terms of his or her strengths and not his or her disabilities and alternative methods of education should be employed because this is what was required

in an environment in order to allow the child to develop psychological functioning and overall personality (as cited in Grindis, 1999). Vygotsky emphasized that many of the needs of handicapped children had already been addressed through the Braille and sign language methods (as cited in Grindis, 1999). While Vygotsky's work was developed for the blind and the deaf students, the ideas could be adapted to other populations.

Social skills and communication ability among individuals with the autistic condition appears to be compromised. Yirmiya et al. (1998) stated that the TOM in the autistic condition affects communication, imagination, and Frith (1989) agreed that individuals with the autistic condition are unable to understand the social dynamics in situations and are unable to act appropriately. Some researchers have examined other pervasive problems associated with cognitive processes that might affect the behavioral features of the condition (Pellicano, 2010). There are many strengths characteristic of individuals with the autistic condition as well as deficits, and they pose a challenge in the research as the full range of symptoms must be addressed. The symptoms of the autistic condition indicate numerous anomalies across numerous cognitive areas (Pellicano, Maybery, Durkin, & Maley, 2006).

## **Supporting Theories in Autism**

Viktor, the wild child of Aveyron, was said to be an incurable imbecile by Pinel, a French psychiatrist (Gaynor, 1973). Itard felt differently and thought the likely reason Viktor appeared so was that he had been deprived of human contact since being abandoned in the woods at an early age. Itard developed an educational plan for Viktor with the goal of teaching him language. Viktor was able to learn under Itard's educational

efforts; however, Itard's attempts to teach Viktor language were unsuccessful (as cited in Mock, Kacubecy, & Kauffman (2003). Itard defined intelligence in the following way.

If we consider human intelligence at the period of earliest childhood man does not yet appear to rise above the level of the other animals. All his intellectual faculties are strictly confined to the narrow circle of his physical needs. It is upon himself alone that the operations of his mind are exercised. Education must then seize upon them and apply them to his instruction that is to say to a new order of things which has no connection with his first needs. Such is the source of all knowledge, all mental progress, and the creations of the most sublime genius. Whatever degree of probability there may be in this idea, I only repeat it here as the point of departure on the path towards realization of this last aim. (as cited in Humphrey, 1962, p. 37).

Itard's plan to teach Viktor language was the first attempt at a personal and intensive educational program (Humphrey, 1962). Today, such a personalized educational plan is called an IEP. Itard's attempts were the beginning of specialized programs for the DD population. Itard's goals for Viktor included: (a) encourage Viktor in social skills, (b) assist Viktor in the improvement of his environmental stimuli, (c) engage Viktor in the expansion of his ideas, (d) teach Viktor to speak, and (e) employ a picture system to teach Viktor to communicate. Itard noted that Viktor's reaction to sensory stimuli were minimal and expressed that Viktor was unable to learn until he was aware of his environment and proceeded to use a sensory-based approach with Viktor. Mock et al. (2003) emphasized that educators must employ special educational

approaches that are tailored to meet the unique needs of their students, while the environment must be suitable to the approach. Mock et al. discusses the past and the future of the special education story which "can be written in many different ways" (p. 2281). Educators have the opportunity to meet the unique needs of the students with the autistic condition in a creative manner that has the potential for success in the public school classroom.

Researchers have recognized unique abilities and atypical cognitive processes among individuals with the autistic condition. Dawson, Soulieres, Gernsbacher, and Mottron (2007), in an attempt to investigate the characteristics and levels of autistic intelligence, examined 33 autistic children and compared them to nonautistic children in scores from two intelligence tests: Raven's Progressive Matrices and Wechsler scales of intelligence. Dawson et al. supported the use of atypical cognitive processes when performing tasks and "autistic intelligence is manifested on the most complex single test of general intelligence in the literature" (p. 661). Dawson et al. recommended that researchers not limit themselves to the Wechsler subtests designed to measure perception and low-level rote memory. Frith (1985) believed that some of the behaviors shown by autistic children reveal "capabilities out of the ordinary, sometimes even rare talent" (p. 82). This indicates a need for more comprehensive research examining the extraordinary abilities shown by some individuals with the autistic condition.

Researchers have examined language ability processes in order to gain an understanding of the language acquisition process. Kana, Keller, Cherkassky, Ninshew, and Just (2006) examined 12 autistic individuals using IQ-matched and age controls in

order to determine mental imaging processes in the subjects. Kana et al. theorized that there was a cortical underconnectivity in autistic individuals and this might be shown in the "interregional collaboration required between linguistic and imaginal processing which would be underserved in autism" (p. 2484). The control subjects were more synchronized than those with the autistic condition in demonstrating cortical connectivity in the language and spatial regions of the brain (Kana et al., 2006). Activation in the language and spatial regions of the brain were different in those with the condition than in the control subjects.

Kana et al. (2006) theorized that this is the reason why people on the ASD relied more upon visual input in order to understand language. Kana et al. supported the theory of the cortical under-connectivity in the autistic condition. People on the ASD have difficulty in understanding complex instructions, jargon and metaphors, and connected discussion (Dennis, Lazenby, & Lockyer, 2001a, 2001b; Happe, 1993; Kana, Minshew, & Goldstein, 1998).

Research efforts into brain development are being undertaken in order to facilitate the early diagnosis of the autistic condition. Wolff et al. (2012) found that there was the likelihood of abnormal development in the white matter pathways of the brain that leads to the manifestation of the symptoms of the autistic condition during the first year of life. White matter fiber tract pathways connect the regions of the brain, which are measured by fractional anisotropy (FA), and revealed the development and organization of the white matter based on the manner in which the water molecules moved through the brain tissue (Brain imaging, 2012). Wolff et al. studied 92 infants at ages 6 months. At 24

months, the infants underwent behavioral assessments. A type of magnetic resonance imaging (MRI) was used to examine the development of the white matter fiber pathways development (brain imaging). Twenty-eight infants met the criteria for ASD while 64 infants did not. Differences were noted in the development of the white matter fiber pathways.

The National Institute of Health (NIH; as cited in Wedeen et al., 2012) found a new technology in brain imaging was able to show perpendicular pathways that ran horizontally, vertically, and transversely much like a grid structure, and revealed the long hidden connections and their structures. Stoner et al. (2014) found disorganized patches in the brain that correspond to areas responsible for social, language, emotional, and communication functions in the brains that had been autopsied of autistic children. Stoner et al. examined the potential of prefontal cortex dysregulation at prenatal developmental stages. Akshoomoff et al. (2002) stated that the abnormality in the brain was thought to occur at a specific time in conjunction with a common pathology in prenatal development. An early diagnosis provides earlier intervention for individuals with the autistic condition and has the potential to lead to better outcomes for the population.

Researchers have addressed the causation of the autistic condition. Thomas, Knowland, and Karmiloff-Smith (2011) suggested that researchers who held to the connectivity based theory of causation still have to clarify whether the anomaly they had observed began in the development of the condition or if the connectivity issues they observed came after any other developmental atypicalities. Thomas et al. pointed out that

researchers had found that the connectivity issues are not unique to the autistic condition, but they were also found in schizophrenia, HIV/AIDS, and dyslexia.

The autistic condition was also known to appear in children who had experienced multiple deprivations, which had been found in a population of children who were adoptees from a Romanian orphanage in the 1990s and were the subjects of a longitudinal study (Thomas et al., 2001). The Romanian children showed the symptoms of the condition in that they have social and cognitive deficits. Munson, Faja, Meltzoff, Abbott, and Dawson (2008) pointed out that the neurocognitive function in ASD had produced few studies, and the studies done in neurocognitive deficits among preschoolers have contributed mixed results.

Researchers have investigated the behavioral symptoms associated with the autistic condition. Dawson, Mundy, Sigman, Ungerer, and Sherman (1986) suggested that some of the behavioral symptoms in the autistic condition are the result of brain dysfunction systems that are involved in social cognition. Joint attention may be impaired in those on the ASD by the inability to "coordinate attention between interactive social partners with respect to objects or events, or to share an awareness of the objects or events" (Dawson et al., 1986, p. 346). Healthy joint attention is exhibited through the successful interactions with others in one's environment.

Klintwall et al. (2011) explored the ability to adapt to his or her environment based upon the sensory input and how that input is received. Klintwall et al. found support for the theory of sensory abnormalities for children who suffered from the autistic condition. Ayres (1979) developed the theory of sensory integration (SI), which

claims that the dysfunction in SI is the inability to adapt sensory input, discriminate, and coordinate. Research has shown a deficit in the manner in which the sensory input is received and this knowledge has the potential to lead to understanding of how an individual with the autistic condition might learn and assist them in ways to facilitate sensory integration.

From the genetic perspective, the autistic condition presents as more of a local than a global information processing (Happe, 1999). Executive function, an overall term that addresses high level brain abilities that are found in action planning, behavior, and working memory, have been studied in autistic children. Frith (1989) believed that the positive and negative symptoms in the autistic condition might be related and of the same origin resulting in a weak central coherence. Frith labeled this as central coherence (CC), which is the ability to synthesize sensory information in its context.

Happe (1999) believed that the autistic mind is not deficient in this regard but, rather has a different mind in the ability to process information. For the nonautistic individual, information processing is often performed at the expense of retaining adequate memory for routine daily matters. In the autistic mind, the savant ability appears to focus on extraordinary ability for details as is demonstrated in the abilities outlined above. Happe's argument with the deficit theory proponents regarding the condition was that they did not take into account the savant skills and talents that many autistic individuals had, including the artistic, musical, accurate recall of numbers and dates, and swift speed at puzzle construction. Shaw (n.d.) countered that the research in SID has yet to yield findings from a quality research design that uses the random assignment of

participants, blind evaluators to examine treatment conditions, matched control groups, and a lack of consideration given to maturation effects. Research is necessary to establish SI therapy as an evidence-based approach in treating the autistic condition.

ABA, promoted by Lovaas (as cited in Heflin & Alberto, 2001), is used to treat the autistic condition and is thought to be successful through the use of operant conditioning and maintaining a successful, empirically based research culture. Lovaas believed that destructive behaviors might have had an environmental determinant. This interest propelled Lovaas to create the UCLA Young Autism Project in 1970, and the population he sought for inclusion in his program were those autistic children without language ability and SIB (Lovaas, 1993).

Lovaas (1993) stated that he learned the environment of the autistic child was one in which he and his colleagues had to isolate the variables in order to make that environment a therapeutic and educational one. Lovaas found the autistic children to have the ability to learn and claimed one of his students learned the entire alphabet in only 2 hours. Lovaas observed the autistic children in the institutional environment and commented that the lack of staff training, general bedlam, and inadequate ratio of staff to clients contributed to episodes of SIB. It was Lovaas's observation that the autistic child desires a measure of control over their environment. In 1964 Lovaas and colleagues began the first comprehensive treatment study of autistic children. Lovaas's major focus was to develop their language. Lovaas stated they learned three lessons from their mistakes in the study:

- 1. While the autistic child might develop language skills, it did not mean that child would improve in other areas but they found instead that the children had little insight and were unable to generalize their responses.
- 2. The children lacked generalization across their environments even in additional environments after treatment. When the children were returned to the institutions they had come from, they regressed.
- 3. Lovaas was disheartened that his colleagues from different psychological perspectives refused to test the treatment programs he and his research associates had developed.

When the children were returned to the institutions, the treatment program Lovaas and his colleagues had developed was not adopted for the autistic children and as shown, they regressed. Those children who were discharged to their parents and wanted to learn about the Lovaas treatment fared better. Lovaas stressed the importance of the parental role "as colleagues" (p. 624). Lovaas's method continues to gain popularity and is desired for its success by parents of children with the autistic condition as well as dedicated professionals working with autistic students.

Heflin and Alberto (2001) emphasized that there was a large amount of empirical literature on the efficacy of ABA through which behavior might be changed if the environmental stimuli were controlled while the reinforcement theory for learning was consistently managed in the classroom. Heflin and Alberto theorized that classrooms that do not afford autistic students adequate structure and design for sensory differences might be disruptive and inhibit their learning rather than enhance the experience.

Neurological researchers have contributed to an understanding of the autistic condition. Schopler was the first to establish the neurological basis of the autistic condition (Mesibov, 2006). Schopler had initially discussed the need to prove his theory for the neurological basis of the autistic condition with Bettelheim, a Freudian clinician and leading authority on the condition in the late 1960s. Bettelheim ridiculed Schopler's ideas by stating, "Why it was that scientists always felt they had to prove experimentally what was obvious just from clinical observations" (as cited in Mesibov, 2006, p. 968). Schopler disagreed with the psychodynanic philosophy blaming parents for the children's autistic condition.

Schopler found that the structure and education surpassed the psychodymanic theories popular at the time which promoted a free-form approach. Through Schopler's findings, the children with the autistic condition who were part of his study improved considerably and the parents sought permanent funding for TEACCH (Mesibov, 2006). Schopler was able to continue his research while he had already established one of the first empirically-based ASD treatment approaches. The structured teaching principles of TEACCH included:

- 1. The culture of autism must be understood.
- 2. Each autistic student must have an individualized person and familycentered plan, rather than a standard curriculum.
- 3. The physical environment must be structured in such a way that the autistic student understands meaning.

- 4. Visual supports were necessary for the autistic student in order to make the daily routines predictable and understandable.
- 5. The use of visual supports affords students with the autistic condition an understanding of an individual task (Texas Statewide, 2009).

The culture of autism consisted of "a pattern of neuropsychological deficits and strengths" (Mesibov & Shea, 2009, p. #). Mesibov and Shea outlined the differences among students with the autistic condition which included (a) heightened attention to details, (b) strength in and preference for processing visual information, (c) variability in attention, (d) lack of communication, (e) need for structure and routine, (f) sensory preferences, (g) tendency to aversions, and (h) attachment to established routines and environments. The gist of the TEACCH structured teaching was its emphasis on the educators' provision for a structured classroom environment, focus on the autistic students' strengths and supplement their weaknesses, use what they were good at to engage them in the learning experience, and support any self-initiated communication.

Callahan et al. (2009), after examining support for the ABA and TEACCH programs through a social validation survey that was distributed to special educators, parents, and administrators, suggested that there was strong competition between the proponents of the ABA and TEACCH models. The findings suggested that the participants showed no particular preference for either model. Social validation was found for components that were inherent in both ABA and TEACCH models and were found to be more socially valid than ABA or TEACCH alone.

Studies regarding autoimmune disorders have been investigated by some researchers. Dietert and Dieitert (2008) discussed research findings that suggested a link between maternal history and incidence of toxic insults associated in the autistic condition that likely were initiated by the production of cross-reactive autoantibodies via the mother and the higher incidence of brain-specific autoantibodies that were "found at a higher incidence in children with autism" (p. 669). Dietert and Dietert (2008) pointed out that this was the case, not only with the autistic child but also with their immediate family members. Dietert and Dietert stated there was a variant of the MET receptor tyrosine kinase that provided a link to the genetics in autism. The MET receptor is involved in the neurobehavioral and immune function. MET is shown to have faulty signaling in those with autism and was suspected to play a role in some neurological deficits.

Genetic researchers had generally assumed psychiatric conditions such as schizophrenia and the autistic condition were two distinct conditions. That has changed in that they now suggest that an examination of genetic architecture is warranted in regard to psychiatric disorders such as the autistic condition, anorexia nervosa, ADHD, Alzheimer's disease, and others have the potential to reveal information about the etiology of these conditions. Some individuals are predisposed to the condition through genetic changes (Sullivan, Daly, & O'Donovan, 2012).

Multiple theories continue to be generated regarding the causation and nature of the autistic condition. While research continues, it is imperative that the findings to date be applied to the home and classroom environments of children with the autistic condition in order to provide a quality of life for the families and others who provide services for them.

#### **Nature of the Study**

A mixed methods design consisting of a phenomenological approach including personal in-depth interviews with the parents and/or primary caregivers followed by a survey questionnaire were the chosen steps for this study in order to learn and describe the participants' personal experiences and examine any common themes that might emerge. The participants have feelings and opinions about their individual experiences with their child and whether the classroom is environmentally healthy. The purpose of this study was to attempt to grasp the nature of their shared phenomenon, to examine any common themes they might have had, and whether the parents and/or primary caregivers were satisfied with a number of variables which included (a) child's academic performance, (b) service provider collaboration, (c) communication, (d) level of parental support and training, (e) educator management of behavioral challenges in the classroom, (f) mental health issues, (g) classroom structure and organization, (h) potential classroom environmental barriers, and (i) educator's knowledge and training about the autistic condition. The phenomenological approach allowed multiple in-depth interviews with the parents and/or primary caregivers in order to examine their experiences and opinions regarding the positive and negative outcomes. This design allowed for triangulation of the data. I was solely responsible for analyzing the data.

The phenomenological design provided me the opportunity to gain an understanding of the process that evolved over time, in the formation of the parental

and/or primary caregiver's attitudes regarding their child's classroom environmental health and through the ability of the parents and/or primary caregivers to share detailed information about the public school classroom environment or context. The phenomenological design promoted the formation of a research epoche while listening to the experiences, knowledge, and opinions in order to provide a valid description of the phenomenon.

The quantitative data were gathered through the use of a Likert rating scale in order to examine the variables outlined in Chapters 1 and 3. The quantitative approach was used to provide the data from the survey questionnaire that either confirmed or denied the presence of any common themes. Creswell, Klassen, Clark, and Smith (2010) labeled the qualitative approach as inductive, while the quantitative approach as deductive. The mixed methods design provided an investigative framework of a philosophical and theoretical induced position and employed the quantitative approach that examined the frequency of constructs.

The qualitative approach allowed me the ability to explore meanings and gather an understanding of those constructs (Creswell et al., 2010). The quantitative data collected in this study provided the ability to test the hypotheses, provided descriptive information, and were used to examine any potential relationships among the variables. The quantitative research provided an understanding of the recurring themes in any potential causal theories and followed up through engaging in the qualitative research (Creswell, 2007). The potential for common themes within the data contributed to an understanding about the phenomenon that has the potential to contribute to policy change

within the public school system regarding those factors that lead to positive environmental health. Positive environmental health might contribute to improved academic performance for autistic students in the public school classroom.

#### **Definitions**

This section defined the terms used in the proposal that might not be understood otherwise. Common terms unique to the proposal and acronyms are defined in this section. The following definitions are provided in order to lend to an understanding and assure homogeneity of the terms used throughout the proposal. I developed definitions when no citations were available.

Applied Behavioral Analysis (ABA):

A scientific approach to improve socially significant behaviors (vocational, language, social, daily living, academic, self-care, and recreation and/or leisure) in which procedures derived from the principles of behavior are systematically applied to improve socially significant behavior and to demonstrate experimentally that the procedures employed were responsible for the improvement in behavior. (Cooper, Heron, & Heward, 2007, p. 52).

Attention Deficit Hyperactivity Disorder: "A chronic condition that affects millions of children and often persists into adulthood. ADHD include some combination of problems, such as difficulty sustaining attention, hyperactivity and impulsive behavior" (http://www.mayoclinic.org).

Auditory Deficit: A processing disorder in which an individual's brain and ears are notcoordinated. The brain does not adequately interpret sounds and it affects speech (http://kidshealth.org).

Auditory Training: An additional physical environment measure that might assist autistic students in becoming less sensitive to auditory sounds (Grandin, 2008).

Autistic condition: APA (2013) defined the essential features of autism spectrum disorder as "persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behavior, interests, or activities. These symptoms are present from early childhood and limit or impair everyday functioning" (p. 53).

Amygdala: "A structure of the medial temporal lobe that plays a role in the memory for the emotional significance of experience" (Pinel, 2003, p. 493).

Antibody: "A globular protein produced by plasma cells that will bind to specific antigens and promote their destruction or removal from the body" (Martini, Ober, Garrison, Welch, & Hutchings, 2001, p. G-3).

Attempt Deligny: The term used to describe the experiments of Fernand Deligny among a group of classic autistic children whom lived on farm/camps in France in the 1970's.

Autoantibodies: "Antibodies that react with antigens on the surfaces of a person's own cells and tissues" (Martini et al., p. G-4).

Autism Spectrum Disorder (ASD): "Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning;

persistent deficits in social communication and social interaction across multiple contexts; and restricted, repetitive patterns of behavior, interests, or activities" (http://www.nimh.gov).

Autoimmune Disorder: A medical condition indicating that the immune system has gone awry and attacked healthy tissue. Diabetes, rheumatoid arthritis, and celiac disease are some of the more than 80 types of autoimmune disorders and studies have shown that mothers with an autoimmune disorder are more likely to produce offspring with autism (Reinberg, 2009).

Brain Dysregulation: Pertaining to the autistic condition; brain growth dysregulation hypothesis is one that describes a dysregulation of normal brain growth.

Collaboration: Working together to exchange ideas for a common goal.

Community Liaison and Outreach Committee (CLOC): A comprehensive training program in Utah designed to train professionals to support students in the public school system who had severe problem behaviors, including developmental disabilities (Sutherland, Lewis-Palmer, Stichter, & Morgan, 2008).

Contextual Factors: Factors such as behavioral problems that contribute to the learning ability of a student (Sutherland et al., 2008).

Culture of autism: "A pattern of neuropsychological deficits and strengths" (Mesibov & Shea, 2009, p. 571).

*Defectology*: Vygotsky's term pertaining to his "research and practice relevant to contemporary special education and school/educational psychology" (Grindis, 1996, p. 77).

*Dendritic*: "One of two types of branching protoplasmic processes of the nerve cell, the other being the axon" (Dirckx, 2001, p. 256).

Design Parameter Rating Scale (DPRS): A rating scale provided to educators to assist in the development of standards and codes that establish school environments that met the unique needs of autistic students (Khare & Mullick, 2008).

Developmental Disability: "A severe, chronic disability of an individual 5 years of age or older" (http://www.law.cornell.edu).

Dopamine: "An important neurotransmitter in the central nervous system" (Martini et al., p. G-11).

*Engagement:* The act of communication among people leading them to mutual agreement on a topic.

*Environment*: A setting, milieu, context, background, or climate. The environment is considered to be the setting for academic and social learning or the home for the autistic student.

Environmental Audit (EA): A tool developed for building designers who specifically engage in facility surveys (Khare & Mullick, 2008).

*Executive Function*: An overall term that addresses high level brain abilities that are found in action planning, behavior, and working memory (Happe, 1999).

Genetics: "The study of the mechanisms of hereditary" (Martini et al., p. G-14).

Heisenburg Uncertainty Principle: "The scientific principle stating that it is impossible to determine with perfect accuracy both the position and momentum of a particle at any given point in time" (Helmenstine, 2014.).

Higashi or Daily Life Method: A teaching method that "emphasizes developing harmony in all aspects of life for children with autism" (Institute, 2002).

Hippocampus: "A region, beneath the floor of a lateral ventricle, involved with emotional states and the conversion of short-term to long-term memories" (Martini et al., p. G-16).

*Hypo-sensitive*: "Lacking a sensory input ability or hypersensitive, which was the most common and was the inability to process and integrate the sensory input quickly" (Grandin, 2008).

*Immunotoxicity*: An assault by a toxic substance on the immune system.

Integrated Approach: An approach that uses different disciplines, such as the treatment for autism might consist of occupational therapy, structured teaching, speech and language training, mental health counseling, occupational therapy, etc.

*Internalization:* The process in which a child gained a reasoning ability through participation in dialogue with others, likely in social play where the child was able to express themself and was able to understand the emotions of their peers (Symons, 2004).

Joint Attention: "An early-developing social-communicative skill in which people (usually a young child and/ or an adult) use gestures and gaze to share attention with respect to interesting objects or events" (Jones & Carr, 2004, p. 13).

*Kinase:* "An enzyme catalyzing the conversion of a proenzyme to an active enzyme" (Dirckx, 2001, p. 535).

Le Packing: A method used in France to treat the behavioral challenges in autistic children, recently banned by the French government, and now officially considered a

form of abuse. Le Packing was primarily promoted by the Psychoanalytic community predominant in France in treatment of ASDs.

Linked Fate: "An acute sense of awareness (or recognition) that what happens to the group also affects the individual member" (Simien, 2005, p. 529).

*Mainstreaming:* Regular and special education school classrooms that are combined.

*Mamillary bodies:* "Nuclei in the hypothalamus that affected eating reflexes and behaviors; a component of the limbic system" (Martini et al., p. G-20).

*Mapping*: A term used by researchers denoting the mapping of the genes in the autistic condition, brain development pathways, or the monitoring of the movements of an autistic child. Mapping was used by Deligny and by contemporary researchers whom Deligny made reference to in mapping in order to make sense of what the autistic child could be thinking.

Medial Septial Nucleus: a region of the cerebral hemisphere whose major functional connections are with the hippocampus and hypothalamus (http://medicaldictionary.thefreedictionary.com)

*Met Receptor Tyrosine Kinase:* "Prototypic member of a small subfamily of growth factor receptors that, when activated induce mitogenic, motogenic, and morphogenic cellular responses" (Furge, Shang, & Vande Woude, 2000, p. 5582).

Montana Children's Autism Waiver: A program for families with an autistic child that was developed by the Department of Public Health and Human Services in Montana State via Developmental Disabilities Program (DDP) management. The waiver is

available through a lottery system to 50 families and covered services included case management, in-home habilitation training, respite, adaptive equipment, environmental modification, occupational therapy, physical therapy, speech therapy, transportation, program design, monitoring, and individual goods and services for a period of three years (Montana DDP Autism, 2008). In the 2015 legislative session, the autism waiver will soon be available to all children with the autistic condition through Medicaid expansion.

*Multisensory Environment*: An environment that directs outreach in the areas of emotional development, self-determination, improved communication skills, relaxation, reduction of maladaptive behaviors, therapy, sensory stimulation, and opportunities for social interaction (Pagliano, 1999).

*Mutation*: "A change in the chemistry of a gene that is perpetuated in subsequent divisions of the cell in which it occurs" (Dirckx, 2001, p. 646).

National Autism Center: An advocacy, research, and educational agency located in Massachusetts.

National Center for Autism Research and Education (NCARE): "A non-public, not-for-profit research supported school located in Las Vegas, NV serving the educational needs of students with the autistic condition in Grades 1-12. The specialized educational program was developed according to the individual's specific need" (NCARE, n.d.).

National Research Council: A research council whose "mission is to improve government decision making and public policy, increase public understanding, and promote the acquisition and dissemination of knowledge in matters involving science,

engineering, technology, and health. The Research Council's independent expert reports and other scientific activities inform policies and actions that have the power to improve the lives of people in the U.S. and around the world" (National Academy of Sciences, n.d.)

No Child Left Behind Act: A 2001 U.S. Act of Congress law that supports educational reform that requires states to provide student assessment of basic skills in order to receive federal funding.

*Nutritional*: A way of eating that promotes optimal health.

*Neurobehavioral*: "Of or relating to the relationship between the action of the nervous system and behavior" (Merriam-Webster, n.d.).

*Neuron*: "A cell in neural tissue that is specialized for intercellular communication through (1) changes in membrane potential and, (2) synaptic connections" (Martini et al., p. G-22).

*Neuropeptide*: "Any of the molecules composed of short chains of amino acids (endorphins, enkephalins, vasopressin, etc.) found in brain tissue" (The Free Dictionary, n.d.).

*Niche Picking*: Situations or niches that were chosen for the autistic student in order to provide an adequate, sound structural and home-environment for the student with the autistic condition (Adameck et al., 2011).

*Option Method*: An autism training approach used in Texas for parents working with their autistic child that employs rewards and positive attitudes to reinforce desired behaviors (Target: Texas Guide, 2009).

Passive Exposure: Defined as being exposed to a diluted measure of a toxic substance or event that has the potential to create individual stress. In the case of being an educator of students with the autistic condition in the classroom environment, behavioral challenges, when they occur have the potential to cause stress for the educator and other staff and students who are exposed to it.

Personal Construct Theory: The theory that holds that individuals had constructs in their mind, an idea of their world that was based upon their own experiences and respond and adapt to events through that idea. (Braun, Davis, & Mansfield, 2006).

Pervasive Developmental Disorder (PDD): PDD has been replaced with the ASD label (Head-Dylla, 2009; Nicholson & Castellanos, 2000; Rice, 2009).

Positive Behavioral Supports (PBS): A philosophy that emphasized that parents should be active participants in the collaboration with professionals and support teams might include parents, siblings, teachers, job coaches, friends, and the person with a disability (Carr et al., 2002).

President's New Freedom Commission on Mental Health: Former President George W. Bush's 2003 commission who wrote "Achieving the Promise: Transforming mental health in America." (Executive Summary, 2003).

*Proinflammatory cytokines:* "Cytokines produced predominantly by activated immune cells such as microglia and are involved in the amplification of inflammatory reactions. These include IL-1, IL-6, TNF-a, and TGF-B." (Everythingbio, n.d.).

*Proprioceptive:* The action of a proprioceptor that responded to stimuli originating within the body itself, especially one that responds to pressure, position, or stretch (Venes, 1997).

*Psychogenics:* An emotional state that is triggered more by the psychological than the physical in its origin.

Psychotropic Medication: "Having an altering effect on perception or behavior" through the use of a medication" (The Free Dictionary).

*Rafts:* The term Deligny used to describe the farm/camps that the group of autistic children, Deligny, and his staff lived in; one that as a group fit together with or without language.

Refrigerator Mother Theory: A reference by Bettelheim that purported that the mothers of autistic children were non-nurturing and cold in nature.

Relationship Development Intervention (RDI): An intervention method whose focus was on the biopsychosocial management of ASD and promotes the involvement of parents and an RDI clinician with the child's physician as leader in the clinical management of the physical and psychological aspects of their child's autism (Gutstein, 2009).

Self-Injurious Behavior (SIB): "Self-injurious behavior involved any number of behaviors by which the individual produces physical damage to his or her own body" (Tate & Baroff, 1966, p. 281).

Sensory Based Intervention: The primary method used to reduce the onset of maladaptive behavioral symptoms in autism and a strategy for behavioral management (Lane et al., 2010).

Sensory Integration (SI): Sensory input taken from the environment and through bodily movement that is processed and integrated within the central nervous system allowing an individual to use the sensory information in the planning and organization of behaviors (Stadele & Malaney, 2001).

Sensory Integration Disorder (SID): "The inefficient neurological processing of information received through the senses, causing problems with learning development and behavior" (Kranowitz, 1998, p. 292).

Sensory Processing: "Sensory processing is a complex set of actions that enable the brain to understand what is going on both inside your own body and in the world around you" (Introduction to Sensory Processing Concepts, n.d.).

Sensory Processing Dysfunction: The failure to process complex sets of actions that enable the brain to understand overt actions and environmental stimuli.

Serotonin: "A vasoconstrictor, liberated by platelets that inhibits gastric secretion and stimulates smooth muscle; also acts as a neurotransmitter present in the central nervous system, many peripheral tissues and cells, and carcinoid tumors" (Drickx, 2001, p. 898).

Short Sensory Profile (SSP): A tool developed by Dunn in order to measure a child's responses to sensory events in daily life (Pearson Education, 2008). The SSP is a 38-item caregiver report measure comprised of those items that demonstrated the highest

discriminative power of atypical sensory processing among all the items from the long version, the Sensory Profile (Tomchek & Dunn, 2007).

Sociocultural Theory: A theory developed by Vygotsky suggesting that "development depends on interaction with people and the tools that the culture provides to help form their own view of the world" (as cited in Gallagher, 1999).

SPELL Method: An autism approach that is "useful in identifying underlying issues; in reducing the disabling effects of autistic spectrum disorders; and in providing a cornerstone for communication" (National Autistic Society, 2006).

Squeeze Machine: An invention by Temple Grandin that allowed her to enter a wooden box designed to press upon her like a squeeze accompanying a hug which reduced her stress. Grandin's idea originated when she saw a similar machine designed for cattle that made them hold still for vaccinations and other procedures.

Structured teaching: "Describes organization of time, space, and sequences of events within the environment in order to make learning activities clearer and easier to perform" (Mesibov & Shea, 2009, p. 573).

Systems of Care: A philosophy of the manner in which the needed support services are provided to children and those that reside within the available service provider agencies. Believed that in order to be effective services must be interconnected and contain systems of prevention as well as systems of early intervention (Kutash, Duchnowski, & Lynn, 2006).

*Temperament:* A combination of mental, physical, and emotional traits or a person's predisposition.

Theory of Mind: "The ability to apply mental states to oneself and to others (Baron-Cohen, Leslie, & Frith, 1985).

Treatment and Education of Autistic and Related Communication handicapped Children (TEACCH): "A clinical service and professional training program, based at the University of North Carolina at Chapel Hill, that incorporated and contributed to an evidence-base of autism interventions started by the late Eric Schopler, Ph.D" (Mesibov & Shea, 2009, p. 573).

UCLA Young Autism Project: A behavioral approach developed by O. Ivar

Lovaas with autistic children without language ability who had SIB. Through the

isolation of some variables, Lovaas found that autistic children had the ability to learn.

Visual Aid: Pictures, symbols, drawings, and charts that are used to enhance learning.

Visuo-spatial Skill: An awareness of where one's body is in relationship to other objects.

Walsh's Resilience Theory: A theory developed by Walsh (1998) used to help individuals develop ways to make meaning of adversity, affirming strengths, maintaining a positive attitude, maintaining spirituality, and having a belief system.

White Matter: "Regions in the central nervous system that are dominated by myelinated axons" (Martini et al., p. G-32).

Zone of Proximal Development: Vygotsky's (1978) theory of learning that stated, "The distance between the actual developmental level as determined by independent

problem solving and the level of potential development as determined through problem solving under adult guidance, or in collaboration with more capable peers" (p. 86).

#### **Assumptions**

It is assumed that the participants answered truthfully, honestly, and to the best of their ability to the questions presented in the interviews and in the responses to the survey questions. Participation in the study was voluntary and based upon a purposeful sampling of the participants. The participants were excited and eager to share information regarding their experiences, knowledge about their child, and comfortably offered their opinions once they were assured of the confidential nature of the interview. The participants shared common experiences, had similar knowledge about their autistic child, and offered opinions about their experiences that were similar to one another.

# **Scope and Delimitations**

The specific aspects of the research problem being examined were confined to the parents and/or primary caregivers regarding their opinions about the overall satisfaction with the public school classroom environment and included sensory supports, classroom structure and organization, educator training and knowledge about the autistic condition, curriculum and IEP development, lighting, ability of the educator to manage behavioral and psychiatric symptoms in the public classroom, communication, parental support and training, and collaboration among autism service providers. The focus of this study was based on what has been examined in the research concerning the lack of parental opinion being regarded among educators and included in the development of educational plans

for the autistic students. The parents were chosen based on the fact that they have a child with the autistic condition who is a student in the public school classroom environment.

One of the delimitations of this study is that the parents of autistic children in private institutions for autism were excluded and their opinions were not sought for the purposes of this study due to limited time to conduct this study. This study might be delimitated by use of telephonic interviews rather than face-to-face interviews with those participants who did not live locally. The potential for the generalizability and transferability of this study could easily be adapted to an examination of those parents who have a child in a private institution with a special education classroom, mainstream classroom with autistic students, or a private school solely for students with the autistic condition.

This study might be delimited to an examination of the experiences, attitudes, and feelings of parents and/or primary caregivers of autistic children in elementary, junior high, or high school in the public school system. The primary intent of the study was to examine parental and/or primary caregivers' experiences, knowledge, and opinion in order to ascertain those constructs that enhanced or impeded their child's academic growth.

# **Limitations of the Study**

The participants were the parents and/or primary caregivers of a child with the autistic condition attending the public school and in the elementary, junior high, or high school setting. The study included parents and/or primary caregivers living in one of several states. A Likert rating scale with an open-ended survey questionnaire was used to

determine the parental and/or primary caregivers' opinions that included educator training and knowledge about the autistic condition, communication, collaboration, parental support and training, and overall structure and organization of the classroom in being one that promoted the environmental health of their child. The interviews were indepth and personal in order to examine the personal experiences that parents and/or primary caregivers have had with professional educators and staff within the public school system and included (a) training and knowledge the educators and staff have about the autistic condition; (b) the IEP development and process; (c) structure, organization, and design of the classroom environment; (d) collaboration among autism service providers; and (e) potential barriers to successful academic growth. A rigorous examination of the parental and/or primary caregivers' experiences and opinions might potentially benefit the literature as well as provide insights into the lives of families who are affected by the autistic condition. This study might have the potential to lead to positive social change in the area of education.

The format of the study included an interview process that used open-ended interview questions that were designed to extract an understanding the parents and/or primary caregivers' opinions pertaining to specific topics or potential issues within the public school classroom environment. The participants were given the option to carry out the interview in the location of their choice in order to make them comfortable within a suitable environment.

Further limitations to the study included the burden that is placed upon the participants due to time constraints or problematic imbalances which might require

necessary detail in order to balance the circumstances for each approach (Creswell et al., 2010). The personal face-to-face interviews were primarily confined to frontier eastern Montana. The phone interviews, while personal were not face-to-face due to the interviewees living in different localities, including Mississippi and other localities within Montana. This factor may have limited the researcher in being able to view body language and facial expressions. The mere presence of the research may have limited the study in that the data might be skewed to some degree (Helmenstine, 2014). The study might be limited by the time taken in order to build trust with the participants that is generally needed prior to a personal interview in order to yield adequate self-representation. A potential limitation might have been the focus on those students with the autistic condition whose parents and/or primary caregivers who chose to participate in the study and respond to the survey questionnaire and might not be representative of other parents not involved in the study.

## Significance of the Study

The research findings have the potential to contribute to the existing gaps in the research literature regarding the need for inclusion of parental opinions in the development of overall educational planning and services for autistic students (Arnini, 2007; ASA Advocate, 1994; Kutash et al. 2006; Mock et al., 2003; Spann et al., 2003). It is far-reaching in that it might provide insights into the need to meet the unique needs of autistic students that are far different from students that are nonautistic or suffer from a DD. Through the results of this study, I pointed out that the previous research had illuminated some evidence-based approaches, based on biomedical researchers who

found brain development to be much different in autistic individuals and might contribute to the need for a low-stimulus classroom environment for autistic students (Happe, 1993; Just et al., 2006, 2009; Kana et al., 2006; Keller et al., 2007).

Positive social change impact from the research findings have the potential to provide knowledge to interested stakeholders regarding the importance of collaboration with parents and/or primary caregivers in order to meet the needs of the families with a child with the autistic condition in the public school classroom environment. Knowledge about the parental and/or primary caregivers' experiences and opinions might contribute to the literature through yielding valuable insights the parents have regarding their child's autism, how they have managed the symptoms, and the effect the experience has had on their families. The input regarding their experiences and the knowledge gained might lead to positive social change in the area of education through the development of plans and programs that promote ways to reduce the barriers and stress that pose challenges in the classroom environment for autistic students, educators, and families.

Autistic students tend to bring the stress from a day at school home with them and are known to have meltdowns. The consistent use of evidence based programs in sensory reduction and behavioral plans in the classroom environment might contribute to improved quality of life for the families. Recognition of the importance by the administrators and educators in the public school to adequately meet the unique needs of autistic students might reduce their own stress as well as assist the students in their ability to learn and achieve academic success. Educators who were adequately trained in autism had shown skills in effectively managing the behavioral symptoms associated with

autism in the classroom environment (Gregor & Campbell, 2001). This research study specifically sought firsthand knowledge from parents and/or primary caregivers in order to use the findings to reduce the stress for the student, educator, and parents and enhance the autistic student's potential for positive academic outcomes and improved quality of life in the home for the families.

#### **Summary and Conclusions**

Biomedical and genetic researchers have provided extensive findings into the anomalies of the development of the immune system and the brain of the autistic individual (Akshoomoff et al., 2002; Bradstreet et al., 2010; Cabanlit et al., 2007; Dietert & Dietert, 2008; Kana et al., 2006). These findings have contributed to ways in which educational settings must be adapted in order to meet the unique needs of the autistic student. In doing so the potential exists for increased awareness about the autistic condition for educators which might reduce stressful events for the educators, families, and students with the autistic condition.

An argument is presented that addresses and challenges educators and administrators to include the parents and/or primary caregivers in educational planning and promote educator training. The inclusion of parents and/or primary caregivers has the potential to foster a positive classroom environment geared toward academic success for autistic students. The parents and/or primary caregivers have essential information about their child and their experiences that has the potential to reduce classroom stress for educators, parents, and autistic student. Schopler (ASA Advocate, 1994) pointed out that

it is necessary to include the views of parents in the educational planning for autistic children.

Chapter 2 is a review of current research literature that addressed the biomedical, genetic, and educational aspects of the areas of the study. The theoretical framework for the study was used to examine biomedical findings, brain development, genetics, learning processes, educational topics, and stress-related factors. Discussions focus on (a) research findings applicable to child development issues in the autistic condition; (b) parent, child, and educator stress; (c) educational guidelines; (d) need for educator training; (e) unique needs pertinent to autistic students; (f) need for educators to provide parental support; (g) need for collaboration; and (h) need for the implementation of evidence-based practices in the public school classroom environment. Chapter 3 is an explanation of the mixed method research methodology, research design, study sample, data analysis, measurement tools, and ethical considerations. Chapter 4 is an explanation of the research method, data analysis, data findings, and presentation of tables. Chapter 5 includes a discussion on the interpretation of findings, the implications for social change, recommendations for action, recommendation for further study, my reflections on the research process, and summary and conclusions.

### Chapter 2: Literature Review

#### Introduction

The purpose of this mixed methods study was to investigate what factors contributed to a successful and positive academic experience for autistic students in the public school classroom environment. Effective autism services require a collaboration of primary stakeholders using an integrated approach with the most current evidence-based practices for the autistic students in the public school classroom environment.

While the bulk of contemporary researchers have focused on the biomedical areas that predominantly investigate the causation of the autistic condition, I chose to examine factors related to ways in which the autistic student might be guided into successful academic experiences through an environmentally healthy classroom. An environmentally healthy classroom structure might utilize those approaches that respect parental and/or primary caregiver input regarding educator knowledge and training, collaborative efforts, educator management of behavioral and psychiatric symptoms within the classroom environment, parental and child/student support, IEP development and process, and classroom structure and organization. The biomedical, nutritional, and genetic areas had contributed knowledge about those pertinent areas, which allowed researchers to contribute their findings towards an understanding of those factors as they relate to learning ability in autistic children. These factors contributed to an understanding of the ways in which a school classroom environment must be adapted for autistic students in order to foster learning, reduce anxiety, and increase communication and social skills.

Mesibov (2004) stated that the intervention studies into the autistic condition had not received adequate funding compared to those in the biomedical and genetics research areas. It is recommended that educators, families, and service providers familiarize themselves with the requirements of an evidence-based classroom and approach, and the daily life approaches that have been developed in autism outreach in order to understand the condition and those barriers that impede an autistic student's ability to learn needed skills in the classroom environment. The classroom environment is where the autistic student likely spends a majority of his or her day, and there appears to be a need for the implementation of existing evidence-based approaches in this setting. This calls for a unified voice to seek necessary funding for further research into those areas that will contribute to an improved quality of life within the daily environment for the parents and/or primary caregivers, educators, and the autistic student.

In this literature review, I examined the need to evaluate parental and/or primary caregivers' opinions regarding the contemporary public school classroom environment, whether the parents felt this environment met the unique needs of autistic students, and potential barriers that impeded the implementation of evidence-based approaches in the public school classroom. An evaluation of the environmental health of autistic students in the classroom, from the perspective of the parents and/or primary caregivers, might contribute to the literature. Through the literature review, the theoretical and empirical studies were examined, which built a foundation that contributes to a comprehensive understanding of the educational factors and well-being of educators, parents, and autistic students. In this literature review, I summarized the impact of stress upon the families and

autistic students in relation to some of the educational factors predominantly within the classroom environment regarding the classroom structure and organization, noise levels, effects of overhead lighting, educator management of behavioral and psychiatric symptoms, educator support of parent and/or primary caregiver support, and curriculum presentation. These factors have a direct impact on the quality of life for educators, families, and the autistic student.

Evidence-based models designed to facilitate learning and assist in behavioral management are not consistently implemented in the public school classrooms. Callahan et al. (2009) stated that only a few evidence-based models specific for students with the autistic condition had been implemented in the public schools and suggested that the identification of a crucial core derived from those evidence-based models had the potential to contribute to the training and outcome measures of programs in the public school system. The audience for the Callahan et al. study consisted of fellow researchers and teachers in evaluating two programs; (ABA and TEACCH) and this study was only one example that demonstrated the lack of parental and/or primary caregiver opinion in one area of the available autism educational services. Parental and/or primary caregiver opinions are primary in the development of any implementation of core essentials among the autism programs that are available for the public school system.

# **Literature Search Strategy**

Qualitative studies were primarily selected in order to review the methodology in order to apply appropriate avenues of research to the present study. The research strategy used to conduct the literature review entailed the examination of literature primarily from

peer-reviewed journals focusing on the autistic condition in relation to the environmental health of the school classroom. The initial search included any common themes in the literature regarding parental views and experiences with the public school classroom system. Contrasting views were yielded in the literature and were used for purposes of the research.

The Walden University library Academic Search Premier was primarily used, which included searches in the behavioral and the educational areas. ERIC and SAGE behavioral and educational databases, behavioral and educational autism publications, and peer-reviewed journals were used. Private autism service provider websites were used. The University of Minnesota and the University of London yielded some studies. Research studies and journal articles on the autistic condition date from as early as 1979 through 1989 to the present time and provided the most current information on educational goals for autistic students because no further research had been done, specifically in classroom organization, behavioral management, and structure, making the earlier studies relevant for the present time. Studies done from 2006 through 2011 presented the need for parental involvement.

The search engines used included Google or Bing. Primary search criteria included the keyword *autism* combined with the following secondary key words or phrases: *education, family dynamics, learning, behavior, barriers, behavior in the classroom, environment, school classroom, parental opinion, communication, mental health, stress, parental stress, family stress, educator stress, brain development, genetics, immune response, medication, learning, professional collaboration, evidence-based* 

practice, evidence-based models/approaches, classroom structure for autistic students, IDEA, special needs in the public school classroom, sensory processing, and teaching. Other search criteria included well-known names in research on DD and some specifically in autism such as Lovaas and Schopler.

The primary goal of the literature review was to investigate the significant issues with some of the educational practices within the classroom environment of the autistic students. Studies were sought that provided insight into the autistic students' overall functioning in the educational settings and the educational characteristics of the public school classroom. The literature review culminated in the examination of the need for a collaborative and multimodal approach in the treatment and education of autistic children, with the opinions of parents and/or primary caregiver(s) being the primary motivating component for its success.

### **Key Variables and Concepts**

### **Background of the Environmental Issues in the Classroom**

A symbiotic relationship exists between each of the issues (e.g., environment and behavior or environment and learning, etc.) that necessitate the use of an integrated approach in working with autistic students. Collaborative efforts play a primary role in whether a student with ASD will succeed academically in the classroom. Khare and Mullick (2008) suggested that the environmental supports necessary for autistic students in the classroom might challenge the prevailing idea of a single classroom environment commonly referred to as inclusion. Inclusive classrooms might not provide the multiple supports necessary for students with the autistic condition. Standards and policy should

be developed based on core components in the various evidence-based programs found to provide positive academic outcomes. Spann et al. (2003) suggested while empirical research was underway, family involvement was found to be minimal in any given educational services topic.

Current programs employed in public schools might be common to the schools that had implemented them; but, the problem was found to lie in the definition of the common components inherent in each program (Wolery, 2000). What means one thing to one school may be defined differently in another school. There is a lack of operational definitions in the programs for autistic students. Wolery suggested the need for a scientific replication that examined all of the sources that give rise to different outcomes.

Several environmental challenges exist in the public school classroom. One predominant challenge lies within the environmental design and overall structure of the classroom. The overall structure might include the manner in which the educator manages the classroom in the educational programming, particularly in the curriculum development with autistic students in mind; managing the behavioral challenges associated with autism; common psychiatric conditions in students with the autistic condition; the classroom lighting; the noise level; structural design; classroom organization; learning presentation; and class size. Additional issues include educator knowledge and training, use of evidence-based programs for learning and management of potential co-occurring autism and psychiatric disorders, awareness of deficits in sensory processing and brain abnormalities, self-esteem issues, and social and communication skills training.

The environmental supports necessary for students on the ASD might range from minimal to substantial as each student is unique (Iovanne, Dunlap, Huber, and Kincaid, 2003). Morson (2009) stated that the Littleton, CO school district had expressed that it was unfair to make adaptations for one disability over another as that has the ability to foster one disability against another. If that is the case, it is more prudent to provide the students with various disabilities those environmental conditions that will foster their learning. It is not a matter of pitting one disability against another but providing for each disability as needed supports dictate. Khare and Mullick (2008) envisioned the findings from their study on environmental design components and the autistic student to potentially contribute to a classroom that creates a number of personalized educational environments within the larger concept in order to meet the many needs that exist in the public school environment.

## Structure and Design in Mind for the Student With the Autistic Disorder

A classroom that is well-equipped in its structure and design is likely to provide a more positive learning experience for the student with the autistic condition. The educator was primary in the effective structure of the classroom for autistic students (Structured teaching, n.d.). The effective classroom structure and organization has the potential to moderate the problems experienced by autistic students. Lytle and Todd (2009) stated that one of the symptoms associated with the autistic condition was that of a heightened stress response that took much longer to resolve. This made it likely that the classroom became even more challenging for those students with the autistic disorder.

Currently, the public school classroom environment has the ability to play an influential role in the lives of children and research on the topic is scarce (Milkie & Warner, 2011). The structure of many classrooms in which the autistic student is a part of might actually contribute to ways it should not be structured. The classroom dynamics might be emotionally charged and chaotic and led by an educator who may be stressed out due to a lack of training regarding the autistic disorder. If a student already has a learning challenge and entered such a classroom, it is likely to create stress for the student, the educator, and the parents and/or primary caregiver(s).

Researchers have failed to address the public school classroom environment. Students in a public classroom environment that is structured and organized have been shown to succeed academically (Hume, 2007). Iovannone et al. (2003) stated while best practices had been developed for instruction of autistic students, many schools had failed to implement the programs. Hurth, Shaw, Izeman, Whaley, and Rogers (1999) stated programs for autistic students must be individualized to meet their unique needs.

Khare and Mullick (2008) stated appropriate design guidelines remained underrepresented for students with the autistic condition. Khare and Mullick stressed that an
essential component of beneficial autism educational services are lacking due to the
failure to be empirically validated in regard to the design of the learning environments.

Khare and Mullick developed an Environmental Audit (EA) for building designers who
specifically engaged in facility surveys. In addition, the researchers developed a
Performance Measure for Pupils with Autism and a Design Parameter Rating Scale
(DPRS), each to be completed by the educators. The results were intended for use in the

development of standards and codes that established school environments that met the unique needs of autistic students (Khare & Mullick).

Parental insights were sought in this study regarding environmental health in its design for the autistic students. Heflin and Alberto (2001) found that autistic students performed more positively in academics in a classroom that was structured and organized to meet their unique needs. Beaver (2006), an architect in England, specializing in building environments for autistic children, stated he rarely heard "concern or interest being expressed about the environmental conditions children" (p. 1) live in; but, in the United Kingdom (UK) and other countries, it was imperative to provide proper care for the growing autistic population in areas beyond their homes.

Autism News (2010) reported that the design of an environment for autistic students must be conducive to their unique needs. The classroom must be designed from the autism perspective in order to reduce behavioral symptoms, promote learning, and organized in such a way the autistic student feels secure, less distracted, safe, and comfortable in the learning environment.

Ruble and Robson (2006) found a link between engagement and the classroom environment. Ruble and Robson defined engagement as behaviors that are compliant and congruent. Engagement plays a primary role in the relationship between educator behaviors, student behaviors, and increased academic growth (Ruble & Robson, 2006). Teffs and Whitbread (2009) stated that many educators were not prepared to handle the challenges an autistic student presented due to a lack of adequate training. In order to

successfully engage a student with autism, the educator must have knowledge of the limitations the autistic student has.

There are classroom contextual factors, which included behavioral problems that contributed to the ability of a student to learn (Sutherland, Lewis-Palmer, Stichter, & Morgan, 2008). Wolery (2000) suggested that the relationship between the ecosystems and behavioral symptoms should be more thoroughly examined. The behavioral symptoms of autistic students in the school classroom environment are discussed later in the behavioral challenges and mental health issues in the public school classroom section of this dissertation.

Coffey and Obringer (2004) conducted a semistructured interview with parents of two autistic children. The parents felt that the classroom size contributed to whether their children would respond appropriately to the educator and the classroom milieu. There was likely a two-fold reason for this in that the educator might be more willing and able to work individually with the autistic child, and autistic students often responded more positively in the smaller environment (Coffey & Obringer, 2004; Grandin, 2008).

Grandin argued that part of the reason she was able to overcome many of her disabilities was due to the individualized small classroom size for her in the 1950s and 60s (Grandin, 2008).

The autistic student responded positively to structure and hence, structured teaching plays a role in providing the autistic student the ability to understand the expectations the educator had for task completion and classroom behavior (Edelson, n.d.; Schopler, Mesibov, & Baker, 1995; Stokes, 2001). Structured teaching had three

components: physical structure of the classroom; visual structure; and teaching method (Stokes, 2001). In order to successfully contribute to the autistic student's academic achievement in the classroom, the environment must be adequate and/or adapted to meet their needs in order to reduce the inherent anxiety an autistic student had (Stokes, 2001). Engagement and the components of structured teaching appear to contribute to positive academic growth for the autistic student. Chandler-Olcott and Kluth (2009) suggested that the educators of autistic students often had to re-think their teaching strategy.

Overall, classroom management generated by the educator included ways in which the educator's positive contributions to the autistic student's ability to gain the organizational skills they naturally lacked (Cooper-Swanson, 2005). Educators might assist the autistic student in understanding the classroom organization through the use of their own organized space, clear physical boundaries, calendar, and schedules that outlines their daily activities.

# **Sensory Supports in the Classroom Environment**

There appears to be a link between lack of adequate sensory supports and behavioral outburst among students with the autistic condition. Lane, Young, Baker, and Angley (2010) proposed sensory subtypes existed in the autistic condition that predicted adverse behavioral symptoms and communication ability. Lane et al.'s study is based on the presupposition that the autistic children's behavioral symptoms are triggered by sensory seeking, sensitivity, or under-responsivity. Lane et al. examined the patterns of sensory processing in autistic children in relationship to their adaptive behaviors.

A parent questionnaire called the Short Sensory Profile (SSP) is used to examine the adverse behavioral symptoms in autistic children aged 3-10 years old (Tomchek & Dunn, 2007). The SSP was developed by Dunn as a tool to understand an individual's sensory patterns (Pearson Education, n.d.). Dunn found marked patterns of sensory processing in individuals suffering from an autistic condition, schizophrenia, Attention Deficit Disorder, and Asperger disorder (Lane et al., 2010). Lane et al. studied 54 children with the autistic condition and their caregivers. The seven sensory domains examined in the study included (a) taste/smell; (b) tactile, movement; (c) visual/auditory; (d) sensation seeking; and (e) under responsiveness. Normative data from the SSP were used for comparison. Lane et al. found 87% of the participants had demonstrated sensory processing dysfunction, particularly in auditory, sensation-seeking, and underresponsiveness areas. While Lane et al. discussed a few additional studies whose findings represented sensory processing dysfunction of those on the ASD, the researchers stated few studies have been done that examine the relationship between sensory processing and the autistic condition.

As early as 1968, Ayres introduced the idea of the relationship between sensory processing and behavior (Stadele & Malaney, 2001). Sensory integration theory according to Ayres had three assertions that included the following.

1. Nonautistic individuals learn through the sensory input taken from the environment and bodily movement being processed and integrated within the central nervous system that allowed them to use the sensory information in the planning and organization of behaviors.

- 2. When a sensory deficit was manifested in the processing and integration function, behaviors occurred that potentially interfered with the learning aspects of conceptualization and motor function.
- Individuals with sensory deficits might respond to learning opportunities that had the potential to enhance sensory input, provided through organized learning activities.

The learning activities contributed to the improved functioning within the central nervous system sensory processing and input integration. This led to enhanced conceptual and motor learning (Fisher, Murray, & Bundy, 1991, p. 4; Stadele & Malaney, 2001). King (2011) stated Sensory Integration Disorder (SID), developed by Ayres was defined as "The inefficient neurological processing of information received through the senses, causing problems with learning development and behavior" (Kranowitz, 1998, p. 292). King stressed that sensory integration therapy was essential for the reduction of maladaptive behaviors and limited learning ability for those who suffered from the autistic condition. King referred to Shore and Grandin as examples of influential individuals who were challenged with the autistic condition yet with the right support from parents, went on to overcome the challenges and succeeded academically. Professionals who worked with Grandin and Shore in the 1950s and 60s recommended lifelong institutionalization for both but their parents refused. Today, both are vocal about the environmental supports that must be made available to autistic students in order to help them meet the same academic challenges.

Heflin and Alberto (2001) stated the classroom's physical environment for the autistic student must be managed through the use of cuing, stimulus reduction, and reinforcement for appropriate behavioral responses. Shore (n.d.) recommended that sensory processing deficits might lead to poor functioning in the classroom and educators must be aware of the autistic student's limitations in this area. Grandin (2008) suggested that children with the autistic condition might do better in an environment that addressed sensory problems and reported that the small class she attended had a controlled atmosphere that was quiet and lacked the overwhelming sensory stimulation. Grandin reported that had the classroom been larger and more active, she would never have had the ability to succeed academically. Silva, the administrator for student programs and services in Riverside, California believed the small class size for autistic students were necessary in order to reduce their sensory and behavioral symptoms (Boutelle, 2008).

Menzinger and Jackson (2009) stressed the importance for professionals in working with autistic individuals to realize that individuals suffering from the condition had behaviors that were emitted in response to a trigger and the research into daily classroom observations into the origin remained unclear. Since the autistic condition is known to interfere with sensory processing functions, that it includes the visual and auditory stimuli present in the daily classroom milieu. Menzinger and Jackson examined three autistic students over a 3-week period in order to determine whether they would react positively or negatively to light intensity or color. Menzinger and Jackson found the students did not have any strong reaction either way which suggested that there was no basis for light intensity in triggering behavioral symptoms in autistic students.

Menzinger and Jackson (2009) emphasized that some students strongly reacted in a negative fashion to shrill noise and increased activity in the classroom. Shore (n.d.) had personally observed fellow ASD students with sensory processing deficits who began to rock back and forth in response to the 60-Hz cycling emitted by the overhead fluorescent lighting. Barrett (2006), in an autobiographical expose on individuals with ASD presented the story of Kenneth, age 11 who described the voices of his fellow classmates as ,"dynamite going off in my ears" (p. 95).

Wiggins, Robins, Bakeman, and Adamson (2009) studied the sensory profiles of young children who were diagnosed with ASD and compared them to those diagnosed with other developmental disorders (DD). The ASD children had increased tactile, sensitivities in taste and smell, and more difficulty filtering auditory stimuli than children that had a DD. Wiggins et al. reported that the parents of children with the autistic condition found that their child responded less to voice and to their name being called than children with the DD. Wiggins et al. stated that this was due to auditory deficits.

Lane et al. (2010) examined 54 children with the autistic condition and some specific ways that sensory processing affected their behavior. Auditory deficits were found to be 92.6% in the participants. The findings revealed clear associations between sensory processing patterns, communication ability, and maladaptive behavior in the participants. The auditory challenges inherent in the autistic condition include sensitivity to loud noises, inability to receive the auditory detail necessary for discerning voices among a number of sounds, and an inability to hear hard consonant words (Grandin, 2008).

Grandin (2008) explained that the sensory deficits might make the child hyposensitive; lacking a sensory input ability or hyper-sensitive which was the most common and posed the inability to process and integrate the sensory input quickly. Grandin suggested that the sensory dysfunction in autistic students was the primary trigger for maladaptive behaviors in the classroom environment and described the auditory difficulties might be compared to using dial-up rather than a high-speed connection on the computer as it takes time for the connection in the central nervous system to occur. Auditory training (AT) was an additional physical environment measure that might assist autistic students in becoming less sensitive to auditory sounds (Grandin).

Coulter (2009), an optometrist, noted that the visual symptoms of autism were "pervasive and severe" (p. 164). Coulter believed the symptoms were the result of a sensory-processing disability and were biological in their origin and explained that autistic individuals, in an attempt to listen to someone may look away from the speaker in order to reduce other stimuli from distracting them. This might be perceived as rudeness or a lack of ability to communicate appropriately if one observing them does not understand the symptoms of the autistic condition.

While some autistic children might have deficits in visual processing, others have superior ability on some vision tasks and it is important for optometrists to know what the symptoms of ASD are in order to assist with timely diagnosis because they are often the first individuals to see the child (Coulter, 2009). Many parents might bring their child to the optometrist because they believe their child has an eye problem. Autistic children often fail to maintain a gaze, persistently attempt to look off to the side, demonstrate poor

eye contact, stare at spinning objects, or repetitively look at objects for extended periods of time. Finger flicking and hand flapping are suggested to be compensations for poor visual spatial skills as the autistic child is not aware of where their bodies are in relationship to other objects or are seeking the sensory input in an attempt to adapt to the environment (Coulter, 2009).

Coulter (2009) stressed the importance of an integrated approach since autistic children had problems in the processing and integration of visual input with proprioceptive, kinesthetic and tactile information. Grandin (2008) stated autistic students constantly scan the environment for visual information to which they might ascribe meaning and described the children as having difficulty "visually holding still" (p. 65). Grandin has spoken to autistic students who complained about the black and yellow caution stripes used in highway or sidewalk repair as actually vibrating when they looked at them.

Murray et al. (2009) stressed that in order to alleviate severe behavioral episodes by autistic students in the classroom, teachers must have an understanding that these learners often responded in ways that were magnified or significantly reduced. It is likely that the autistic student's behaviors are being emitted due to a sensory-based need that is not being met. Murray et al. stated the challenges lie in an educator's ability to understand medical terminology with use in an educational service delivery model.

Evans (2011) encouraged the use of appropriate modifications in the enhancement of educational services for the autistic student. Important modifications include visual aids, evaluation of sensory processing needs, limitation of distractions, consistency, and

activities designed to aid in social and emotional skills growth. Stokes (2001) developed visual input intervention aids for autistic students which were designed to help them understand classroom rules and expectations. This was achieved through the use of specific visual representation systems geared towards communication, social skills, and expressive communication. The visual representation systems might include photographs, line drawings, written words, and realistic drawings.

Grandin (1995) stated when she thinks her thoughts were in pictures and it had enabled her to develop entire systems of any project she had undertaken. Barrow (2011) reported the story of Endow who was diagnosed with the autistic condition as an adult by the physician treating her autistic son. Endow reported that she thinks in pictures that she can actually see. This enabled Endow to create pottery from the pictures she sees in her mind and stated she takes the thoughts with their swirls of different colors and made them come into the piece of clay she was working on. That piece of pottery holds Endow's thoughts and she described it as an event where if she can get her thoughts outside of herself then she was able to put words to it.

A number of supports are required in order to enhance the classroom environment for the autistic students. These include the physical structure and organization of the classroom environment, behavioral intervention(s), visual and auditory structure and aids, communication and social intervention strategies, and educators trained in evidence-based autism approaches. Stadele and Malaney (2001) promoted a multisensory environment (MSE) in order to reduce negative behavior and increase optimal performance in the autistic student. Pagliano (1999) found that optimal multisensory

environments would direct outreach in the following areas: emotional development, self-determination, improved communication skills, relaxation; reduced maladaptive behaviors, therapy, sensory stimulation, and opportunities for social interaction with nondisabled children. The MSE might provide autistic students the opportunities to manipulate their own environment through reduced stimulation.

Grandin (1995) admitted she purposely avoided situations that would potentially trigger panic attacks, which she regularly suffered from and brought on by overstimulation. Grandin developed her own device to self-soothe while she spent one summer at her aunt's ranch in Arizona. Grandin watched the cattle enter a cattle shoot that would squeeze tighten the animal to hold it in place in order to give it an injection. This allowed the animal handler to perform any number of functions where the animal must hold still. After using the cattle squeeze machine on herself as a college student, Grandin eventually designed her own "human squeeze machine" (p. 58) out of plywood. Whenever Grandin felt overwhelmed, she would enter the machine and experience a sensation she described as "a wave of relaxation" (p. 59). Lane et al. (2010) emphasized the importance of sensory-based intervention strategies as the primary approach to reduce the onset of maladaptive behavioral symptoms in autism and a strategy in behavioral management.

Grandin (1995) is vocal about another factor that contributed to her success in life, her mother. Grandin's mother was not one to be silent about the supports her autistic daughter required. Shore (2003), diagnosed with high-functioning autism and Asperger's Syndrome, related personal experiences in a publication. Shore's mother was

instrumental in manipulating his environment for success, chiefly through sensory integration, imitation, movement, and music. L.D. (2008) reported his autistic son had to be removed from the regular classroom as he was overstimulated which led to an increase in self-abusive behaviors which was evidenced by bite marks on his wrists and hands.

Moore (2005) suggested that since the autistic condition was a social disability, the appropriate classroom environment for the autistic student was one that took their sensory hypersensitivities into account. With Shore and Grandin, two well-documented examples of successful individuals with the autistic condition who have openly declared their parents to be the ones who contributed to their success, it makes one question why parental opinion is not the priority in the many areas wherein lie the challenges in successfully managing the disorder in the classroom environment and why the empirical studies addressing this topic do not exist.

Worth (2008) discussed ways in which hospital physicians that treated autistic children and worked with the parents suggested the following: (a) control the environment, (b) reduce sensory overload, (c) make use of visuals and touch, (d) schedule all procedures in advance, and (e) enlist the parents in the process. Worth emphasized that parents are the best resource for a hospitalist because they know their children better than anyone else. The parents have the experience and knew the tactics that will work in order to have an otherwise anxious autistic child cooperate in the hospital. Parents have a great deal of experience with physicians and no doubt, with educators. Marks, who practiced at the Cleveland Clinic, commented on the parents by saying, "They know these children and want to participate in their medical care. They are the only ones who

know what is normal for their child. If you are smart, you are going to utilize them to your advantage" (Worth, 2008, p. 3).

### **Increased Stress for Students, Parents, and Teaching Professionals**

Children with the autistic condition often have a high degree of stress which naturally affects others in close proximity. Kanner (1943) revealed that autistic children had extreme fearfulness and increased anxiety. Some students became rigid and experienced increased agitation when the activity levels increased in the classroom (Menzinger & Jackson, 2009).

The diagnosis of the autistic condition has left the parents of an autistic child having to cope with a complex developmental disorder (Gupta & Singhal, 2004). Kenny & Corkin (2011) completed an exhaustive search of health literature and nursing databases about the impact of stress on the parents of autistic children, in that they found recurrent themes, which included (a) the impact of the diagnosis of autism, (b) marital satisfaction, (c) attachment and resilience, and (d) parental mental health and well-being. Kenny and Corkin stated that the coping strategies employed and positive experiences were the factors that enabled the parents of autistic children to have improved well-being. Eisenhower, Baker, and Blacher (2005) found that the mothers of autistic children reported more parental stress than other groups due to the difficulties with adjustment, depression, and experienced overall increased stressors. The mothers of autistic children ranked the highest in the adverse impact, symptoms of depression, and were found to be the lowest in positive impact of the autistic condition (Eisenhower et al., 2005).

The parents and/or primary caregivers of a child with the autistic condition are often overwhelmed by the stress brought on by care the children require. Fleischmann (2004) stated that the parents of autistic children were often unable to secure adequate support services and were judged by others who failed to understand the behavioral symptoms associated with the condition. Kidd and Kaczmarek (2010) reported in a study with ten mothers of autistic children who were students in the public school that nine of the mothers, upon the advice of a psychologist removed their children from the schools due to the increased levels in anxiety their children experienced. The mothers reported that the increased anxiety was primarily acted out in increased behaviors upon arriving home, commonly referred to as "melt downs," and two of the mothers reported episodes of self-harm. Barrow (2011) reported in an article about the autistic condition, the feelings of Colston, the mother of a son with classic autism about a bad day with her son as being one in which she felt she does not have the reserves of strength needed within her to help her son through the day.

Colston (as cited in Barrow, 2011) stated that the bad day is one that began with a tantrum and by the time they left the house she wore oatmeal and her son had not had his breakfast. The mothers experience their own stress in response to their child's anxiety. Sharpley, Bitsika, and Efremidis (1997) posited that there were three primary factors which contributed to increased stress for parents of autistic children: (a) the diagnosis of a condition that was permanent; (b) the behavioral symptoms of autism were not well received by society and often, by immediate family members; and (c) lack of adequate social support for parents. Special Education Monographs (1990) found that parents of

autistic students reported higher levels of stress and ineffective coping skills than parents of students with other disabilities and the stressors included feelings of isolation, financial stress, and inability to pursue a meaningful career.

Boyd (2002) reported some parents withdrew when their own stress levels increased, chiefly in response to a lack of adequate social supports and negative feelings about their child's behavior. Boyd examined the opinions of parents in integrated preschool classes through a survey sent home with the parents. Parents who responded were primarily mothers who had a child in the special education classes. Boyd stated that the social workers within schools had a unique opportunity to link the parents of children in special education classes to the appropriate services in order to effectively help them cope with the stressors and assist the parents in the adaptation to their child's disability. The National Center for Autism Research and Education (NCARE, n.d.) in Nevada stated that a high priority should be placed on the availability of centralized services for families of autistic children.

Benson (2006) suggested that the effects of autism on the family were particularly severe due to behavioral problems, communication and social deficits, and dependency of child upon parent. The combination of the deficits associated with autism and the level of behavioral problems often created a repeated source of stress for the parents of autistic children (Benson). Hartley et al. (2010) suggested that there was a need for interventions designed to support parents of autistic children in order to ameliorate ongoing stress.

Hartley et al. (2010) found in a study with 391 parents with children on the ASD in comparison to a matched representative sample of parents with children that have no

disabilities, that the parents of the children with ASD were at an increased risk of marital dissolution and strategies needed to be developed in order to enhance services in this area. Gupta and Singhal (2004) pointed out that the studies had shown that the parents of autistic children were at a higher risk for negative psychological effects, higher risk of depression, social isolation, and marital discord. Sloper and Turner (1993) found higher levels of stress in parents of autistic children.

Boyd (2002) stated that those parents that received adequate social support were less likely to suffer the effects of stress than those parents who had not received adequate social support for their child with the autistic condition. A lack of social support services was a potent predictor for depression and anxiety in mothers who had an autistic child (Boyd). Poor prognosis was believed to be chiefly due to a lack of adequate support services, limited financial resources, and negative attitudes (Gupta & Singhal, 2004).

Autism in the family appeared to be a catalyst for the proliferation of stress as it had the potential to cause the families to become enmeshed in a complex mire of difficulties, especially when new stressors arose (Benson, 2006). The idea of the potential for stress proliferation was not something researchers had examined and explained that attention to the idea of stress proliferation was important as it had the potential to reveal how the multifarious processes of the initial stressors might expand and exercise their collaborative effect on psychological harmony and adaptation (Benson, 2006). Costello and White (2001) pointed out that there were a number of factors linked to family well-being; social and emotional health of children, and brain development. Through

addressing these factors it might potentially reduce the burdens associated with the autistic child's behavioral disorders.

Benson (2006) found that 45% of the parents who were surveyed in the study scored well above the recommended cut-off point that was used to identify clinical depression. Stress proliferation was a strong predictor of parental depression and that raising an autistic child created marked psychological distress for parents (Benson, 2006). The key finding from that study revealed that parental well-being was directly and indirectly affected by their child's autism and the associated stress proliferated into other areas of their lives that were not related to the child's autism (Benson, 2006). Wethington (2000) suggested stress was a contagion and had the ability to affect the daily structures present in our lives, such as work, home, and school.

Parents of children on the ASD spectrum are grappling with a disorder that has an unknown etiology, severe cognitive impairments, social and communication deficits, and severe emotional and behavioral disorders in their child. Gupta and Singhal (2004) pointed out that a diagnosis of the autistic condition left the parents with qualms about their future and the future of their child and they experienced depression and sadness. The result of the family distress and the response to it potentially contributed to how well a child on the ASD spectrum responded cognitively, behaviorally, and socially. The stress among family members led to a poor prognosis (Gupta & Singhal, 2004). The serious effects of the child's autistic condition were more of a burden for the mother than the father as mothers were more likely felt to be responsible for the child's behavior and mothers were found to have poor coping skills, poor self-esteem, and psychological

distress (Gutpa & Singhal, 2004). Educational provision (2009) believed single parents who had a child on the ASD experienced greater stress than other parents.

Pillay, Alderson-Day, Wright, Williams, and Urwin (2011) reported it was the psycho-educational outreach methods that included stress management and behavior management techniques that contributed to a reduction of the depressive symptoms in a group of mothers with autistic children. Pillay et al. conducted an evaluation of the intervention support groups for parents of children with ASD. The parents were trained in behavior management, problem solving, and strategy development which the parents stated they found valuable. Bayat (2007) found that the families with autistic children showed evidence of resiliency in such factors as family connectedness, closeness, making positive meaning of a child's disability, and spiritual and personal growth. Bayat pointed out that there were several themes that contributed to family resiliency according to Walsh's (1998) resilience theory, including (a) making meaning of adversity, (b) affirming strength, (c) maintaining a positive attitude, and (d) maintaining spirituality and having a belief system.

Bayat (2007) qualified this option by pointing out that the families must first have the ability to organize and utilize resources, be flexible and connected to one another, and be successful communicators. Bayat pointed out that Walsh's theory of family resilience nor family resilience, in general had been researched directly in the field of disabilities. Bayat recommended that it was important for service professionals to recognize that the families had strengths and the potential for resilience.

Educators suffered from increased stress as a result of the exposure to the proliferation of stress which was theorized to potentially be a "linked fate" for members of common quarters, such as a classroom or a household (Wethington, 2011, p. 234). Educators experienced multiple stressors in teaching autistic students due to a number of factors which included passive exposure and the stress contagion that existed in the school classroom (Wethington, 2011). Jennett, Harris, and Mesibov (2003) stated while stress was common for educators, it was the special education educators that had additional stressors due to their responsibilities associated with implementation of a student's IEP, behavioral management expectations, increased responsibility in meeting parental demands, and the successful academic progress of students with behavioral and cognitive impairments. Jennett et al. stressed that it was important that increased educator self-efficacy and decreased burnout be priorities in order to prevent turnover and improve employment for education professionals.

Milkie and Warner (2011) suggested the following barriers existed and must be eliminated in order to reduce the experience of stress for teaching professionals.

- Positive classroom environments must have adequate material resources in order to nurture a student's academic growth.
- 2. Educators had the desire to feel respected by their colleagues.
- The bureaucracy and demand for paperwork might leave an educator feeling they do not have time for their students.
- 4. Educators must feel they are in control of the curriculum.

5. Educators who had students of varying skill levels were not able to promote a positive classroom environment.

A negative classroom experience not only affects students and parents but also has an adverse effect on educators. The negative classroom experience had the potential to upset the parents when they must deal with their autistic children when they return home from school, left the educator feeling they have no control over the environment, and peers and staff members were affected in "a mutually reinforcing, bidirectional process" (Milkie & Warner, 2011, p. 7). Another factor, the lack of support from their supervisory staff, was reported by some educators caused them to have increased stress reactions and frequent work-related stress (Cherniss, 1988).

Fauzan (2010) stated the classroom structure and environment for students with the autistic condition should be one of predictability that reflected consistency which might reduce the agitation and stress the autistic student experienced. Fauzan recommended that educators be prepared to make gradual changes over time in order to reduce conflict. This method has the potential to lessen stress for everyone.

#### **Behavioral Challenges and Mental Health Issues**

With adequate training in autism, the educators and parents and/or primary caregivers would understand the behavioral challenges and mental health issues that are common with the autistic condition. APA (2013) stated that individuals that suffered from autism often had a range of behavioral symptoms, which included "hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors, and, particularly in young children, temper tantrums" (p. 72). The APA stated that there were

peculiar responses to sensory stimuli, such as oversensitivity to sounds and exaggerated reactions to lights or odors. Mood or affect abnormalities were common in children with autism and they might laugh or cry for no obvious reason. There might be a lack of emotional response or extreme "fearfulness in response to harmless objects" (p. 72). Head-banging and finger, hand, or wrist biting might be present. As the autistic child becomes older, depending upon the intellectual ability for insight, the potential for depression in response to the disability might be present (APA, 2000). Charman, Pellicano, Peacey, Peacey, Forward and Dockrell (2011) stated that due to the emerging themes being discovered about the autistic condition this necessitated specific knowledge and education in teaching autistic students. It is imperative for teaching professionals to be aware of the expected sensory and emotional responses in autistic students.

Kanne, Abbacchi, and Constantino, (2009) reported that co-occurring autism and behavioral symptoms significantly impacted the autistic child's functioning. Individuals with the autistic condition might be impaired in their ability to tell others about their symptoms likely due to conditions such as major depression, anxiety, and behavioral challenges associated with ADHD, which have been shown to have high rates among this population (Kanne et al., 2009). The participants recruited for the Kanne et al. study included the families of autistic children between the ages of 3 and 18 years to participate in a longitudinal study that examined the co-occurring psychiatric symptoms and autism. The parents reported their children had severe mood problems.

Kanne et al. (2009) found that the environment played a large role in the expression of psychiatric symptoms in the autistic children. Kanne et al. stated there was

more than one methodology needed in order to provide an understanding about the reasons for increased psychiatric symptoms in the autistic student and it was likely "directly related to environmental factors" (p. 862). Kanne et al. relied on informant report rather than any direct observation within the classroom.

Kanne et al. (2009) suggested that it was important to take into account multiple informant perspectives rather than just one, that is, parental or educator report, in order to provide an understanding of the behavioral symptoms. Kanne et al. stated that due to the large variance in behavioral symptoms in autistic children, it might be the environmental context factors that contributed to an exacerbation of such, and if so, these were valuable options in which to study intervention outcomes. Lane et al. (2010) previously showed that there was a link between sensory processing dysfunction and maladaptive behavior in the classroom. A classroom environment that was not conducive to meeting the unique needs of an autistic student contributed to an increase in psychiatric symptoms among this population (Kanne et al., 2009).

Swartz, Lopez, Vazquez, and Cruz (2003) stated it was necessary to examine behavioral treatment methods that were effective for the autistic student in the inclusive classroom environment that were likely to contribute not only to successful achievement in academics but might be translated for use in the home and in the long-term for those with the autistic condition. Swartz et al. proposed that improper environmental stimuli for this population might lead to inappropriate behavioral problems. Butter (2002) pointed out that the behavioral interventions that were being done in classrooms that promoted learning in "other" children are being used with autistic children. The student with the

autistic disorder had unique needs compared to other children and those measures might not be an appropriate intervention.

Andis et al. (2002) recommended that the responsibility for children's mental health in the schools was the responsibility of not only the school professionals but that of mental health and family services providers. Andis et al. suggested school personnel might work collaboratively within the classrooms with mental health professionals, thereby learning their expertise in behavioral management strategies. Mullick and Butter (2002) suggested these methods were not utilized due to financial constraints and failure to implement adequate behavioral approaches.

Educational provision (2009) stated the behavioral symptoms arose when the autistic student experienced stress or fear and it was imperative to identify situations that led to stress inducing responses such as this and address them. Conroy, Asmus, Boyd, Ladwig, and Sellers (2007) stated that as more children were being diagnosed with ASD, more were found in the general education classrooms, necessitating the use of effective intervention strategies geared at reducing problem behaviors that were disruptive to the classroom, peers, and educators. Conroy et al. examined the relationship between antecedent classroom factors and behavioral outbursts of five students with ASD in the naturalistic classroom setting. The descriptive study was undertaken in five general education classrooms in five elementary schools in the southeastern United States. Five teachers and five assistant teachers participated in the study. The students were observed engaging in activities and in the use of materials according to the various classroom curriculums, student activities, and educator's schedule. Conroy et al. reported that the

students had fewer disruptive behaviors in the group setting compared to the independent class work.

Conroy et al. (2007) found that the students had higher rates of disruptive behaviors when adults were in close proximity and found a moderate to strong relationship between educator directives and a student's disruptive behaviors. Conroy et al. stated adult-directed activities produced less disruptive behaviors than child academic activities, assuming the activity was independent. Conroy et al. stated that their study contributed to the literature because they supported findings from previous research indicating a relationship between student problem behaviors and educator directives.

Kern, Choutka, and Sokol (2002) stated that most behavior was likely to occur due to some type of environmental trigger and often necessitated an environmental adaptation in order to alter the occurrence of problem behaviors. Blakeley-Smith, Carr, Cale, and Owen-DeSchryver (2009) suggested that the examination of problem behavior in the classroom had been the topic of some autism research in order to advance appropriate assessment and behavioral treatment methodology.

Adamek et al. (2011) suggested that temperament potentially played a role in leading to problem behavior in children diagnosed on the ASD and should be examined more thoroughly in the research in order to understand individual differences.

Temperament differences in children with the autistic condition and normal children were currently being examined in the research due to the link between temperament and problem behavior (Adamek et al., 2011). Problem behaviors included aggression, self-injury, and temper tantrums which potentially damaged a student's quality of life by

limiting opportunities in the home and in the community, particularly regarding education and socialization (Koegel, Koegel & Dunlap, 1996).

Adamek et al. (2011) pointed out that activities or situations that were not a good fit with an autistic child's temperament increased the likelihood of behavioral problems. Niche picking interventions were discussed by Adamek et al. and were defined as situations or niches that were chosen for the autistic student in order to provide an adequate, sound structural and home-environment. Adameck et al. stated the opportunities for niche picking were only marginally being taken advantage of and even if niche picking were offered for the short duration, it had the potential to lend to intermittent non-beneficial niches that the autistic child might better be able to tolerate as it might increase learning and improved quality of life.

Kanne et al., 2009) pointed out that a significant number of research studies stressed that a large number of individuals with the autistic condition had serious emotional and behavioral difficulties, and were primarily suffering from depression, anxiety, and mood disorders. Boyd and Shaw (2010) stated autistic adolescents were at a high risk of being diagnosed with a psychiatric diagnosis of depression and/or anxiety. Students in the special education classrooms often had mental health disorders and issues that reduced their ability to learn, failed to achieve academic success, and the classroom environment contributed to a negative learning experience (Atkins, Frazier, Adil, & Talbott, 2003; Catalano, Haggerty, Nyre, Vernberg, & Robers, 2007; Osterle, Fleming, & Hawkins, 2004; Rones & Hoagwood, 2000; Weist, 1997). Milkie and Warner (2009) suggested there were four components to mental health that must be taken into

consideration in the classroom environment: (a) attentiveness in the ability to learn, (b) externalizing problems or fighting among students, (c) interpersonal behavior, and (d) internalizing problems that led to depression or anxiety. Students who experience a lack of resources and educators who feel they were missing adequate resources or training might contribute to negative classroom environments.

The inclusion of mental health services into the public schools is making headway. Adelman and Taylor (2004) stated the U.S. Department of Health and Human Services endeavored to bring mental health services into the schools a decade ago. The department recognized the need to improve children's mental health. The idea is to foster collaboration among school administration and personnel, mental health professionals, policy makers, primary care service providers, and other stakeholders in order to adequately meet the needs of this population. School settings were the ideal location to provide mental health and accompanying support services as they were easy access for children (Kutash et al., 2006).

Adelman and Taylor (2004) discussed the shared agenda between NCLB and the IDEA. The recommendations outlined in the president's New Freedom Commission on Mental Health completed the goals of the shared agenda (Adelman & Taylor, 2004). The researchers emphasized the goals of the President's New Freed Commission which included Goal Number Two, mental health care was consumer and family driven. The recommendations regarding Goal Number Two are as follows.

- Every adult with a serious mental illness and every child who suffered from a serious emotional disturbance will have an individualized plan of care.
- 2. Families will be fully involved in the orientation of the mental health system in moving towards recovery.
- Federal programs will be aligned for improved access and will be accountable for mental health services.
- 4. A comprehensive State mental health plan will be created.
- The rights of individuals with mental illness will be protected and enhanced.

Adleman and Taylor (2004) emphasized that the schools had the opportunity to assist the parents in their own recovery and in turn, this would allow the parents to play a beneficial role in their child's academic progress. Adleman and Taylor emphasized that school systems are currently out of compliance with the mandates regarding special education in meeting the needs of those students who suffer from serious emotional disturbance (SED). The schools are not meeting the mental health needs of this population. The authors suggested that this might only be achieved through a community and school approach that is coordinated and integrated and suggested that since the student population is so diverse it was imperative that their needs are accommodated in the following ways.

 Mental health was understood in terms of psychosocial problems as well as disorders, and in terms of strengths as well as deficits.

- The roles of schools/communities/homes were enhanced and pursued jointly.
- 3. Equity considerations were confronted.
- 4. The marginalization and fragmentation of policy, organizations, and daily practice were countered.
- 5. The challenges of evidence-based strategies and achieving results were addressed.

Adelman and Taylor pointed (2004) out schools might not be in the business of mental health but they were there to assist in helping students to achieve academic success and recognition of mental health and psychosocial needs should be a primary concern. When these issues prevented a student from succeeding in the public school system, the challenge must be met by the school (Adelman & Taylor, 2004). Milkie and Warner (2009) suggested the research regarding the factors that influenced mental health within the classroom environment was sparse. Milkie and Warner suggested that the classroom has the potential to lend to an understanding of the student's stressors. An examination of the environmental factors influencing mental health might contribute to approaches that potentially assist the autistic student in achieving emotional and behavioral health through their development.

Weist and Evans (2005) reported that students in the general and special education classrooms received mental health services that often (a) had gaps in service delivery, (b) experienced a lack of quality assessment, (c) minimal family and educator

engagement regarding services, and (d) a lack of coordination of mental health and social supports for families and the student.

Kutasch et al. (2006) stated there were divergent perspectives among those professionals who actively brought mental health into the school systems and they included (a) clinical psychology, (b) ABA, (c) special education, (d) developmental psychology, and (e) psychiatry. Kutasch et al. stated a child's need for mental health services was only provided when their IEP contained a provision for the services. Kutasch et al. stressed that the areas in need of empirical evidence regarding outcomes were those in the students who suffered from serious emotional disturbance in the special education classroom due to their inability to achieve academic success. Kutasch et al. pointed out the lack of adequate research studies that examines the effectiveness of mental health services for students in special education classes.

Rones and Hoagwood (2000) agreed that there was a lack of research studies that specifically addressed students who had emotional disorders that were in the special education classroom. Kutasch et al. (2006) emphasized that in order to successfully implement adequate school mental health services and interventions, a partnership with parents and the establishment of new roles for the educators must be achieved. Kutasch et al. (outlined a number of barriers that prohibited the successful implementation of school mental health for students and those included (a) inadequate empirical research evidence, (b) financial barriers, (c) lack of community based treatment providers, (d) lack of resources, and (e) outdated training methods.

Markle and Clark (2007) emphasized the need to initiate collaboration between behavioral health services and educational services in order to meet the burgeoning need of students who suffered from the autistic condition. Perry, Prichard, and Penn (2006) found that the parents felt one of the most important strategies to meet their autistic child's educational needs was effective behavioral management in the classroom. Wagner et al. (2006) stated that the parental survey in their study revealed the characteristics the parents felt were important and that should be incorporated into the programs for their children. Since families are the important key in beneficial service delivery, it is the family feedback provided that will initiate this delivery (Markle & Clark, 2007).

Successful partnerships between the policy makers, school administration, parents, clinical professionals, and autism experts are needed in order to develop the quality services the autistic student require. Andis et al. (2002) stated that the partnerships between local, state, and federal entities were ineffective as they often acted separately and were uninformed about each other's efforts in meeting the mental health needs of the children. Andis et al. encouraged parental participation in the development of governmental policy regarding mental health services in the schools through the development of a shared agenda. Weist and Paternite (2006) discussed the limitations that were inherent in the traditional school mental health programs and suggested that these services should include an integrated approach encompassing the student's family, school, and community.

#### **Lack of and Need for Educator Training**

There is a need for adequate educator training in autism. Training has the potential to provide the educators, students, parents and/or primary caregivers the information and resources in being able to manage the condition in the classroom and in the home. Tutt et al. (2006) suggested that there had been minimal attempt to recount eminent educational practices in the autistic condition to a broadened psychological understanding about the condition and that the common educational practices were often discarded in order to develop curriculum that met the unique needs of the autistic student. This had forced educators to use an amended approach that combined the elements of numerous approaches in order for them to understand the behaviors associated with the autistic condition (Tutt et al., 2006).

Tutt et al. (2006) suggested that many of the educational approaches that included (a) TEACCH, (b) Daily Life Therapy also known as Higashi, (c) Lovaas method, (d) Option Method, and (e) SPELL method had none or minimal empirical evidence base. Rogers and Vismara (2008) reported that Lovaas and colleagues had published articles in 1987 and 1993 that described the intensive ABA used on some very young autistic children in that 50% of them responded positively. While intervention programs had been developed solely for autistic children, most of which had impacted the public school systems, the interventions were very specific to the autistic condition and were not designed for others with developmental disabilities (Rogers & Vismara, 2008). The intervention programs have given parents of autistic children anticipation that their children might respond positively to the interventions.

Fox, Dunlap, Hemmeter, Joseph, and Strain (2003) found that the educators of children with adverse behavioral symptoms felt unable to meet their needs due to their inability to develop a classroom environment suitable in meeting those needs. Fox et al. promoted a teaching pyramid model that was designed to encourage social skills as a method to reduce behavioral challenges in children and stated that early education approaches must consist of relationships that provided positive supports which had the potential to contribute to an increase in positive behaviors. Fostering supportive relationships allowed children to develop self-confidence and a sense of safety that contributed to the positive behaviors rather than an examination of adult behavior and the classroom practice was the predominant issue rather than a child's behavioral challenges (Fox et al., 2003).

Ruef, Turnbull, Turnbull, and Poston (1999) found that educators expressed that the school programs and support services for students with mental retardation and/or the autistic condition were inadequate in regard to educator training that contributed to reduced morale among the teaching professionals. The educators felt their school districts were inflexible in providing them with any real solutions in meeting the needs of a growing population of students who suffered from mental retardation and/or the autistic condition (Ruef et al., 1999). Boyd and Shaw (2010) emphasized that research had shown the importance of providing adequate social and mental health services, particularly within the classroom environment for autistic students. National Autism Center (2009) promoted the first step planning processes for the autistic condition treatment services in the classroom environment that included a collaborative team that would promote the use

of evidence-based practices. Steps in the planning process included (a) capacity evaluation, (b) an examination of any barriers that potentially undermined the planning process, (c) collaborative strategies to combat any barriers, (d) establishment of a training process, (e) development of resources, and (f) on going school staff.

Blakeley-Smith et al. (2009) emphasized that in order for the autistic student to receive a successful academic experience, it required a collaboration of parents and teaching professionals to adequately address behavioral challenges in the environment and took into consideration the interaction and environmental variables. Blakeley-Smith et al. called this a transactional approach that is used to explore a context-based assessment in order to determine whether the student was competent to meet the demands of educator-based classroom curriculum. Blakeley-Smith et al. suggested that the classroom environment might have to be adapted in order to see a reduction in the autistic student's behavioral challenges.

Boyd and Shaw (2010) stressed the importance of school educators receiving adequate training in the evidence-based practices available in autism models and an awareness of the specialized services needed for autistic students. Teaching professionals must be aware of the effect of depression and anxiety on an autistic student's ability to adjust and learn within the classroom environment. Boyd and Shaw stated that a number of legal lawsuits and legal decisions regarding due process are pending on this issue and others.

Mock et al. (2003) suggested that the special education field had a valid criticism leveled against it in that it had a history of the implementation of educational

encouraged school professionals to recognize the need to address and remediate educational methods that were commonly used with students in special education classes. There was a need for implementation of evidence-based practices in special education and decision-making based on an evaluation of the efficacy of the varying models available that provided reliable data (Mock et al., 2003). Mock et al. stressed that with the implementation of IDEA, evidence-based models can be used in intervention methods while continuing the free education to children in special education.

There are important lessons to be learned from Itard's work with Viktor in that Viktor's behavior changed dramatically through Itard's educational intervention attempts (Mock et al., 2003). Scheuermann, Webber, Boutot, and Goodwin (2003) stated while the NCLB required that highly qualified educators teach students in special education classrooms, this raised concern for educators of autistic students regarding exactly what made an educator highly qualified. Scheuerman et al. pointed out the following problems:

(a) teaching licensure varied from state to state, (b) teaching staff in special education had ongoing shortages of people, and (c) the staff shortages created questions regarding whether the staff that had been hired had the skills required to meet the needs of students with autism in the public classroom. Scheuerman et al. pointed out that there is not one single-theory approach that was currently being used in meeting the needs of autistic students.

The thoughts of Scheuermann et al (2003) hold true today. There is a wide variation in the symptoms of autism and, while some might be treated as standard, other

symptoms are unique to the individual. The one method approach limited the educator in meeting the autistic student's needs successfully and the educator should be able to succeed at meeting their needs (Scheuermann et al., 2003). The school personnel training programs for educators of autistic students might include a holistic approach that allows the educators to learn discriminatory skills in order to recognize those methods that effectively meet the individual needs of the autistic student. Scheuermann et al. emphasized that educators should be trained in multiple evidence-based approaches.

Hess et al. (2008) developed a web-based autism treatment survey (ATS) wherein 185 respondent teachers in Georgia reported on 226 students on the ASD. The intention of the survey was to identify the educational methods used with some of the students on the ASD. The areas examined included: (a) interpersonal relationships, (b) skill based, (c) cognitive, (d) physiological/biological/neurological, (e) other, and (g) none. Skill based was the most frequently used in the school environment.

While the respondent educators reported the use of TEACCH (3.78%) and Lovaas' University of California Los Angeles (UCLA) Young Autism Project (1.08%), 7.03% used unspecified, combined models in the classroom environment (Hess et al., 2008). Hess et al. reported that due to the limitations of the internet survey, it was unknown how accurate it was that the programs were even implemented in the particular classrooms. Hess et al. suggested that the findings revealed that more instruction was needed for teaching professionals in regards to the evidence-based practices for the autistic students. Hess et al. emphasized that the school administrators should take

leadership roles regarding best practices for teaching professionals who work with those students on the ASD.

Gregor and Campbell (2001) stated educators in Scotland felt that they had adequate support from school administration while there appeared to be a low level of specialized training in the autistic condition. A majority of the educators in the study felt that the school psychologist was not helpful due to their lack of providing coping skills training to the educators and their absence from the classroom milieu. Gregor and Campbell suggested that the more specialized training in the schools included (a) in the autistic condition for the educators and support personnel, (b) restructure the role of the psychologist, (c) provide more training in coping strategies, and (d) more in-service training. Gregor and Campbell pointed out that a difference in attitude existed between those educators who were experienced in working with autistic students compared to those who had little experience. The educators who were familiar with autistic students felt more prepared and confident about their ability to cope with the behavioral challenges common in autistic students.

For experienced educators of autistic students, Prather-Jones (2011) found that the educators who remained attributed the reason as having received adequate support from administrators and their colleagues. In a qualitative investigation, Prather-Jones collected data in 13 personal interviews with educators in a metropolitan Midwest area who taught in elementary, middle school, high school, and an alternative school. The qualitative study had a focus group component in which seven educators participated.

Prather-Jones (2011) pointed out that it was the school administrators who developed the academic environment of the particular school and many did not understand the importance of collaboration and lacked knowledge about the needs required by the special education educators. Of particular importance, school administrators must provide staff development, access to materials, professional support, and mentoring (Prather-Jones, 2011).

Murray, Baker, Slutsky, and Paris (2000) stressed that in regard to the sensory problems inherent in autistic students, that teaching professionals must understand that when sensory issues were not recognized, and certain behaviors that arose from the specific sensory issues, another behavior was likely to take its place in order to meet the child's sensory needs. Murray et al. suggested that the educators be aware of behavioral approaches designed to meet the autistic student's sensory needs.

Educators must be aware of the medical terminology associated with the medical realm of ASD in regards to adequate educational service delivery. Murray et al. (2000) supported an educational approach that was holistic and comprehensive in its intervention model of educational services. Wolery (2000) emphasized that the educators should be aware of the need to teach autistic students ways to interact with their world, understand the behaviors associated with the condition, and maintain flexibility in teaching methods with this population. Wolery suggested that there is a need to understand the relationship between the behaviors that autistic students displayed. The critical components of an effective approach in educating the autistic students included a quality classroom environment, being aware of the interactions between child-parent and/or primary

caregiver(s), and an awareness of the risk and the opportunity in the daily events (Wolery, 2000).

Kutash et al. (2006) suggested that there were risk and protective factors that can be established in the classrooms. A risk factor is one that is an environmental condition based on empirical research findings that contributes to the exacerbation of behavioral symptoms. A protective factor is an environmental condition based on empirical research findings which fosters a reduction in behavioral problems in the classroom. Protective factors include parents and educators who care about the child and provide the supports necessary for the student to succeed but it all depends on whether the school administration and child service providers promote ways for the student to succeed in the classroom. Kutash et al. stated a challenge existed in the implementation of the evidence-based models into the schools and suggested there was a move in that direction based on the need to facilitate learning.

Kutash et al. (2006) stated while the research suggested training, once that occurred there was an even greater need for ongoing training after the programs had been implemented. Fixsen, Naoom, Blasé, Friedman, and Wallace (2005) stated that successful implementation of training was based on four factors which include

- Competent practitioners received coordinated training, coaching during the learning process, and performance evaluations.
- Institutions provided support that included timely training, coaching during the learning process with skilled supervision, and evaluation of the outcomes.

- 3. There was active involvement by the communities and consumers in the selection of the programs and practices and evaluation of such.
- 4. Funding avenues through state and federal agencies, policies that created positive environments for the implementation, and operation of the programs.

Markle and Clark (2007) stated that challenges existed in the educational experience of autistic students due to the lack of adequate training for educators. The authors emphasized that the classroom curriculum failed to adequately meet their unique needs. The National Autistic Society (NAS, 2006) in England recently reported that over 70% of the schools expressed dissatisfaction with the amount of training the educators had received about the autistic condition and over two-thirds of the parents of autistic students in the mainstream schools were dissatisfied with the way in which the teaching professionals understood the condition. Leach and Duffy (2009) suggested that since there was a large amount of legislation and research that supported the idea of inclusion in the public schools, perhaps it is necessary to see that educators were provided adequate training and knowledge regarding the autistic condition. O'Neill, Johnson, Kiefer-O'Donnell, and McDonnell (2001) stated that the implications of the need for training in evidence-based approaches for this population merited the need for the training to be available to educators who worked with the autistic students as well as the availability of consultants who were experienced in behavioral support strategies.

O'Neill et al. (2001) cautioned that inservice trainings might be helpful; but, it was necessary to recognize the need for expertise when working with autistic students.

Warber (n.d.) suggested that the educators of autistic students may or may not have the necessary training in autism to give autistic students the attention they required in the classroom. Warber suggested that while inclusion had some positive influences on the autistic student, experts are not in agreement about whether it is the best environment for them due to educators might not able to provide undivided attention to an autistic student in an inclusive classroom. Hess (2008) stated that the educators were often not aware of what intervention to use and this might cause them to use practices that are not evidence-based.

Braun et al. (2006) suggested helping may work through a model of shared process, targeting professionals working primarily with parents of children who had maladaptive behaviors. The qualities of helpers and parental characteristics potentially lend to successful outcomes. Braun et al. stated that the partnership was a necessary component followed by a holistic approach in the shared model of success and there is a sequence of related events that must take place in order to facilitate the shared process. These events include (a) relationship building, (b) exploration of the problem, (c) an understanding of the situation, (d) setting goals, (e) strategy planning, (f) implementation of plan, (g) a review of the results, and (h) the final outcome. Braun et al. stated one of the primary qualities for the helper to possess was that of effective communication skills, chiefly in the enhancement of the process.

A helper must be an active listener, able to prompt others, able to explore conversations, be empathic, and facilitate change through negotiation and problem-solving. Braun et al. (2006) specifically pointed out that for those working with the

parents, it is imperative that, as helpers they established communication with the parents about what they were doing and the reasoning behind it while they practiced modeling the shared process model in order for the parents to learn how to use the methods with their children. The helper professional was encouraged to attempt to demonstrate the qualities in the interactions with the parents and recommended necessary skills which might be needed throughout the different stages of the process (Braun et al., 2006). The characteristics for a successful partnership with parents included the following.

- The ability to work closely together
- Shared decision-making
- Complementary expertise
- Goals and process that were in agreement
- Mutual respect and trust
- An open and honest relationship
- The ability to communicate clearly
- Flexibility and understanding
- The ability to negotiate

Rogers (as cited in Braun et al., 2006) stated helpers must possess not only knowledge and skills but certain qualities that complimented their expertise. These qualities included (a) empathy, (b) respect or unconditional positive regard, (c) genuineness, (d) humility, (e) enthusiasm, and (f) positive thinking (Rogers, as cited in Braun et al., 2006). Phaneuf (2010) stated that the dominant ideas of Rogers influenced those in the helping professions as well as in the field of education. Family Partnership

Training (n.d.) stated that the outcome was determined by whether help had been provided in the end and it was the relationship between the parent and the helping professional that made the difference. A partnership grounded in mutual respect for the expertise and knowledge of both the parent and the helping professional must exist in order to employ a successful outcome in helping an autistic student (Family Partnership Training, n.d.).

Teffs and Whitbread (2009) suggested that the level of preparation for educators included a lack of training in the ASD that left the educators unable to handle the classroom's environmental challenges the autistic students might often present. Teffs and Whitbread developed an online survey specifically for educators in Connecticut who were randomly chosen from a database that contained the names of current educators and school personnel in the public schools in order to explore the manner of training the educators and administrators received and how competent the teaching professionals felt in teaching the autistic student population. Teffs and Whitbread pointed out that the educator preparation training programs in Connecticut consisted of training that was designed to meet the needs of students with mild to moderate disabilities and not specialized training designed to meet the needs of the autistic students. The findings revealed that the educators had no formal training in the characteristics of ASD, instructional strategies, IEP implementation, behavioral supports, social skills training, and communication and assistive technology. Only 5.5% of the educators felt well prepared for instructing a student with ASD.

The educators reported that the training they had received came from working with children with ASD, what they had read in books or journals, and stated they could benefit from more training and support in order to provide adequate services for students with ASD. Teffs and Whitbread (2009) summed up their findings by stating that the Connecticut educators were not supported and were rarely trained to teach students with ASD, whom half spend at least 80% of the day in the public school classroom environment. Callahan et al. (2009) stressed the importance of the need for improvement in training about autism through the identification of critical autism practices from the comprehensive approaches available that can only occur through a process of empirical validation through experts and stakeholders within the field.

Callahan et al. (2009) stated an evidence-based approach that acknowledged the unique needs of autistic students in their educational environment might contribute to a number of positive outcomes. Callahan et al. cautioned that there are a number of eclectic program methods currently being employed in autism that should be "resolved systematically, empirically, and amicably" (p. 88) and urged that the lack of educator training and an evaluation of the program processes were something that should be a priority.

The National Autism Center (2009) outlined goals designed to engage the educator, parents, and the autistic student in order to assist the student in reaching their academic potential. The goals must be outlined in the student's IEP and it was important that communication among the stakeholders commence regarding the approaches that will be used in order to meet those goals. The National Autism Center cautioned teaching

professionals to avoid choosing treatments without familial input as some treatments might have already been shown to produce ineffective results with specific children.

The National Autism Center (2009) suggested the goals be developmentally appropriate and achievable for the autistic student. Since parents were the experts on their autistic child's condition and knew what their strengths and weaknesses are, parents should be encouraged to be active participants in their child's educational planning (National Autism Center, 2009). Murray et al. (2007) emphasized that support of family choice was detrimental in order for teachers and administrators to form a successful partnership with parents of autistic students. The National Autism Center suggested it was important for teaching professionals to recognize any biases they might have related to parental participation or feelings related to that participation.

Charman et al. (2011) stated that one of the reasons for the variability in outcomes for the autistic students might be in part, due to a lack of knowledge on the part of those professionals who worked with them and stressed the importance of adequate educational outreach as the classroom was where the children spent most of their time. Charman et al. concluded their remarks by adding that their study revealed some areas of best practices that were not fully recognized, such as the high ambitions and aspirations that the educators held for their autistic students and educators modified curriculum that included social communication and independent living skills. The topic of classroom environmental health was not mentioned. It is suspected that an improvement in environmental health was assumed when educator training was enriched through adequate training and experience.

Bain, Brown, and Jordan (2009) stated that an educator who was skilled in the evaluation of intervention methods might lead the parents of autistic students in a positive direction. Bain et al. found a need existed for training future educators the necessary skills in order to critically evaluate interventions to determine whether they were evidence-based. In a study with three educational levels that used the Interventions and Sources Survey (ISS), which consisted of 50 items in order to examine whether the participants were aware of certain interventions for dyslexia, autism, ADHD, three specific categories of interventions were chosen: evidence-based, primarily anecdotal, and controversial in order to ascertain the participant's beliefs about each (Bain et al., 2009). The participants were found to endorse certain interventions without any knowledge of whether the intervention was evidence-based or without any prior knowledge of the intervention (Bain et al., 2009). Bain et al. recommended university based skills acquisition in the critical evaluation of interventions at the university level through the case study methods and the methods that required the student to investigate the evidence-based literature.

Spann et al. (2003) reported that while research had shown the need for parental involvement the parents remained having little input into goal development and interventions. While evidence-based models with theoretical rationale were available and even legislative backing, parents remain uninvolved in participating in the educational services provided to their autistic children and therefore, satisfaction with these services was minimal (Spann et al., 2003). Spann et al. recommended that the relationships

between parents of children in the special education classes and the teaching professionals continue to be examined.

Spann et al. (2003) examined 45 parents of children with autism and other special needs through the use of a 15 item survey questionnaire and interview method to determine their involvement in and opinions of the educational services their child received from their school, particularly revolving around the IEP process. Findings revealed positive comments while the negative comments revealed a lack of education on the educator's part into the autistic condition, lack of communication with parents, and educator attitudes regarding the student. Stichter et al. (2006) stated that there was a need for specific expertise within the research literature regarding the characteristics of ASD that might contribute to the multidisciplinary team designed to provide treatment for those on the ASD spectrum. Stichter et al. described the Huron Intermediate School District (Huron ISD) and the multidisciplinary team's attempt to provide evidence-based practices to special needs students.

Stichter et al. (2006) recognized that additional training, program development, and collaboration were needed for this population. Stichter et al. stated that the effective instructional teaching methods for autistic students included (a) structured environments, (b) curriculum that targeted domain areas, (c) intensive instructional programs; (d) evaluation and monitoring, and (e) parental involvement in the process. Rosen, Rotteram-Fuller, and Mandell (2011) developed and administered a quantitative and semistructured survey to eight educators as part of a pilot study and found that some educators were not resistant to having autistic students in the classroom and were satisfied with their skills in

behavioral management of the autistic students. The educators suggested that the problem existed with the autistic student being unprepared to cope with the general education classroom

Educational Provision (2009) reported that stakeholders such as professionals, service providers, and parents felt that there remained many teaching professionals that knew little about autism and the unique needs the students had. Parents expressed dissatisfaction about the needs of their autistic child being met and the long delays in a request for help by professionals (Education Provision, 2009). Some educators were willing to help but lacked the support they required (Educational Provision, 2009). Conroy et al. (2007) expressed that educators missed opportunities in the events naturally happening in the classroom to use them in the development of individualized interventions for autistic students.

The need existed for providing the educators skills in order to be aware of such opportunities in the classroom. Carr et al. (2002) viewed the training opportunity as "a process of mutual education," as it afforded systems change rather than merely changes for a single individual (p. 17). Jordan (2008) described the education of an autistic student as an effective treatment in itself and suggested that only high quality teaching skills could enhance the autistic student's learning experience. National Autism Center (2009) stressed that the implementation of effective interventions in the classroom must be based on a process that contributed to systemic change while supporting educators who were acting as part of the team. Such a plan consisted of five steps in order to build a viable program which included (a) the use of a planning team, (b) addressing barriers and

providing a needs assessment, (c) evaluation of outcomes, (d) the development of a training plan, and (e) sustainability (National Autism Center, 2009).

In light of some of the methods of intervention in autism, the use of collaborative planning is imperative. Interventions such as one that occurred in Harrodsburg, Kentucky wherein a teaching professional placed nine year old autistic student, Baker, in a cloth bag with a drawstring or the use of the recently banned packing therapy in France pointed this out (Lovett, 2011; Goeb, Bonelli, Kechid, Lenfant, & Delion, 2008). These intervention methods were used to calm autistic students down. Four thousand five hundred citizens of Mercer County in Kentucky responded to the Baker case by signing a petition demanding improved educator training and the way in which students with special needs were handled (Lovett, 2011).

Packing therapy, promoted by the psychoanalytic groups in France who believed the autistic children developed behaviors as a response to dysfunctional maternal relationships, had been denounced in France by some parents of autistic children (Lancet, 2007). There were concerns about the therapy as it had been no empirical basis that supported its use; however, a clinical trial was currently underway (Goeb et al., 2008). The practice has since been banned in France and the status of the clinical trial is unknown.

School administrators are likely the key professionals that have the ability to bring needed change to the public school classrooms. Celiberti (2012) interviewed ENeumann, a teacher familiar with ASD, who felt the school administrators were often unaware of the evidence-based practices in autism and were not prepared to meet the unique needs of

the autistic students. Neumann participated in training 350 school administrators in New Jersey through a community grant received from Autism Speaks Family Services. The curriculum Neumann and others developed was based on a survey she had done in fulfillment of a master's thesis geared towards what school administrators knew about autism. The results revealed those areas that the school administrators felt they could benefit from and included (a) more understanding about autism and the autistic student's unique needs, (b) evidence-based practices, (c) ways to provide support to educators, and (d) resources available (as cited in Celeberti, 2012).

Neumann felt that the more school administrators were aware of the complex needs in educational provision for autistic students, the better able they would be to make decisions on their behalf. Lord and McGee (2001) stated it was a challenge for the school system, parents of autistic students, and the communities in implementing helpful approaches in educator training in that it was not just one attempt at a single training but a "continuum of services across time" (p. 183). There was not a single data system used in any of the states in order to track the number of trained specialists, which programs were employed, educator training preparation numbers, number of early intervention programs, use of psychologists, speech therapists, behavioral therapists or others involved in the autism educational services (Lord & McGee, 2001).

## Lack of and Need for Parental Training

Scheuermann et al. (2003) noted that children on the ASD responded positively when teaching applications were consistent between the school and the home environments. In order for this to succeed, a collaborative team must exist between

educators and parents in evidence-based approaches. The educators and staff will be skilled in curriculum development and evidence-based educational approaches. The UCLA Young Autism Model offered parent training as part of their program, designed to inform parents about the autism condition, required curriculum development, and appropriate methods of training for educators. The parents engaged in a three day workshop in order to learn evidence-based intervention models and provided the parents an opportunity to practice strategies and receive feedback from the program coaches. After the workshop parents attended various workshops the program offered, usually occurring quarterly.

Weekly phone contact was maintained between an educator trainer and the parents in order to discuss behavioral challenges. The National Autism Center promoted parent training due to the fact that autistic children often had difficulties in skill discernment across multiple environments, thus a coordination of efforts could be useful in order to teach the parents skills so they could continue to teach their autistic children in the home or in the community. Those opportunities might include play, social interactions with their peers, and adaptive skills such as toilet training, hygiene and self-care, and safety skills. Schools might support parents by providing materials needed to work on specific skills, provide ideas and training that might occur in the naturalistic settings, communicate with parents regarding the child's educational goals and progress, and make home visits in order to provide ideas on specific strategies that can assist them in meeting their child's goals in the home. Such endeavors appeared to place the parents in an advocacy role, for which no empirical evidence existed in the research (Lord &

McGee, 2001). Research of this nature regarding the parental role of advocacy on behalf of an autistic child might be beneficial training for the parents in order to increase their usefulness in an advocacy role.

One of the issues that parents face is in understanding the differences between the clinical and educational systems they encounter when they seek autism services for their child. Both systems were used in the diagnosis and classification of autistic students in public schools (Dahle, 2003). Dahle sought to compare and contrast the diagnostic criteria with educational system requirements regarding autism. When a child was to receive educational services within the public school system, the child must undergo additional evaluations in order to qualify for these services.

Dahle (2003) used examples of parents whose child had been diagnosed by their physician with a pervasive developmental disorder not otherwise specified. The parents underwent meetings with social workers regarding the new diagnoses and were relieved their child did not have a more serious autistic disorder. The parents next met with the school and provided the paperwork from the child's physician and agreed to further testing required by the school in order to qualify for services. After an evaluation of the child, the parents were told their child had autism and they became upset. Other situations included the failure of the school personnel to inform the parents that they suspected their child had the autistic condition but rather, the child was developmentally delayed and placed in the least restrictive classroom.

Three years later, the school professionals informed the parents that their child met the eligibility requirements for the autistic condition. At this point, the parents were

left in a quandary and concerned that their child had not received adequate educational services for the past three years. Dahle (2003) stated that situations such as this left the parents wondering who was right; the physician or the school professionals and pointed out that the school professionals do not use the DSM-IV-TR in order to diagnose autism but, rather it is the public school's responsibility to ascertain what services a student is eligible for under IDEA that has 13 federal disability categories, one of which is autism.

The definition of autism was promulgated by each state that defined the eligibility criteria for autism and each state varied in both the definition of autism and what diagnostic tests were required (Dahle, 2003). In the educational system, when a student is referred for special services, the criterion is somewhat similar to the DSM-5 in that the educational system requires a deficit in communication and social interaction. For educational purposes, these deficits must significantly affect the student's ability to function successfully in the classroom environment. Sensory stimuli are known to cause repetitive or unusual movement as well. Clinical assessments are not relied upon by the educational system but rather, the educational assessments and tests are the determining factor in whether a student will receive services specific for the autistic condition.

Some of the tests used by the educational system may be administered by a physician, mental health therapist, psychiatrist, or school psychologist (Dahle, 2003). The student must have impaired language skills in order to meet educational eligibility. Dahle recommended that the employment of an advocate by parents in order to help them understand that there are two systems (educational assessments and testing and DSM-5 criteria) that will play a role in the services their child might receive and help the parents

facilitate an effective transition between systems. Stichter et al. (2006) showed that there were ways to meet the training needs of parents through the parental training that was provided by the Huron ISD wherein the cost involved was covered through local and state grants. This was achieved through collaboration efforts, as discussed earlier.

Braun et al. (2006) suggested it was important to understand that in the helping process there was not a one size fits model. Braun et al. recommended a model that included the awareness that the families must be understood in their specific social context or cultural tradition and it was a matter of flexibility and adaptation to meet their specific needs. Braun et al. reiterated the concepts of the personal construct theory that states that individuals hold constructs in their mind, an idea of their world that is based upon their own experiences and respond and adapt to events through those ideas. Braun et al. suggested that those who worked with parents realize that in order to help individuals it would be useful to do so in ways that assisted them in finding alternatives that were useful and would make sense of the difficult experiences that face them.

For those working with parents of autistic children in the public school classroom, the helping model might provide a framework that included (a) fostering ways that facilitated an improvement in the manner in which services were provided, (b) provide comprehensive information to parents about their child's suspected autism, (c) meet the needs of the staff training in order to improve services to the student as it directly affects families, and (d) monitor ongoing staff performance post training (Braun et al., 2006). Parents must be informed of the concepts of a helping model and be matched to helpers

or educators that were able to adapt to one another. Parental training has been shown to help the parents cope with their autistic child's behavioral challenges (Boyd, 2002).

Montana DDP Autism (2009) required parents to receive intervention services that were conducted in the home with the parents and other family members who cared for the autistic child. The goal was to teach the parents to act as the professional in their child's care as well as train their child for 10-15 hours per week. The program goal was that at the end of the 3 year program, the parents, through their own experiences would be able to better help their child in the maintenance of the skills they had learned. In the 2015 legislative session, the program will expand to include more families through the expanded Medicaid program the legislature agreed to accept. Gray (2006) stated that the research studies had shown there appeared to be an emphasis on skills enhancement for those who worked directly with special needs children that included parents.

Parents might also be trained in ways to effectively advocate for their autistic child. Gupta and Singhal (2004) pointed out the need for those interventions that focused on alleviating parental stress and suggested the use of coping theories to develop programs in parental training that included (a) problem-solving, (b) communication skills' improvement, (c) the use of humor, (d) establishing and/or utilization of social networks, (e) relaxation techniques, and (f) effective coping strategies. Gupta and Singhal suggested it had been found that the education of parents and inclusion in the development of direct intervention services had the potential to foster parental empowerment, leading to increased collaboration between parents, educators, and service provider agencies. Gupta and Singhal stated that the past research involved the education

of parents in ways to become their child's therapist in order to train their autistic children in behavioral control, communication skills, and play. Gupta and Singhal cautioned that research had also identified those parents who can and cannot be used effectively in intervention strategies and might require extensive parent education, and those included a parent who suffered from depression, inadequate social supports, low income families, single parents, and undergoing divorce. Gutstein (2009) stated that the goal was not to train parents to be their child's therapist but, rather to assist them in ways that showed them different ways to cognitively process their ideas and to use their time effectively in fostering their child's skills.

Aman et al. (2009) reported that the combination of the medication risperidone and parent training, rather than using resperidone alone, showed reduced behavioral challenges with autistic children and that the combination surpassed medication alone on measures of adaptive behavior. Peart (2012) reported that the Yale researchers conducted a federally funded multisite trial study on 124 children, ages 4 to 13 on the ASD at Yale University, Ohio State University, and Indiana University. The participants in the study had severe behavioral challenges and daily episodes of SIB. A structured parent training program was part of the study that attempted to teach parents ways to effectively respond to the behavioral challenges in order to assist the autistic children in daily living adaptation. Peart reported that senior researcher Scahill and his team recently began to conduct a study that examined parent training alone in the treatment of ASD.

Ingersoll and Dvortcsak (2006) stated that while parent training was highly promoted, it was not likely to be successful based on the fact that educators were often

not trained and were not aware of the evidence-based parent education models. For the autistic students in the early childhood special education (ECSE) classroom, it was common for an educator to be unable to individually meet with the parent and their child and parent training was rarely part of the ECSE (Ingersoll & Dvortcsak, 2006). National Research Council (2001) stated that the training programs for parents of autistic students were a primary component of intervention programs. The National Research Council examined the effects of the implementation of a parent training model program designed for use in the ECSP classroom in the public schools in Portland, Oregon. National Research Council had a desire to improve the classroom environment for autistic students wherein state and grant funding allowed them to engage in a collaborative effort with Portland State University, the Oregon Department of Education, and Oregon Regional and Special Education Program in conjunction with part of the Oregon Statewide Regional Program Autism Training Sites (RPATS).

Developmental and naturalistic behavioral strategies were two of the teaching techniques that were part of the parent training intervention which were chosen primarily because they were two intervention techniques known to be effective in a parent teaching context to assist autistic students with social, communication, and parent-child interaction skill building. Ingersoll and Dvortcsak (2006) held parent and educator training sessions concurrently. The educators participated in pilot training workshops on the parent training model that provided the educators with an overview of the program as well as the effectiveness of the parent training for children with ASD. The educators who participated in the ongoing full training workshops provided by Ingersoll and Dvortcsak

went on to train families and students with ASD while the researchers went on to provide further educator training at other RPATS sites in Oregon.

In a satisfaction survey regarding the educators' opinion about the parent training model they felt it was a positive option for the classroom and would recommend it to others. Ingersoll and Dvortcsak (2006) stated that the inclusion of an empirically validated model for parent intervention training techniques specifically for students with ASD was one that should be implemented by the school professionals within ECSE publically funded classrooms. Ingersoll and Dvortcsak suggested further research was needed that examined short and long-term effects of the parent training model in special education curriculum for preschool students with ASD.

## **Need for Collaboration and Integrated Treatment Protocol**

Public schools historically provided the needed supports and access to mental health services to children who required such services; however, the provision of such services often were not done in a collaborative fashion. The services functioned in parallel with one another making them ineffective in both systems, such as education and mental health (Kutash et al., 2006). Kutash et al. recommended that school-based mental health services be clearly delineated for each system. Bridges must be built between special education and general education, particularly in the empirical literature as neither cites each other's studies.

The systems of care (SOC), a philosophy of the manner in which the needed support services were provided to children reside within the available services agencies and in order to be effective must be interconnected and contain systems of prevention as

well as systems of early intervention (Kutash et al., 2006). SOC for children addressed a continuum of services from children's services provider agencies that were integrated and collaborative, in order to meet the multiple needs required by a child with a long-standing and persistent mental health and/or behavioral disorders. Many children who received services through the SOC were in special education classrooms.

At the heart of the SOC is its strategy to provide parental support while valuing parental input into decision-making plans for the child. The IEP existed for special education students and the SOC was compatible with the IEP in its philosophy to support the strategy of a team of professionals accompanied by parents as equal decision-making partners. Kutash et al. stated that the empirical evidence was growing in the need for a comprehensive and integrated approach, and was available through a public health model.

Kinney, Strand, Hagerup, and Bruner (1994) stated that individuals were better able to engage in and make needed changes when they were able to play a role in the planning and development of services. Kinney et al. emphasized that within the human services field, a philosophy of a partnership in decision-making strengthened interventions tailored to meet the unique needs of individuals and those which considered needed changes in their environments.

In the State of Montana, Department of Public Health and Human Services (DPHHS) early intervention autism services for families included the Children's Autism Waiver that met the needs of 40-45 children, ages 15 months to 4 years of age at the time of enrollment who were diagnosed with autism (Montana DDP Autism, 2009). The

Montana Children's Autism Waiver, a 2 million dollar program that began in 2009 and was funded through a combination of state and federal funding for services to the youngest population of children with autism (Montana DDP Autism, 2009).

The autism waiver was developed by DPHHS DDP management. Various agencies, such as the Office of Public Instruction, Children's Mental Health, Child Care, Family Support Specialists, behavioral therapists, Montana Developmental Center staff, DDP Evaluation and Diagnosis clinicians, Quality Improvement Specialist, Waiver Specialist, and other DDP staff formed a workgroup and acted collaboratively to define the need for early intervention and assessment as being primary (Montana DDP Autism, 2009). There were 50 slots available and families were chosen through a lottery system. The families received services for a period of 3 years and included 20-25 hours per week of case management, in-home habilitation training, respite, adaptive equipment, environmental modification, occupational therapy, physical therapy, speech therapy, transportation, program design, monitoring, and individual goods and services (Montana DDP Autism, 2009). Pagliaro (2010) reported that a web-based treatment platform was available through the Montana Children's Autism Waiver program that allowed parents to work collaboratively with a behavioral specialist through a program called Rethink Autism (Rethink, n.d.). Parents communicated directly with behavioral therapists familiar with ABA and a coordinated treatment plan was developed for each child. The goal of the Montana Children's Autism Waiver program was to expand with the hopes that those children who had participated will enter the public school system without needed supports.

Garfinkle, Emerson, and Sturm (2013) reported positive outcomes among the first cohort of children diagnosed with autism who completed the program with 48.6% no longer scored as clinically autistic and 77% were no longer eligible for other DDP services. Oster (2013) reported that the statistics for the 3-year Children's Autism Waiver program had shown that at the end of the three years the children who received services had a 77% success rate and no longer considered to have a diagnosis of autism. Fein et al. (2013) agreed that it was possible that those diagnosed with autism did not necessarily remain that way.

While the Montana Children's Autism Program treatment strategy and family support plan was collaboratively developed by behavior specialists, families, and other needed service providers, there was no mention whether the behavioral support was available to the autistic child within the public school classroom beyond the age of 8 and there is a question of what happens to an autistic student after the age of eight who may need continued supports in the classroom. A question remains about the autistic children who were unable to participate in the program and what happens to this population in the classroom environment and academic success.

One of the goals of the Montana Autism Waiver was to afford parents the role of being the professional and expert on their child's care as they worked with the service providers and professionals (Uken, 2011). This was in contrast to barriers that potentially prevented parental involvement by professionals who carried a negative view of parents through the belief that parents were unable to make competent decisions on behalf of their autistic children (Spann et al., 2003). Arnini (2007) believed that the key element in

the successful relationship between parents and professionals was parental involvement in decision making and pointed out that those parents who received adequate support were more likely to be engaged in their child's education.

Arnini (2007) suggested that the surveys and needs assessments be utilized in order to get an idea of parental opinion about the services they would like their autistic child to receive and what potential barriers might be that impede parental involvement. Parental involvement was more likely to occur when parents received adequate support from the school professionals and particularly, in special education where the literature suggested that the parental involvement contributed to positive growth and development in children (Arnini, 2007). Arnini (2007) addressed the lack of parental involvement in support groups for the parents of students in the preschool special education classes and potential barriers to their participation in the Cranston Public School System by sending out a needs assessment survey to 85 families, of which 26 surveys were returned. The data were used to evaluate the supports and services available within the Cranston Public School System. The findings revealed that those parents who responded felt positive about the level of support received from the school professionals while time constraints and location of their attendance to support groups was a problem for them.

O'Neill et al. (2001) discussed the collaboration in Utah that was composed of parents, school district representatives, and state agency representatives who formed the Community Liaison and Outreach Committee (CLOC). The CLOC met periodically with the faculty of a comprehensive training program designed to train professionals to support those students in the public school system who had severe problem behaviors,

including developmental disabilities. The CLOC provided input on outreach, teaching, and research. O'Neill et al. stressed that in order to meet the challenge of addressing the need for adequate training for school professionals and personnel, it was necessary to collaborate to provide the resources required by the school staff.

Carr et al. (2002) stated that the models of assessment and intervention had traditionally held that they must be expert-driven rather than consumer-driven. The experts were the behavior analysts while the parents and teachers contributed in offering aid in implementation strategies (Carr et al., 2002). Carr et al. explained that the philosophy of positive behavior support (PBS) emphasized that the parents should be active participants in the collaboration with the professionals and support teams might include parents, siblings, teachers, job coaches, friends, and the person with a disability.

Carr et al. (2002) emphasized that the literature had called for this collaboration for a number of years. Stakeholders moved beyond a passive role to an active one where they were able to provide essential qualitative perspectives in the assessment plan, determined the adequacy and appropriateness of intervention strategies, determined the practicality of a specific approach in relation to the network of support as it related to the student, and afforded an understanding of the likelihood of those outcomes that might contribute to an improved quality of life for the student.

Ruef et al. (1999) suggested that stakeholder focus groups should be used in order to determine the various perspectives and priorities, any potential barriers that included those of a structural and organizational nature that impeded a positive outcome, proposed solutions, and proposed strategies of change. Ruef et al. expressed concerns over the

failure of adequate documentation regarding the quality of life for individuals with mental retardation, autism, and for those individuals who were involved in their care.

Ruef et al. believed there were few documented cases of this population that reported a reduction and/or elimination of behavioral challenges and gained a quality lifestyle through receipt of the supports they required.

Ruef et al. (1999) believed that the opposite had been found in that there was a failure of the stakeholder systems to provide adequate support and it was the families of children with mental retardation and/or autism that had shown extraordinary adaptive skills as they provided their children with a positive quality of life despite their disabilities. In the examination of five stakeholder groups in the Ruef et al. study, it was found that all five groups expressed inadequacies in the school programs, a lack of training for educators, a lack of needed resources, and burdensome bureaucratic administrative systems. Ruef et al. stressed that the families of children with intellectual challenges and/or autism described the services they received as negative and one parent in particular, rejected the advice from one educator that the parent put Tabasco sauce on her autistic daughter's fingers as a means of punishment for her behavioral challenges.

Some parents reported abuse of their child from the individuals who provided the support services to their children (Ruef et al., 1999). All five stakeholders supported the use of positive behavioral support but the majority of the comments were contributed by others, such as family members, friends, and the teachers (Ruef et al., 1999). Ruef et al. reported that three subthemes emerged from the study, (a) skill building for the child with intellectual challenges and/or autism, (b) skill building for parents and other support

persons, and (c) system and environmental change and adaptation. Ruef et al. observed that the most concrete solutions regarding the best practices came not from the administrators and policy makers, but from parents, friends, individuals with disabilities, and teaching professionals who contributed positively through descriptions of ways to adapt the school classroom environment. Ruef et al. cited Adelman and Taylor (1997) who contributed the idea that the schools must promote "a primary, essential 'enabling' component specifically aimed at addressing learning barriers by weaving together school and community resources" (p. 55).

Ruef et al. (1999) questioned why researchers had not contributed to an improved quality of life for the children with intellectual challenges and/or autism and serious behavioral challenges; but, believed the lack of research advances was due to a wide schism between researchers and families regarding an agreement on what relevant research meant. For families the importance of having the option to receive adequate support services was a priority. Ruef et al. attempted to fill the gap between research to practice through the examination of five stakeholder groups; administrators, policy makers, families, friends, individuals with intellectual challenges and/or autism with behavioral challenges, and teaching professionals.

Charman et al. (2011) suggested that collaboration was critical in order to promote a quality education for the student with autism and emphasized that best practice included an emphasis on the collaboration between families, service providers, and those with autism. Gray (2006) undertook an assessment of special education needs in England. The target population included children who suffered from severe disorders including

autism, multi-sensory impairment including visual and hearing, learning difficulties, behavioral, emotional, and social impairments. Gray reported that the children with autism, multisensory deficits, and behavioral challenges were the primary focus of the investigation. The areas examined included the educational, social, health, and leisure activities.

Interviews were conducted with stakeholders from volunteer agencies in addition to the distribution of a questionnaire that was given to agency representatives from education, health, and social services. Focus groups were held with policy making agencies, schools, parent representatives, and service providers. Gray (2006) reported a positive response rate with the questionnaire and approximately 400 individuals participated in the focus groups. The responses received from the participants attempted to determine what the needs were, and common themes were found regarding some key areas. One of the agreed upon needs was that of a holistic approach in order to meet the needs of the target populations. Gray emphasized that "the task is not to improve individual elements of provision in isolation" (p. 4), but the development of comprehensive support in all the areas for the children.

Gray (2006) pointed out the need for stakeholders to address the gaps in services regarding family support and experts who worked closely with the professionals in treating the children and specifically addressed the need for professionals who worked with autistic children to provide multi-agency training, increased staff training, and collaboration with parents. Priority should be given to collaboration, particularly with the students who "present the biggest challenges and who are likely to need a highly

coordinated approach" (p. 13). Gray suggested that the current training for the staff might not take into consideration the severity of the level of a student's need and recommended that the various agencies pool their knowledge and skills in order to provide successful ways that met the complex needs of some students. Regarding special education students who were impaired and in need of special provision, Gray addressed the professionals as teams in providing educational support services for the special needs students and stated that the outcome of the needs assessment and interviews provided an awareness and positive view of the need for stakeholders to effectively collaborate in order to produce positive outcomes for this group of children.

The School Wide Positive Behavioral Supports (Implementation Blueprint, 2010) suggested the use of leadership teams which consisted of representatives from mental health, administration, families, special education, general education, higher education, professional development, and evaluation and accountability who met regularly in order to address team planning in the United States. The Implementation Blueprint suggested that initiatives be assessed and integrated in an organizational restructuring in order to blend their funding streams and resources, primarily in order to contribute to the development of a comprehensive school wide system that focused on positive behavioral supports.

Gupta and Singhal (2004) suggested that the professionals who provided services promote the idea that parents should be an important partner in the planning and development of services as this partnership supported the dynamic role that parents played. Gupta and Singhal supported the idea that the focus of professionals who

promoted child-centered intervention approaches to that of family-centered and emphasized that the research had found that inclusion of the parents in the service-delivery planning promoted successful intervention methods.

Family empowerment was promoted through a program called Relationship

Development Intervention (RDI) whose focus was from the biopsychosocial management of ASD (Gutstein, 2009). RDI promoted the involvement of parents and an RDI clinician with the child's physician as leader in the clinical management of the physical and psychological aspects of their child's autism. Gutstein suggested that the RDI curriculum had the potential to afford successful communication, social skills building, and adaptive functioning in the autistic child. The role of the RDI clinician as mediator specialist provided feedback to the physician while training and advising family members. While RDI had been in existence for over ten years, there were no controlled studies that had been done that examined its effectiveness (Gutstein, 2009).

Lord and McGee (2001) pointed out the need for those advocates who acted in a collaborative fashion to understand the culture (i.e., vocabulary, policy driven) of education, understand the autistic disorder in regard to the individual's unique educational needs, and an understanding that intervention strategies were necessary components in building positive environments. It was equally important for those advocates to maintain a knowledge which would enable them to offer education to parents and educators in order to resolve any disputes or provide information to establish and/or sustain that positive environment.

## **Need for Parental Input**

National Autism Center (2009) stressed the importance of potential school factors that limited parental input and those barriers included (a) teaching professionals might feel unable to provide support due to their workload and personal conviction that they do not have the skills to provide support, (b) parents might feel teaching professionals were authority figures and might fear that their ideas might conflict with theirs, (c) parental involvement might be limited by the lack of education professional outreach efforts regarding encouragement for the parent to get involved in their child's educational planning, and (d) the student is not always involved in treatment or intervention planning designed to improve their skills.

Lynch and Irvine (2009) agreed with the National Autism Center (2009) that the parents of autistic children had the most knowledge regarding their child's support needs and hence, were the experts and that they should be included as part of the collaborative team in the child's educational planning. Research findings done in the 1980's and 1990's have yielded recommendations on the ways in which schools might develop parental collaboration. Iovannone et al. (2003) argued that while evidence-based strategies had been found, school districts had failed to integrate the research findings.

Lynch and Irvine (2009) proposed that the common themes found in the current educational interventions might be used in the development of educational strategies for the ASD population. Some parents report that they feel the IEP neglected to meet their autistic child's unique needs in a comprehensive manner. The parents stated that communication is lacking with the educators and when it occurs, it is in a negative

manner that solely addresses the child's behavioral challenges. Sayers (2011) agreed as the mother of an autistic child in the public school system, she was not able to receive adequate communication regarding any changes in her child's IEP.

Sayers (2011) personally observed her child not being offered the use of a picture exchange program which was in their child's IEP but rather, the educators offered the use of sign language which was something that failed to work for her child. Effective collaboration must include the parents of autistic students as part of the team, parent training, and successful communication with education professionals must be established in programming planning and interventions (Ingersoll & Dvortcsak, 2006; Ruble & Robson, 2002).

Spann et al. (2003) reported that through the IDEA, parents were entitled access to their children's school records, participation in the development of special education services received by their child, and in the evaluation of those services. Spann et al. emphasized that the education professionals must participate in establishing communication with the parents, invite the parents to participate in activities in the school, seek parental input regarding the plans for their children's education, and assist the parents in taking action steps to meet their own needs. Sayers (2011) pointed out that the services her autistic child had received were different than those on the child's IEP while Spann et al. (2003) reported that the parents had no choice in services and the services that their child received were not the ones the parents had requested. The parents felt that the services the school provided were not related to ways which their children's

needs might be met, were ineffective, and they were unable to communicate with the teachers regarding their own perspectives on raising an autistic child.

Spann et al. (2003) suggested the areas that were imperative in future research included those that examined the communication between the schools and parents of children on the ASD, parental input into the IEP process, and parental satisfaction with school-based services and suggested that through the examination of these factors, it might contribute positively to improved school-based services for all disabled students in the public school classroom. Lord and McGee (2001) pointed out that the parents should not only be included in the IEP process but that they have the right to any school records kept on their child.

Shore (2001) expressed that in the past the school administrators and the educators often felt that the parents were "part of the child's problem" (p. 301). Shore stated that the school administrators opined that the education professionals were not psychologically skilled to assist the parents of students on the ASD. Inquiries by the parents about simple things that occurred in the daily classroom routine regarding the student went unanswered. Shore expressed that in contemporary times, parental involvement is more encouraged than when he was in school and suggested that after an accurate diagnosis had been achieved, it was important for the parents to know their child's legal rights which should come from their educators who will know to refer the parents to other available resources. Grandin (2007) reported that her mother and her elementary school educators worked as a team to assist her in the development of social skills. The communication was positive between Grandin's educator and her mother in

that if she presented behavioral challenges in the classroom, her mother was sure to hear about it from her educator.

Spann et al. (2003) pointed out that the parents expressed overall satisfaction with the services the school provided to their children, particularly with those services provided in the IEP process. Lynch and Irvine (2009) pointed out that Spann et al. likely overestimated parental satisfaction and argued that a discrepancy remained in regard to parental satisfaction on all three measures on the IEP process in the Spann et al. study and that the findings reported moderate to low levels of parental satisfaction. Neither Spann et al. nor Lynch and Irvine (2009) discussed the need for parental opinion on overall classroom environmental structure or design.

Schopler (as cited in ASA Advocate, 1994) suggested that the most important approach in any autism program development and research, specifically for use with professionals who worked in the autism field, was the use of parental input. Schopler stated that the parents of autistic children were unique in the experiences they have had with their children and might contribute to school program priorities in a positive manner. Schopler was adamant in that a multidisciplinary training program was to be based upon the parent's perspectives and included social workers, educators, psychologists, speech therapists, and psychiatrists. Schopler promoted problem solving that included a professional collaboration with an emphasis on the parental perspectives. There were six principles that have guided Schopler's TEACCH approach in research and service delivery which included the following:

1. Autism involved a lifetime struggle.

- 2. A formal assessment was imperative.
- 3. The use of the autistic individual's strengths in visual processing might contribute in overcoming their difficulties in auditory processing, organization, and memory and were most effective for teaching independent learning and reduced behavioral challenges.
- 4. Effective teaching approaches might enhance skills in autistic children and contribute to an acceptance of their shortcomings.
- 5. Behavioral and cognitive theories were the most useful intervention strategies.
- 6. Training professionals must understand that the comprehensive problems raised by autism regarding their own background in specialty training in order to address the whole child (ASA Advocate, 1994).

Schopler (as cited in ASA Advocate, 1994) suggested that ongoing research was imperative and to quickly make available to the parents, those research findings in order to provide the parents the information to incorporate into their autistic child's treatment program. Schopler suggested that the mainstreaming of autistic students worked best when it was the result of collaboration among teaching professionals and the parents.

Boyd and Shaw (2010) recommended that the teaching professionals form a team with parents in order to provide information on the available empirically-based research strategies. Boyd and Shaw stated that it was imperative that the researchers continue to study school-based practices and early intervention strategies that might potentially benefit educators and autistic students. Webber, Simpson, and Bentley (2009) suggested

that the sharing of information and decision-making with parents of students on the ASD revealed the willingness of school professionals to work together.

Arnini (2007) focused on parents of children in special education classes and sought what their understanding might be in the special education services available to them, how they acquired the information, and what level of support they received. The higher the parental involvement, the more likelihood the child would have academic success (Arnini, 2007; Boyd, 2002). Arnini stated the study confirmed the previous research findings that parents who felt supported were more likely to be involved in their child's education. Arnini stated the parents described the school staff who provided that support as the social workers, educators, and other staff. Parents found information from a variety of sources that included "the school system, outside agencies, pediatrician, family, friends, and the internet" (Arnini, 2007, p. 22).

Kohler (1999) examined the parental satisfaction with the services their children had received. Kohler's study included the families of children who were autistic and/or had pervasive developmental disabilities (PDD). The children ranged from age 3 to 9 years and displayed (a) language delays, (b) lacked social skills, (c) cognitive abnormalities, and (d) behavioral challenges that included self-harm, aggression, and self-stimulation. Kohler referenced the fact that previous research dating back 10 years had recommended the examination of parental opinions and satisfaction regarding early intervention approaches.

Kohler (1999) expressed that parental concerns might lead to improved existing services and that parental opinion far surpassed the opinions of childhood educators and

professionals as parents were the primary caregivers. Kohler conducted a telephone interview with 25 families in western Pennsylvania. The questions included

- 1. What services their child received.
- 2. How the families were involved in their child's services.
- Ways in which the service providers ensured that their services
  maintained continuity or were organized around a common set of the
  child's needs.
- 4. What problems the family had reported. Kohler stated a number of problems occurred due to the families' inability to even access the services that were needed and families were not involved in the program development or the implementation of any interventions.

Parents reported that their child was given services that were different from those they had requested and they were of the opinion that they had to fight for what they wanted for their child. Kohler (1999) reported that the parents felt the educators, family members, and published materials surpassed the psychologists, friends, physicians, and social workers in helpfulness measures and experienced minimal collaboration with the professionals occurred. The lack of collaboration with professionals and services received from multiple providers contributed to parental stress. Kohler suggested that the study's parental satisfaction data had the potential to educate school administrators, policymakers, and helping professionals regarding the importance of the early intervention approaches.

Charman et al. (2011) emphasized the need for professionals to consider family values and preferences for their child in the reliable implementation of approaches and interventions for the autistic student. Educational Provision (2009) stressed the need for inclusion of parental knowledge and opinions on their child's skill in the development of the approaches used. It is important to recognize that the parents of children with the autistic disorder have worked with their child for a number of years and have used their negotiation skills in seeking those services appropriate for their child. The skills developed by the parents would not have developed had it not been for their lived experience and stated that one of the challenges that faced them was the school's inflexible nature and a failure to have adequate knowledge about the autistic condition (Educational Provision, 2009).

Braun et al. (2006) maintained that the important task-oriented framework within the helping process that fostered the parent-professional relationship was one of a partnership that was defined as: (a) active involvement; (b) shared decision-making, complementary expertise; (c) agreement of aims; (d) mutual respect and trust; (e) openness and honesty; (f) clear communication; and (g) negotiation. Braun et al. suggested that knowledge about parental characteristics might contribute to a determination of the process professionals should take with the individual parents and included: (a) motivation, (b) barriers that prevented the parents from engaging in the process, (c) beliefs they held about the services and other staff, (d) socioeconomic circumstances, (e) parental expectations of the outcomes, (f), and (g) cultural factors.

Markle and Clark (2007) discussed the Pennsylvania-based NHS Human Services instrumental in the creation of autism schools. NHS's primary goals included the advisory boards that consisted of parents as key stakeholders in the decision-making processes regarding services to meet the needs of autistic students. On the extreme end, many parents of autistic children have pulled their children out of the public school system, and chose to homeschool the children as they believed the education professionals lacked adequate knowledge about the autistic disorder and failed to implement strategies that would contribute to their autistic child's academic success (Kidd & Kaczmarek, 2010). While homeschooling has its challenges, the parents report when their autistic child's unique needs are met they have improved well-being.

### **Evidence-Based Approaches**

While some evidence-based approaches for use in the public school system have been developed, they are often not implemented (Callahan et al., 2009; Dingfelder & Mandel, 2011). One of the barriers to successful implementation is due to school administrators' obligation to adhere to the IDEA and NCLBA (PL 107-110, Sect. 1001). While the public laws require school systems to implement evidence-based practices, administrators report an inability to access the research, and/or that the research failed to provide useful recommendations to their particular need(s). Dingfelder and Mandell pointed out that the administrators often relied upon the collective community information that generally originated from staff members. It appears there is a great deal of reliance upon the information that emanates from organizations and agencies such as National Autism Center, Autism NOW, and Autism Speaks which potentially falls under

"practice wisdom (non-empirical indicators that are naturally built into practice and include the opinions of colleagues, client statements, and practitioner observations and inferences" (Dingfelder & Mandell, 2011, p. 4). The lack of implementation of evidence-based approaches might be achieved through collaboration with others.

The National Research Council (2001) acknowledged that there is a lack of data in the efficacy for one approach over another (Dingfelder & Mandell, 2011). Problems existed in that while some evidence-based approaches might be combined to meet the needs of certain autistic students, no empirical evidence existed that supported the use of the combined approaches (Chasson, Harris, & Neely, 2007). The largest amount of autism research to date has been focused on preschool children that had left the school administrators with little guidance in the best intervention approach to be used with specific children (Akshoomoff & Stahmer, 2006; Dingfelder & Mandell, 2011).

Research with the autistic population has primarily been undertaken with middleclass Caucasian students and focused on a single intervention that targeted one specific behavior (Dingfelder & Mandell, 2011; Kurtz, 2009). Other problems existed in the lack of an evaluation of randomized efficacy studies in the comprehensive treatment approaches and when they were undertaken, it was generally through a research team hired by the treatment developer (Kurtz, 2009; Odom, Bryant, Maxwell, & Hawkinson, 2010). Kurtz suggested there was limited research with autistic children on the selected treatment interventions in the community and/or school environments.

Perry and Condillac (2003) stated that there was a substantial amount of differences in opinion and contentions among the professionals in the autism field

regarding the treatment approaches and stated that the field of autism was rife with its "cure of the month" (p. 22) phenomenon. It would behoove professionals working in the autism field to agree that credibility resides in evidence-based approaches. Kurtz (2009) pointed out that the need for research into what we do not know might lead to increased research funding for between-group studies and randomized controlled trials that might potentially provide guidance into what strategies might succeed with certain autistic children

Odom, Collett-Klingenberg, Rogers, and Hatton (2010) suggested that autism research was moving forward in establishing an agreed upon set of standards, something that was currently lacking in the literature. While public law and insurance company mandates evidence-based treatment implementation, minimal guidance was afforded to service providers and families regarding the necessary criteria needed for an evidence-based program and where they are even found (Odom et al., 2010). Cooper-Swanson (2012) reinforced the idea that educators must be trained in evidence-based approaches in autism in order to meet the unique needs of the autistic students in the public school classroom.

### Attempt Deligny: Deligny's Unique Approach

Deligny deserves recognition for the attempts he made to assist autistic children and their families in France throughout the 1960s and 1970s. Delacharlery and Delacharlery (2011) reported that there are over 600,000 autistic individuals in France; 180,000 of them children. The children are not allowed to attend public schools for more than two hours per week, if that, and are highly discriminated against (Thompson, 2011).

Thompson (2011) discussed the irony of the current state of affairs in France because Itard, who cared for Viktor, the wild boy of Aveyron, over 200 years ago, went to great lengths to educate Viktor and ultimately was the first educator to develop a rudimentary system of visual symbols used in order to communicate with Viktor.

Bettelheim was credited with employing the term, refrigerator mothers, which held that mothers were responsible for their child's autistic condition (as cited in Badcock, 2010). Kanner stated he often encountered parents of autistic children who appeared to be emotionally cold and not fond of frivolity but at least understood autism to be more of a genetic anomaly than a nurture issue (as cited in Badcock, 2010).

Veer (1996) reported that Vygotsky was influenced by Wallon's theories as Wallon discussed some social and cultural ideas. Heurtevent (2012) reported there was a culture of abuse that existed in France due to the outdated psychoanalytic theory that is predominant in France, one that adhered to the refrigerator mother theory of the 1960s. Heurtevent appealed to the international community when he stated, "I am inviting you today to help we French address the problem with autism in France. My belief is that the moral duty to intervene exists. In France, the human rights' infringement for autistic people are severe and persistent" (p. 1). Even with the abolishment of the packing technique, the psychoanalytic community continues to dominate child psychiatry in France and fight back, despite the research advancements in autism.

Sicile-Kira (2010) reported that she had left France 17 years earlier when she realized if there were any hope for her classic autistic son's future, she must leave. What persuaded her to make that move were the words of her psychoanalyst who concluded

that Jeremy was autistic because he suffered separation issues from breast-feeding. This the analyst gleaned from watching him spin round objects (which reminded him of his mother's breasts) and chase after one that he "lost" when it fell and rolled under a piece of furniture. (p. 1).

Sicile-Kira had recently attended an international conference on autism where she saw parents who were advocates for their autistic child, educational administrators who believed that the autistic students might succeed and supported them, educators who were trained in autism educational treatments and were excited and filled with creative teaching ideas, collaboration, and communication between the schools and parents, and the realistic goals they all shared.

In 2011, Robert, the film-maker of "The Wall" lost a court case that three French psychoanalysts brought against her alleging she had misrepresented them in the film that aired on the Youtube.com channel. The film focused on the French psychoanalytic approach used by Lacan that theorized that mental health problems, including autism are the result of poor mothering skills (Jolly, 2012). The film compared two French autistic boys; one had been treated in American approaches while the other was locked away in an asylum for many years and treated in the psychoanalytic approach. In the 1970's, Deligny was concerned that children with the autistic disorder were excessively medicated and minimally cared for in French asylums (M. Mace, personal communication, October, 2010).

Chew (2013) reported that the parents of autistic children in France continue to protest which caught the attention of an organization called Autism Europe. In 2002 the

organization attempted to address the issue of failure with France to provide education services to autistic children. The European Committee of Social Rights leveled criticism towards France for their failure "to achieve sufficient progress in the education of autistic children and had made autistics an excluded group" (Chew, 2013, p.).

Ce Gamin La was a film about a 16 year old mute autistic boy named Janmari (La Cinema, n.d.). Deligny believed in the use of the camera as a powerful educational tool. This was one of the methods he chose to document his work with autistic children and teens. Deligny left behind documented sources and film archives of the experiments he conducted in Monoblet, in the mountainous region south of France known as the Cevennes (Princess Sarah, 2011). The experiments of Deligny took place in the rural areas of the Cevennes and were held on seven farm camps, approximately 15 miles from one another and members of his family and assistants/educators were hired to oversee the autistic children (M. Mace, personal communication, October, 2010). Deligny called the camps, "rafts" and the seven of them, "rafts in the mountains" (M.Mace, personal communication, 2010). Mace explained Deligny's use of the term *rafts* as

But there is also another reason for the use of the word rafts: As you know, a raft is made of a series of logs placed in parallel and tied together and then tied with another series of logs tied perpendicularly to the first set of logs. The horizontal pieces of wood represent the speaking adults who live here and the vertical ones represent the children. Each individual alone either speaking or autistic cannot stand against the ups and downs of this life, but in joining us together we form a solid assemblage that can defy the storms of life, even life without language. And

this image depicts pretty well the purpose of this community here: the goal is not to change the autistic children to make them speak and behave like speaking adults, no, no. It is not to try to find the cause of their behavior, or the origin of a sickness they would have. And it is not to have the speaking adults become autistic, no, no. The goal is to create a common ground, to find a lifestyle in which both speaking and autistic persons can participate, can take initiatives in the framework of the daily life. It is, for the speaking adults, to find what they lack, what they lack so badly in the eyes of the autistic children that make them non existing, not being there, completely ignored. As if they were invisible in their eyes. (M. Mace, personal communication, October, 2010)

Deligny did not seek assistance from an institution nor did he receive funding for the experiments (La Cinema, n.d.). The work is preserved in a film series available on DVD that consists of three films, one that will be discussed here; Ce Gamin La or This Kid Here. Ce Gamin La was "Attempt Deligny," an experiment in a rural environment, one in which Deligny accepted children with the autistic condition as they were noncommunicative, behaviorally challenged, and appeared to have never gained any sort of child development (Princess Sarah, 2011).

Janmari was the first autistic child to arrive at Monoblet. Janmari's parents had sought out Deligny after they failed to receive any care for their son through the French physicians who had deemed Janmari incurable (M. Mace, personal communication, October, 2010). Deligny had gone to the south of France in order to make a film about a boy named Guy who was labeled as intellectually challenged. Janmari's parents lived

nearby and heard of Deligny's work with Guy. The parents met with Deligny and he agreed to help Janmari. Deligny moved to Monoblet where the parents lived in an apartment complex and he eventually set up a network of care for many children with seven farm camps in the south of France (M. Mace, personal communication, October, 2010; La Cinema, n.d.). Mace stated Janmari was a water seeker, which is common among autistic individuals, and he would put his ear to the ground to listen for the underground water. Once left alone at his apartment complex courtyard Janmari took an axe and began to dig in the spot where he heard the underground water running. He unearthed the water pipe and dug a hole to let the water escape from the pipe. Fire trucks were called and Janmari was the center of attention. Mace reported that Janmari found many underground sources of water at Le Serret, one of the Deligny farm camps. Le Serret was set up at the base of a mountain slope and overseen by 15 assistants/educators who cared for the previously institutionalized children (M. Mace, personal communication, October, 2010).

Princess Sarah (2011) stated that Attempt Deligny consisted of individuals who had a willingness to return to nature, adhered to a hippie lifestyle; but, worked hard as it was a rough thing to do in the wilderness but the children were a joy to live with and this time was that of living in nature as the hippies did in the 1970s. Mace (M. Mace, personal communication, October, 2010) stated that at Le Serrat, "they could tell you of the joy to be autistic, a joy that no psychiatric hospital wall in the whole world could tell about. They have seen it along the years, manifested in the lives of the many children that came

to live here. I will tell you here just a part of it" (M.Mace, personal communication, October, 2010).

Deligny's assistants/educators were idealistic young volunteers such as Mace. The idea was to allow the autistic children to live in freedom, "out of the framework of all psychiatric institutions, against all opinions, all preconceived ideas, against the current, the tide of modern psychology, in all freedom." (M. Mace, personal communication, October, 2010). Mace reported that Deligny, in collaboration with many parents of autistic children who were customarily institutionalized, was influential with the parents in the removal of the children where they made their home with Deligny and his staff. The parents were concerned about what they felt was the lack of progress and heavy sedation the children received at the institutions. Mace reported when the children arrived at Monoblet they were of varying ages, unable to walk, toilet, dress, or feed themselves and while at the institution the children were literally crawling around on the floor and the staff performed all of their activities of daily living (ADLs) for them. Mace stated that while in the institutions, the children engaged in SIB through head banging, scratching their skin, poking their fingers in their eyes, biting themselves, and pulling their hair out. Janmari was diagnosed with deep encephalopathy and psychotic features, was highly restless, and maintained no attention span which made it impossible for the physician to determine his IQ (M. Mace, personal communication, October, 2010).

Upon arrival at Monoblet, the children who arrived from the institutions were taken off all of the medications and they were fed a vegetarian diet. Mace (M. Mace, personal communication, October, 2010) stated that initially the children took time to

learn to perform their ADLs and Janmari was able to do this. Once that task was achieved, the children were allowed freedom in order that Deligny might observe or map what they did and where they went. The assistants/educators engaged in their own routines which consisted of gathering firewood, goat herding, cutting potatoes, building items, planting, cooking, baking, washing the dishes and clothing, fetching water, and other routine farm work tasks. Upon observation of the staff, the children eventually began to follow them and imitate their actions.

The environment was structured in that they all were to get up at the designated time and engaged in designated chores and tasks throughout the day. Eventually, the children began to initiate the tasks the staff had undertaken and performed them alone or with the use of gestures from the staff. The children were observed using knives to cut potatoes, washed and rinsed the dishes and placed them in the drying rack, prepared and kneaded bread dough, herded goats, walked to nearby villages with the staff to shop, worked in the garden, hauled water, gathered wood, hammered a post with a boulder, played outdoor games with the use of staff cues and gestures, and appeared to understand what was required to complete a task or in game playing (M. Mace, personal communication, October, 2010).

What I observed in the film, Ce Gamin La was the autistic child's ability to complete the various tasks, act with persistence until the task was achieved, and express pleasure with themselves upon the completion of their task. All of the children appeared to have classic autism. An excerpt from the recorded memoirs of Mace stated the following about Totosh, an autistic boy in the Attempt Deligny regarding what is

perceived by Mace to be Totosh's reaction when he learned to wash the dishes: knowing that a few months ago I was crawling on the ground, that's nothing but a miracle.

November 15th: I hope I am going to the terraces again today! Yes, I am going! I jump and clap just to the idea of going over there. I like to play with water. I want to play with water with M\* today. I hope he will accept me to play with the dishes in the water!

I am coming close to M\*, just at his side and not 50 feet away like the first time I came! When M\* has bathed a plate and places it between the two basins, I stretch my hand and barely touch the plate with the end of my finger as if it was to take the plate, to see if M\* does not protest and oppose my action. No, in the contrary he makes a movement that is inviting to take the plate and bath it in the second basin. So I do and I bathe the plate, take it out and bathe it again, and again. I make the water rolling down the plate like a waterfall. What fun do I have today! It makes me clap my hands and jump again and again.

Now, for me to do this simple gesture, to take this initiative, to act and using my hands. During my childhood I have never been able to use my hands, even to feed myself or to dress myself; autistic at the degree 10 on a scale of 10. Nothing, absolutely nothing, this is what I could do all my life! And now I am a happy camper (literally) here, playing with water, bathing plates, pots and silverware. I am now feeding myself, dressing myself (with a little help from my friend), I walk, I clap my hands, I jump, I am really as happy as could be. I don't bite my

wrists to the bone anymore. I don't bang my head against the walls anymore. I am much less upset with people at least with the people here I should say.

Yes, it's like I am born again, as if I had a new lease on life. What a joy to be autistic... here. Not at my parents' home with all the streets, all the noise, all the cars, all the drugs, no, no... Here. (M. Mace, personal communication, October, 2010).

Each of the autistic children in Attempt Deligny was responsive to their environment. In the film, from the cues and gestures used by the staff, it appeared those were given for direction for the routine in daily activities. Mace reported there was no use of language in communicating with the children (M. Mace, personal communication, October, 2010).

Wallon (1947, 1956) developed the theories of direct observation and child development that were the inspiration for Deligny. Deligny attempted to incorporate Wallon's theories into the care he provided for children that French society had deemed pathological and uneducable (Deligny, n.d.). Wallon's theories on psychogenetics, which attempted to examine the effects of a child's environment(s); both human and physical on their psyche (Wallon, 1956). Wallon suggested that the environment was the source of how a child developed their motives which determined their reactions. Wallon developed the theory of the five developmental stages in childhood that included

- Impulsive and emotional (0 to 3 months)
- Sensorimotor and projective stage (1 to 3 years)
- Categorical stage (6 to 11 years)

# • Adolescence stage (as cited in Bailly, 2009)

Wallon (1956) stated that there should not be complete dependence upon observed behavior in its natural setting, but that it should be accompanied with artificial experimentation that required "strictly determinate conditions upon an animal" (p. 1) in order to learn the manner in which they might react and that the goal of psychogenics was one that revealed the effect that the environment had on an individual. Two sets of conditions existed in psychogenesis; the organic and what happened in a child's environment. Neural circuitry was believed to be responsible for certain functions upon activation and subsequent development depended on a variety of opportunities in order to manifest it (Wallon, 1956). Early childhood development, according to the Wallonian theory required stimulus even when imaginary, in order to establish links with the varied activities, both sensory and motor.

Wallon (1956) believed hormones, as internal factors contributed to the child's developmental process and distinguished from a child's operational field, being that of an object's position to the perceptual field, being that of an object's practical position in relation to others. Wallon (1947) discussed the role of rites in more primitive societies in their adherence to rituals as being the catalyst that moved the society toward a sense of control over their environment and the eventual act of imitation which led to a growth of representational depictions. The mental functions became differentiated through routine, and arose from situations that allowed the experience to occur (Wallon, 1947). Stokes (2001) discussed the need for structured teaching with the autistic students and researchers and emphasized the autistic child's unique needs, sensory processing

difficulties, preference for a stable environment and consistency, tendency to distractibility, and resistance to change.

When Deligny accepted the autistic child as they were, that meant he did not attempt to change them and his idea was to observe them and involve them in the structured daily life of the rural farm environment. In the film, Deligny demonstrated on paper the paths, maps, or lines he observed the children to follow each day and emphatically insists that the autistic child had no language and suggested that language is not fundamental to a relationship. Mace (personal communication, October, 2010) quoted the words of Deligny regarding his view of teaching an autistic child language, "The autistic has no language, we cannot expect them to enter our world of language. We must enter their world." During the course of the film which was completed in three years, the children respond positively to routine tasks. The recording of the behavioral challenges is apparent and the staff does little to divert the behaviors as the child, when the behavior disrupts their task, the child immediately returns to the task and completes it.

Ce Gamin La records a distinct environment that shows the children aptly responding to education through the use of the natural setting; the staff use of taps by sticks to stones and helper gestures that were repeated in each daily routine, as needed whether it involved picking up firewood, planting, doing dishes, fetching water, or baking bread. There is no language used with the children in Ce Gamin La. Powell and Jordan (1993) suggested that language was to be used sparingly with autistic children. Jordon (2008) recommended the limited use of language with the autistic students, "teaching thinking skills may need to be done nonverbally, whereas attempts to enhance linguistic

abilities may need to be done with explicit attention paid to the making of meaning and with less demand placed on a problem solving task" (p. 6). Discussed earlier was Conroy et al. (2007) that pointed out a strong relationship between a teacher's directive and a student on the ASD who became disruptive. Deligny demanded no eye contact in addition to refraining from any verbal effort with the autistic children (M. Mace, (personal communication, October, 2010). In a recent NIH funded study undertaken by UCLA, it was confirmed that gestures were successfully used with 40 autistic children (Kasari, Gulsrud, Freeman, Paparella, & Hellemann 2012). The focus of the study was in its assessment of language, vocabulary and cognitive abilities in children who were assessed at the age of 3 and 4 and later at the age of 8 or 9 years old. Activities examined included the child's ability to initiate interaction with an adult, variety of individual play time, and the quality of parental interactions.

Kasari et al. (2012) found that the children who began attention focusing therapy early in life had acquired more advanced language skills by the time they reached the age of 8 years old. The children who demonstrated increased flexibility in object play had shown better memory and cognitive skills at the age of 8 years. The children who were taught the use of pointing or gestures in gaining an adult's attention at the earlier ages were found to have more advanced language skills by the time they were 8 or 9 years old. It appeared the children with the autistic condition might benefit from individualized assistance in ways to express themselves which required a unique approach in education.

Mace (personal communication, October, 2010) described his experience and what he entitled his "preambule" in the Attempt Deligny as follows

"Do you remember that the very first article I read about autism was in a newspaper called "The Open Mouth"? Well, here is what I discovered many years later: Open your mouth for the speech-less (the autistic children), in the cause of all who are appointed to die. (A Bible Proverb). Yes, open your mouth, the true "Open Mouth", for the autistic children, this proverb speaks directly to me. I owe them therefore to "open my mouth for the speechless", to speak in their behalf.

Let me tell you in what deplorable condition they arrived to us: they were between 4 and 12 years old when they came to us, sometimes bedridden, or crawling on the floor, or walking but barely using their arms, theirs hands! They had never washed themselves, never eaten by themselves, never gotten dressed by themselves, never, ever (Continued in Appendix L).

## **Summary and Conclusions**

The predominant concern for parents of autistic students is one that is centered upon their child's learning environment and whether it is conducive to their academic progress. The issues that were examined are the manner in which challenges have affected the student, family members, and educators regarding increased stress. The parents express frustration over the lack of an educator's knowledge about ASDs and the inadequate training they have received in order to academically profit their child. Much of the previous research primarily includes the educator's opinions about potential classroom curriculum or interventions and parental satisfaction with some programs. The parental experiences of having an autistic student in the public school classroom

environment, knowledge about their child's behavioral challenges and abilities, and opinions about the classroom environment have not been adequately examined.

The findings revealed that there is a failure to gain the perspectives of the parents for use in educational planning. This study provides the opportunity for the parents to express their voice regarding their personal experiences. The opinions and ideas of the parents and/or primary caregivers have the potential to contribute to policy changes and methods that will likely provide insights for professionals that might contribute to the manner in which interventions are included in the public school system regarding the ASD approaches. While the public educational service providers struggle with complex issues regarding students with the autistic condition, this study might lend information about the ways in which the collaborative efforts between stakeholders might make a difference in administration of program implementation as well as open previously unavailable funding sources.

The mixed method approach is beneficial for this study in its ability to provide information on the lived experiences of a specific group of individuals and the relationship among the variables in order to understand the psychological constructs from a phenomenological perspective (Nastasi & Schensul, 2005). The quantitative approach has the potential to yield validity to the research findings. Maxwell (2005) suggested that while the qualitative approach had led to an understanding of the processes, the quantitative approach had led to revealing common themes in the variables and point out potential causation assertions. This would add validity to the mixed method findings,

particularly since the personal interviews and the resulting data with the participants is likely to bear common themes.

The focus of the study is to learn about the experiences of parents with the public classroom environment and what it means to them in order to describe their experiences and put it in a format that will help other parents struggling with the same adversities. The use of the mixed methods approach will enhance the reliability that standing alone, the qualitative or quantitative could not provide. Woods et al. (2004) stated that it had been argued that the use of multiple methods had the ability to increase the confidence in the findings.

Chapter 2 was a review of the literature that revealed the ways in which the pertinent collaboration might be created among the stakeholders. Chapter 3 includes an explanation of the barriers inherent in the educational system and provided ample insights into ways those barriers potentially challenge the system.

### Chapter 3: Research Method

#### Introduction

In this study, I used a mixed methods design which consisted of a phenomenological approach in personal, in-depth interviews and a quantitative approach through the use of a survey questionnaire to explore the experiences, feelings, and opinions of parents of an autistic child who was receiving educational services in the public school classroom environment. The goal of the investigation was to determine whether the parents opined that the public school classroom environment was a healthy one in which their child was able to succeed academically. The findings might act as a catalyst for change in altering the lives of its participants and the environments their child engages in. My goal was to examine the variables that might contribute or not to an environmentally healthy classroom and to provide a voice for families of autistic students in the public school classroom in order to potentially improve the quality of their lives.

Many theories have been developed in order to address the symptoms of autism in the public school classroom. Some approaches have had success; but, there remains no standard approach that is used in the classroom. There is a reluctance that remains on the part of school administrators and personnel to implement evidence-based models in the public classroom (Ayres, 1979; Grandin, 2008; King, 2011; Kranowitz, 1998; Shore, 2001; Stokes, 2001). Often, it is a matter of an educator picking and choosing what he or she has heard from others to be effective, and many educators have not had adequate training in ASD and minimal knowledge about autism (Callahan et al., 2009; Dingfelder & Mandel, 2011).

The qualitative research approach for this study is one that allowed me to afford the participants the opportunity to explain their experiences and share, through self-reports, those experiences they had on having a child with ASD in the public school system. Creswell et al. (2010) suggested that one of the strengths of qualitative research is in its concentration on the meaning of the experiences and what that might lend to the development of theory in research. The in-depth methods of data collection that include interviews are an integrative and precise manner of inquiry (Creswell et al., 2010).

Qualitative research provides knowledge about the context and allows the voices of the participants to be heard; the qualitative method eases the data collection methods for measures that are non-existent and affords more of an understanding of certain concepts. An examination of the data was completed to ascertain whether any common themes arose among the participants regarding their opinions of the classroom environment and how this has affected these areas of their lives.

The mixed methods approach was designed to allow a researcher to gain an understanding of pertinent social and emotional health issues and seek evidence rooted on the research questions and theoretical position (Creswell et al., 2010). The qualitative method allowed me to identify what might be unknown, explain why and how events occurred, and the effect those events had on the families. Creswell et al. stated that the quantitative approach was useful for an examination of the extent of what is known about an event and primary patterns of association that might include conjectures of causality. The mixed methods design allowed me to intentionally collect the strengths of each the

qualitative and quantitative method in order to answer the research questions (Creswell et al., 2010).

The quantitative data afforded me the opportunity to gain insight into areas explored not only in the personal in-depth interviews, but also through the responses to specific survey questions that addressed what experiences the participants went through in seeing that their child succeed in the public school classroom. The mixed methods design provided me the opportunity to examine multiple perspectives in order to determine the larger scope of the experiences the parents have had in dealing with an autistic child in the public school system. The mixed method of the qualitative and quantitative approach provided me the opportunity to gain a comprehensive understanding of the problem.

Maxwell (2005) stated that the qualitative and quantitative methods each have different strengths and are used to address different sorts of questions and research goals. With the mixed method design, it allowed me to investigate the personal experiences of each interview participant and what it means to them as well as obtaining the data indicating common themes in the opinions regarding the manner in which educational services are provided to their child with the autistic condition in the public school system.

The phenomenological structure for the study is the best suited approach in order to yield a comprehensive description of the central phenomenon emerging from the experiences that foster insights among the parents. The narrative approach would have allowed me to interpret the meaning of the participants' stories; but, I felt in using the phenomenological approach, I would afford the parents and/or primary caregivers(s) of

children with the autistic condition the opportunity to voice their feelings about their experiences. My role has allowed me to provide a description of what they voiced in the interviews and sought the common themes in the meanings among the participants.

The ethnographic approach is the examination of a cultural concept which makes it an approach that is not beneficial in what is being examined in this study: a phenomenon. LeCompte and Schensul (1999) stated that an ethnography builds theories of cultures in order to explain how people think, behave, and believe. The grounded theory approach focuses on the generation and development of a substantive theory regarding the process (Creswell, 2007). The grounded theory approach is not the best suited in order to provide a description of the phenomenon experienced by the parents of autistic students. The case study includes extensive information about the setting regarding a case and the case is studied with clear boundaries (Creswell, 2007).

In this study, I focused on the meaning of the experiences for the parents of autistic children about the phenomenon through which I attempted to describe the shared experiences of the parents, hence providing an essence of the parents' shared experiences. The personal in-depth interview with each of the participants allowed me to hear about their experiences and how they arrived at their specific level of satisfaction with each of the questions that were presented to them.

### Setting

The purpose of this research was to investigate whether the parents and/or primary caregiver(s) of children with the autistic disorder felt the unique needs of their autistic child were being met in the school classroom environment. The children's

services outreach organizations that I collaborated with were ones that provided outreach and resource services to families of a child with a DD. The other was an office consisting of a sole-practitioner therapist who provided mental health services to children and their families. The two agencies were of primary consideration to me because it was a viable way to recruit parents of children with the autistic condition who were students in the public schools. These organizations were relevant to the study due to their knowledge about meeting the needs of families with a child with the autistic disorder.

## **Research Design and Rationale**

In this study, I used a mixed methods design in order to examine the experiences, feelings, and opinions of parents of a child with the autistic condition in the public school classroom environment regarding the autism educational services their child receives.

The use of the triangulation of data was employed in order to maintain the validity of the study.

## **Qualitative Design**

The phenomenological approach consisted of personal, in-depth interviews with eight parents and/or caregivers of an autistic child in the public school classroom. The research questions that were a part of the qualitative approach employed the following questions with accompanying probes, if needed.

1. What is the lived experience of the parents and the process they underwent regarding the adequacy of current educational services their child receives in the public classroom?

- 2. What is the opinion of the parents regarding the quality of the classroom structure for their child?
- 3. What is the parents' opinions regarding the current environmental health of the public classroom in its ability to afford their child the best learning experience?
- 4. What do parents think might be the environmental health barriers that exist in the public classroom, if any?

I explained to each participant that the classroom structure and overall environmental health included the classroom organization consisting of the following:

(a) sensory supports such as lighting, (b) noise level, (c) stress reduction and behavioral management of the students by the classroom staff, (d) availability of any integrated treatment methods used by any service provider professionals within the classroom or option of off-site services, (e) teacher training in evidence-based programming for autism, (f) knowledge of mental health issues common in autism, (g) educator knowledge of programs designed to reduce student and parental stress, (h) educator awareness/receptiveness of the need for parental input, (i) opportunity for parental input into the IEP, and (j) input into child's daily activities and successful engagement within the classroom.

The structured interview guide (Appendix H) was used to assist in the guided discussion between the participant and me pertaining to the research questions. The qualitative research questions were developed in relation to the 32-question survey questionnaire (Appendix C). The guide provided a set of planned questions to assist and

prompt the participant in the recollection of their experiences with the public school system. The guide became the tool to extract the participants' recollection of events rather than a guarded and standard response. The Structured Interview Guide contained the following questions and prompts

1. What is the lived experience of the parents and/or primary caregivers and the process they underwent regarding the adequacy of current educational services their child receives in the public school classroom?

Prompts: What has the experience been like for you in seeing that your child received adequate educational services in the classroom? Tell me the details about what you have gone through. Please share examples and background information of how the experience has affected you as well as your child. Please tell me the details about the relationship between you and your child's educator, if any regarding these issues.

2. What is the opinion the parents and/or primary caregiver have regarding the quality of the public school classroom structure for their child? Go over each one.

Tell me your opinion about the quality of the

- Classroom structure for your child.
- Organization.
- Overhead lighting.
- Management of behaviors associated with autism.
- Educator knowledge about autism.
- Noise level.

- Educator management of behavioral /psychiatric symptoms.
- Effective communication with educator.
- Participation in Individual Education Plan (IEP).
- Support from your child's educator for you and your child.
- Knowledge of mental health issues common in autism.
- Knowledge of programs designed to reduce parental stress.
- Whether there is the availability of an integrated treatment approach, consisting of mental health, occupational therapy, speech therapy.
- Opportunities for expression of parental input into daily activities based on parental knowledge about their autistic child.
- 3. What is the parent(s) and/or primary caregiver's opinion regarding the current environmental health of the public school classroom in its ability to afford their child the best learning experience?

Prompts: Tell me whether your child has improved academically or not and I provided an explanation of environmental health as it pertains to the public school classroom.

4. What do parents and/or primary caregivers think might be the environmental health barriers that exist in the public school classroom, if any?

Prompts: An explanation of environmental health as it pertains to the public school classroom and what constitutes environmental health in this context and what

might be considered a barrier to adequate environmental health. Tell me your opinion regarding any environmental health barriers that might exist.

## **Quantitative Design**

The quantitative approach provided the opportunity to follow up with the qualitative method in order to further investigate any common themes. An agency advertising flyer (Appendix I) was distributed through the stakeholder agencies. An online survey advertising flyer (Appendix J) was distributed to the internet websites specified in the IRB. An online survey consent form (Appendix E) was within the Surveymonkey.com survey questionnaire and filled out prior to an individual's participation in responding to the survey. The 32-question survey questionnaire asked the same questions in a more expanded format than was presented in the personal interviews. The only difference was the parents chosen for the personal, in- depth interviews had the opportunity to expand on their thoughts about their experience(s) with their child with the autistic disorder as a student in the public school classroom.

The survey questions consisted of a rating scale that examined their level of satisfaction regarding the following topics.

- Classroom organization
- Classroom structure
- Effect of overhead lighting
- Noise level management
- Behavioral/psychiatric disorder management
- Level of communication with educators and educational staff

- Level of personal involvement in the development of IEP
- Level of educator's training and knowledge of autism
- Level of support provided by educators and administration
- Educator suggestions for reducing parent/child stress or parental training in autism

Research Question 5 is specific for the quantitative portion of the study and was designed to seek the parent and/or caregiver's level of satisfaction with the overall educational services conducive to the environmental health of the student with the autistic condition in the public school classroom. The independent variable is the educational services while the dependent variable is the parent and/or caregiver's level of satisfaction with the educational services their autistic child has received. Research Question 5 and the hypothesis were as follows.

5. What is the parents' and/or caregivers' level of satisfaction with the educational services their child receives in the public school classroom in being one that contributes to positive classroom environmental health?

Null Hypothesis: The level of satisfaction with the educational services the parents and/or caregivers of an autistic child who is a student in the public school classroom in being one that promotes positive classroom environmental health is significant.

Alternative Hypothesis: The level of satisfaction with the educational services the parents and/or caregivers of an autistic child who is a student in the public school

classroom in being one that promotes positive classroom environmental health is not significant.

A few of the survey questions pertained strictly to Research Questions 2, 3, and 4 of the qualitative portion and were exploratory in nature. A quantitative basis was sought for these questions to lend credibility to the research design. These responses were designed in order to formulate an idea of how the parents and/or caregivers might view the issues.

The goal in the use of a mixed methods design was to determine what environmental factors might contribute to the parents' formation of their opinions regarding the public school classroom environment and how their experience(s) had affected their feelings and opinions as well as what factors contributed to poor academic performance in their autistic child. The use of personal in-depth interviews provided an opportunity for the parents to express their feelings and opinions regarding what they felt might be barriers that prohibited their child from successful learning in the classroom environment. The in-depth interviews with the participants did offer important topics that created new or additional survey questions.

The survey questionnaire provided an opportunity for participants to provide feedback on their level of satisfaction of the educational services their child receives which led to a basis for common themes. Options on the Surveymonkey.com website included a silver package that allows a researcher to add a comment section to specific sections of the survey which was done and the comments collected to add to the mixed method design nature of the study. The mixed methods design allowed me to have

multiple in-depth interviews with the parents and to examine the parents' experiences in the positive and negative outcomes and to utilize the findings from the survey questionnaire in order to determine their level of satisfaction and the emergence of any common themes among the participants.

The mixed methods design provided an opportunity to understand the process the parent and/or caregiver went through that might have evolved over time. It is important to understand what factors contributed to the formation of the parent's attitudes regarding the academic success or not of their child with the autistic disorder in the public school classroom environment. Through the mixed methods design, the parents and/or caregivers were able to share detailed information about whether they felt the school classroom afforded the autistic student positive environmental health. Creswell et al. (2010) likened the qualitative approach as inductive, while the quantitative approach as deductive. The use of the mixed methods design allowed me to gain an understanding of what parents felt were the complexities associated in caring for an individual on the ASD who was a student in the public school system.

The mixed methods design allowed an investigation of the perspectives of the parents in order to bring meaning to the singular perspective and use of an investigation framework of a philosophical and theoretically induced position that employed the quantitative approach that examined the frequency of constructs and from a qualitative approach, explored meanings, and gathered an understanding of those constructs (Creswell et al., 2010). The qualitative data collected in this study allowed me to collect descriptive information and examine any common themes that arose while the

quantitative data offered the opportunity to examine the participants' level of satisfaction in specific educational services areas.

#### Role of the Researcher

All aspects of the study were conducted as follows

- Recruitment of participants included meeting individually with potential interview participants in order to determine if they were appropriate for the study.
- Provided and obtained the consent forms and discussed with the
  participants the limits of confidentiality and option to leave the study at
  any time.
- 3. Obtained community partner letters of cooperation.
- 4. Conducted all personal interviews.
- 5. Administered, monitored, and collected the data from the survey questionnaire.
- 6. Analyzed and input all of the data into the selected statistical packages;
  Statistical Package for the Social Sciences (SPSS) to conduct the
  quantitative analysis and NVIVO software to conduct the qualitative
  analysis.

I have over 17 years' experience working for agencies that provide services to young adults with DD and their families. In my previous employment, I worked as a medical social worker in a nursing home for three years and am currently employed as a mental health community program officer in the frontier region of eastern Montana. The

responsibilities of the position include the monitoring of publically funded Medicaid in 17 counties and collaboration with numerous stakeholders.

Through these two positions, I have been exposed to many individuals with physical and/or mental health disorders and oftentimes, their family members. I work with parents of adults and children with mental health disorders and some of whom have co-occurring DD and mental illness. This brings me in direct contact with educators, service providers, and parents of children who most often have been or are in the public school system. I frequently receive calls from concerned individuals on behalf of a child who has autism and the parents have been unable to receive needed services within the region. I have been a Court Appointed Special Advocate (CASA) board member for over three years and a board member for the Empty Stocking Fund, a group that oversees that local needy families with children receive Christmas presents. I have an associate of arts degree as a paralegal, a bachelor's degree in psychology, and a master's degree in general psychology. In addition to working towards fulfilling the requirements for a doctorate, I am taking chaplaincy classes.

Maxwell (2005) believed the potential existed for the relationship between the researcher and the participants might affect a researcher as well as the participant. The research relationship the researcher established might affect other parts of the research design (Maxwell, 2005). Maxwell suggested that any decisions made about the relationships with the research participants must be well thought out and interviews conducted should reflect a "working research partnership" (p. 84). Ethical considerations dictate the parameters of a researcher and participant relationship.

A limitation of the potential for bias was initially sought through seeking more than eight to 10 participants; however, the number of committed participants was limited to eight individuals. This attempt was unsuccessful as 24 participants were approached and agreed to participate in the personal interviews and which 16 reneged. There was strong participation in the survey questionnaire which yielded 109 responses, 82 of which were included in the study.

Researcher bias was an additional consideration in that it is important for the researcher to remain objective and value-neutral when evaluating research (Mehra, 2002). In a conversation with one of the students, Mehra pointed out that the student had used their mediation skills in the qualitative approach to research. Mediation skills have benefited me through past employment.

I am a degreed paralegal with 4 years of mediation experience in personal injury. For successful mediation in conflict resolution, it is important for the mediator to be objective in determining precisely where two conflicting parties stand on a given issue. For purposes of this research, I was the outsider and it was my role to seek the experience of the parties involved and value their expert opinions on the conflict. As is the case with the mediator, it was imperative for me to set aside any personal bias and use my listening skills in order to reach a fair and equitable settlement between the parties. The mediator reports the impartial facts and findings to the governing body which is similar to that of the researcher when reporting the research findings.

Communication skills were necessary in order to provide an atmosphere that would be comfortable for the interview participants. The participants appeared to feel

comfortable and were not pressured in volunteering information about their experience. The participants were assured that I had no preconceived ideas about their experience and they expressed what they felt about their experience. I attempted to act as a facilitator in the process of sharing their stories. While the interview questions were formatted, the free flow of ideas was encouraged in order to allow the participants a forum in which they would be heard.

# Methodology

# **Participant Selection Logic**

The participants that were chosen for inclusion in this study were based on the criterion that they were a primary caregiver of a child, adolescent, or teenager diagnosed with an ASD who were students at a public school. Participation in the research study was open to all ethnic groups. While the majority of participants were expected to be derived from recruitment measures with the community partners, a few were chosen after a screening of their suitability because they had already expressed an interest in participating and were not affiliated with the community partners. The personal interviews were conducted in person or telephonically as some participants were not local residents.

The phenomenological portion of the study included eight personal, in-depth interviews with parents and/or primary caregivers of children diagnosed with ASD. The primary caregivers included family members, such as parents or grandparents who had primary custody and/or care of the autistic child. The interviews were conducted either in person or telephonically. Rajendran (2001) discussed the goal of a researcher is not one

to pass judgment on any particular setting for the research but the research focus was on whether a study generated theory, contained descriptive data, and provided an understanding of a phenomenon.

Qualitative studies may be complex and researchers should not attempt to limit the field but work instead to reveal the many dimensions that are inherent in the research (Rajendran, 2001). While the telephone interviews did not provide a chance for the researcher to evaluate facial expression, it was important to note voice inflection during the course of the telephone interview. The quantitative portion of the study included the use of a Likert survey administered to approximately 109 participants via Surveymonkey.com. The survey participants were anonymous as an online survey advertising flyer was distributed to internet resource/advocacy websites and posted on Facebook support pages for parents of autistic children. Methods of data collection were triangulated in order to validate the findings.

Ample data were provided and adequate time was spent in the field in order to foster working relationships with the interview participants with whom a trusting relationship was established with the participants in a personal, in-depth interview. It has been my experience that when a parent of a child with autism or other DDs discovers that you are interested in their stories, they feel comfortable in relaying their experiences and/or concerns with you. Collaboration and member checking occurred with each of the participants through a post interview transcript review which each participant found suitable or had minimal changes.

The interview participants were referred through Best Beginnings of Custer County, MT or expressed interested through hearing about the study from others or through the Walden Participant Pool. The eight interview participants completed the online survey questionnaire. I met individually, either in-person or telephonically with each referral from these venues in order to establish that they were eligible, based on the criterion mentioned above. Reciprocity was provided to each participant who contributed information in a personal interview through a Visa gift card in the amount of \$10.00. All but one interview participant accepted the gift card. The rationale behind this decision was based on showing appreciation for the time and effort they took in participating in the research.

The Code of Federal Regulations of 2005 stated that the Institutional Review Board (IRB) must determine that certain requirements are met to reduce any risks to the participants through the use of incentives in statistical research survey questionnaires (Berry, Pevar, & Zander-Cotungo, 2008). Berry et al. pointed out that grant funded researchers who administer survey questionnaires often employ the use of incentives and the IRBs could benefit from research on the topic in order to provide a standard approach regarding its ethical appropriateness.

While the sample size is important in qualitative research in order to provide a sample size large enough to claim saturation, it is left to the judgment of the researcher to weigh the quality of the participants' responses against its intended use (Sandelowski, 1995). The sample size was determined based on the repeated number of participant responses and the use of judgment as to the point of redundancy. For the purposes of this

study, it was found that saturation was apparent after the third interview at which time the participants began to repeat similar experiences and/or opinions regarding the same issues at hand, such as the educator's knowledge about autism.

#### Instrumentation

A Likert rating scale was administered through Surveymonkey.com and an agency advertising flyer (Appendix I) and online survey advertising flyer (Appendix J) was made available to and distributed through the participating organizations and to individuals for the period of April 2013 through May 2014. The data from the quantitative portion of the study were collected from Surveymonkey.com in May 2014. The Likert rating scale was developed by Likert in 1932 as a means to investigate attitudes (Edmondson, 2005) and is in the public domain. A digital audio recording was made of each personal interview for recording purposes. Each interview was transcribed and a sample interview transcript is included in Appendix K. Approximately 80 hours went into interview transcription and the average interview transcript was 25 pages in length. Journal notes were made keeping record of any thoughts about an individual interviewee

The data collection consisted of notes and audio-recordings of personal interviews, responses to the 32-question survey questionnaire, and field notes solely for researcher reflective purposes in order to reduce bias. All of the hand-written notes, digital recorders, and flash-drive are locked in a filing cabinet. The anonymity of the participants was protected by assigning identifying numbers to the material. The

transcripts are contained in a Microsoft file on the computer, a flash drive, external hard drive, and a hard copy is locked in a file cabinet.

Based on IRB approval (No. 03-21-13-0099018), the phenomenological approach was used in the gathering of the interview data that emerged from this study. Eight personal, in-depth semistructured interviews were conducted in–person and/or telephonically with the participants. The strategy employed with the personal interview participants was based on determining if there were any common themes in their stories that are likely to form a within-case analysis through the detailed description and common themes of each case and the themes within them.

A cross-case analysis might suggest recurrent and common themes within the participants' stories which might provide an interpretation of the meaning of the case (Creswell, 2007). Through this analysis I attempted to describe a meaning of each participant's personal account that may provide knowledge about the environmental health of the student with the autistic condition in the public school classroom. Probes were employed with the participants when a key issue arose that needed further exploration. Each of the personal interviews lasted up to 2 hours or more for a total of over 18 hours.

#### **Procedures**

Arrangements were made to meet with Best Beginnings of Custer County, and David, LCPC in order to explain the purpose and nature of the study. The community partners were given an agency advertising flyer explaining the availability of a study consisting of personal interviews and a survey questionnaire which they distributed to

their clientele via e-mail newsletter or posted within their respective agencies. Letters of cooperation were obtained from each community partner agency and are attached in Appendix F.

Interview participants lived in Billings, Forsyth, and Miles City, Montana, and Mississippi. Two participants were the result of the collaboration with Best Beginnings, one referral from the Walden Participant Pool, and the remainder through word of mouth from other interview participants or friends. A time was arranged to meet with each local individual participant. Telephone contact was made with the out-of-area or out-of-state participants in order to screen for their appropriateness for participation in the study. Each individual chosen to participate in the personal interview was provided with an informed consent form and a participant interview guide which explained the purpose and the parameters of the study including confidentiality issues, such as limits to confidentiality. Each form was discussed with each participant.

The informed consent form was received from all interview participants. All participants who wished to complete the online 32-questional survey questionnaire were asked to complete the online consent form before beginning the questionnaire. After the personal interviews, any participant who found sharing their experiences with the researcher stressful was given the option of following up on one low cost counseling session with David, a licensed mental health professional. None of the interview participants felt they needed this service. The personal interview data were recorded through a digital and/or cassette tape recording instrument, researcher notes, and subsequent journal entries about the interview.

The 32-question survey questionnaire was undertaken with an informed consent embodied within the introductory paragraph to the study. The online survey advertising flyer was distributed to various internet autism advocacy websites and autism parent support groups on Facebook who were considered partners only in the sense that they agreed to make known the availability of the survey on Surveymonkey.com through their Facebook page, website or via their monthly e-mail newsletter. The survey was posted on the websites once and five times during the past year to the advocacy agencies who had Facebook pages.

This proposal has undergone the IRB process twice and expired on March 20, 2015. The reason it was extended was due to the lack of cooperation on the part of parents and/or primary caregivers to participate in a personal interview despite repeated and frequent requests to do so. Best Beginnings and other parents and/or caregivers' contributed repeated attempts to engage people which ultimately paid off after a year of hard work in collaborative efforts.

# **Data Analysis**

#### **Data Collection and Procedures**

Initial approval for research was granted by the IRB (Appendix A) on April 17, 2013 for the commencement of the survey questionnaire and personal in-depth interviews.

### **Quantitative Procedures**

On March 13, 2014 the IRB renewed approval for the research (Appendix J). The survey questionnaire was posted on surveymonkey.com. Surveymonkey.com is an online

website fee for service business providing data survey design, data collection, and data results download into Microsoft Excel or SPSS at the completion of a survey. While the data from the survey questionnaire was downloaded into SPSS, care was taken to check each individual response for accuracy rather than rely solely upon the Surveymonkey.com findings. Each individual survey response was printed off and checked against the Surveymonkey.com findings. Several corrections were made in that some of the Surveymonkey.com responses were inadvertently placed in missing data locations where an individual only filled out one or two questions and left the survey site. This happened repeatedly so the data provided by Surveymonkey.com was in effect of no effect for the purposes of this study.

A Likert survey questionnaire was posted on Surveymonkey.com and interested participants recruited from the partner agencies Best Beginnings of Custer County, MT and mental health services provider, David, LCPC were notified that the survey was available and parents were asked to participate by responding to the survey questions. Participants were also recruited from Facebook pages and autism service and advocacy agencies listed on the IRB application, the Walden participant pool, and by word of mouth. The survey questionnaire was conducted anonymously and no identifying data was collected about the participants. While the interview participants were not unknown, their responses to the survey questionnaire were not identified when they participated at the end of the interview.

While the qualitative data provided an in-depth understanding of the phenomenon of the study, the quantitative data provided an additional knowledge base to the study and

was used as a means to provide a triangulated description of the phenomenon. The plan for the integration of the mixed methods design was designed to provide a description of the phenomenon and provide confidence to the study through the use of the numerical data report focusing on the parents and/or caregivers' level of satisfaction. The idea was to provide a connection to the larger picture of the phenomenon through an expansion of the meaning of the phenomenon and elaborated upon the findings through use of the mixed methods design, an attempt to foster validity.

The SPSS was the most suitable based on its many capabilities in handling large and complex amounts of data and its ease of data mining. Participant survey questionnaires that contained responses to only three questions were eliminated from the data analysis. Out of 109 responses, 82 responses were useful for data analysis. The initial coding was organized by a hand tally of 32 survey question responses consisting of yes (y) or no (n) responses followed by survey responses to a-g.

The next step for the coding was done in the SPSS with the quantitative data by assigning a, b, c, respectively and y/n for yes and no, and g or h for other survey comments. The first task was to organize the data into groups that are of research topic interest (e.g., noise level) and corresponded to the research questions. The next step entailed reading the data in order to create a category system. Each category was expected to contain meaningful data within each respective category and once this was achieved, the coding of the survey results occurred. A number would be best suited for each category of the data contained in a-g and y/n.

Note-taking was useful in the formation of category creation and code development in regard to the interview responses. Workbook I (n.d.) suggested the use of a code guidebook; one in which is used as a process guide when creating codes and as an analysis guide. The codebook guide was used as a reminder for the researcher what the codes are meant to represent. Once the coding was completed, the data were easier to interpret and tables or bars were appropriate in order to view the frequency of question responses.

The quantitative analysis of the survey questionnaire was conducted through SPSS in order to examine the hypotheses through use of the frequency of responses and percentage of responses within a given category. The frequency feature was used chiefly to determine the number of the specific response choices and whether the findings were significant or not in that the parents and/or primary caregivers were satisfied or not satisfied that the educational services their child receives are ones that promote positive environmental health in the public school classroom. The analyses revealed what areas they were or were not satisfied with and the frequency in which they occurred and the percentages of those who fell into the respective categories.

#### **Oualitative Procedures**

To reflect the qualitative data from the phenomenological portion of the study which provided data, the QSR NVIVO is designed as an electronic data analysis tool that had the ability to analyze unstructured information, documents, and audio and visual recordings (Rich & Patashnick, 2002). The QSR NVIVO has the ability to securely store the database and files together in one file, merge, export, and import Microsoft

documents, highlight important points, assign visual codes, capability, analyze qualitative data, and graphic display of the codes (Creswell, 2007). The categories and themes that emerge from the findings were color coded and numbered for ease of retrieval.

Classification nodes were constructed in the node link on the NVIVO software that allows a researcher to create the most commonly referenced comments and their sources. The nodes classification lists the number of references to a particular node as well as the number of sources meaning that one person may have referenced a particular topic more than once. While analyzing the qualitative data at least three unexpected themes arose and are included in the findings in Chapter 4.

Creswell (2007) suggested that three important steps in data analysis was the relevant placement of the data reflected through naming each segment, reflecting the combination of codes into larger categories or themes, and creating graphs and tables reflecting any comparison. The analysis of the data is expected to begin with the creation of files in order to organize and manage the data. The transcripts were entered into NVIVO. All of the journal and field notes from the personal interviews were also entered in order to form any initial codes. The data that were transcribed was done so through Microsoft Word. It was important to develop any significant statements made by the participants in order to assign meaning to the phenomenon.

Creswell (2007) suggested that a researcher first describe their own experience with the phenomenon in order to set aside their experiences so that the focus might remain on the participants. I drafted a description of my own experience with the phenomenon in an attempt to voice my own thoughts. This effort allowed me to put on

paper any thoughts I had about the phenomenon and better prepare me to focus on the participants in each interview. A reflective journal was created in order to make a record of my thoughts on the interview process and of any potential key participant statements for theme foundation that may have emerged.

Interviews were begun in April 2013 and the final interview took place in March 2014. Multiple interviews were scheduled and at the agreed upon time to carry out the interview either in person or on the telephone. Some potential participants failed to answer the phone or did not show up in person to be interviewed. Phone calls and e-mails went unanswered and it was decided out of respect for their wishes no further requests were made to these particular individuals. During the interview notes were taken of any significant/profound statements made by the participants that could be grouped into common themes. A thick description was taken in each personal in-depth interviews of what the participants experienced as they discussed how that experience impacted each of their lives. Lastly, the textural (what the experience was for the participant) and structural (how the experience came to be for the participant) were combined by describing the essence or a summary of the participants' experiences.

It was important to represent the voice of the parents and/or primary caregivers in order to accurately reflect their experiences in seeing that their child maintained positive academic growth. The analyses of the categories were compared to the findings from the literature review. The analysis was purposeful in order to establish the evidence for a confirmation or lack regarding what previous researchers had suggested.

### Threats to Validity

The data were collected in a variety of ways in order to reduce threats to the validity of the study. Ways to enhance the validity of the study were achieved through interviewing participants, digital audio recordings of the participants, my notes, and the survey questionnaire responses. It was important to accurately reflect the content of the participants' descriptions in order to provide an accurate telling of their actual experiences. The transcribing of the data must accurately convey the participants' meanings from the personal interviews; hence, the transcripts were transcribed verbatim.

Once the data were transcribed, discussion was initiated with each interview participant in order to reflect the meaning of their personal experiences. The descriptions of the textural (what), and structural (how) was specific to each participant's personal experience. An attempt was made to convey a clear articulation of the phenomenon examined in order to provide an essence that included a description of the experience and an accurate reflection of the context in which it occurred (Creswell, 2007).

I made a number of attempts to accurately portray the participants' experiences and used the following methods: (a) prolonged engagement, (b) member checking, (c) triangulation of data, (d) use of a thick description, and, (e) use of journal notes. These are some of the ways employed to reduce threats to validity (Nastasi & Schensul, 2005). An attempt was made to insure the transformative value of the research through ongoing appraisal of methods, researcher self-reflection, thoroughness, and objectivity. Ethical considerations were adhered to in all aspects of the research study. An attempt was made

to limit threats to validity by employing the use of digital audio recordings, and notetaking during the personal in-depth interviews.

Potential sampling issues were confronted through the use of gathering an adequate sampling size; comparison samples were sought in similar studies, and use of a consistent data analysis approach across the databases. Purposeful sampling was employed as the phenomenon required individuals and stakeholder agencies as those that maintained an understanding of the research problem (Creswell, 2007). Sample size was maximized through thick descriptions of the participant interviews and documentation of common themes that emerged and finalized in the data analysis.

### **Issues of Trustworthiness**

Avenues to address trustworthiness included continual assessment of the validity and data analysis in order to assure that the study can be replicated for future researchers. The findings provided from the personal interviews were plausible and the descriptions were intended to provide an accurate reflection of the meaning of the phenomenon to the participants. What was attempted was an examination of the consistency of their shared stories through the common themes that emerged. The quantitative findings revealed areas that can be explored further and those included the parent/primary caregiver's opinions about their child's medical and/or mental health provider.

#### **Ethical Considerations**

The ethical considerations included: (a) obtaining informed consent forms; (b) whether to engage in reciprocity with the participants; (c) gaining entry to any field sites where the research takes place; (d) maintaining confidentiality; (e) gaining letters of

agreement with stakeholders; (f) treating participants with respect and not engaging in stereotyping; (g) avoiding deception; (h) protecting a participant's anonymity if desired; and (i) causing no harm. Creswell (2007) pointed out that ethical considerations were to be well thought out through the research study process. The research study was undertaken with vulnerable populations, parents of a child with an autistic condition and his or her family who had likely been subjected to a number of stressors. It was important to communicate to the participants the intent of the study and share the research findings with them. Voluntary participation was sought for the study and explained that they are free to quit the study at any time.

Disclosures to service providers and educators were discussed with the participants. The limits of confidentiality and the option of recording participants during the interview process were discussed with the participants prior to each of the personal in-depth interviews. The potential for consultation with a colleague regarding the information that might be provided to me by the participants were discussed in order to seek the participant's prior consent in the event it is necessary to discuss information that will be provided by the participant. The use of and limits to confidentiality was discussed with the participants in order to determine whether they want all information to remain strictly confidential. At the conclusion of the study, I met with those individuals who participated locally and telephonically with those interviews conducted telephonically in order to wrap-up the study and debrief the participants and determine whether they had any questions. I conserved any relevant notes and it is part of all the available data. The option of scheduling a therapy session due to stress of an interview was discussed with

each of the interview participants prior to the interview and at the conclusion. All expressed they felt that was not necessary but understood the intent and were appreciative.

## **Summary**

This chapter presented information about the mixed method research design and methodology that was used in evaluating the parental experiences, knowledge, and insights into the parent and or/primary caregivers' opinions and feelings about their child's academic experience in the public school classroom environment. The setting, rationale, researcher role, instrumentation, quantitative and qualitative procedures, data analysis plan, potential threats to validity, trustworthiness, and ethical considerations were described. Chapter 4 is a report of the original data and the analysis.

## Chapter 4: Results

#### Introduction

The purpose of this mixed method study was to examine the level of satisfaction of parents and/or primary caregivers of children with the autistic condition in the public school classroom. The phenomenological approach provided common themes, while the quantitative approach revealed the parent and/or primary caregiver's level of satisfaction with the educational services that their child has received in the public school classroom. The parents and/or primary caregivers were asked their opinions on their level of satisfaction with the educational services that their child receives in the public school classroom in order to gain an understanding of their phenomenological experiences in seeing that their child receives adequate educational services. Data were gathered through personal in-depth interviews and a 32-question survey questionnaire, which was available through Surveymonkey.com and a hard copy given to those participants who were unable or unwilling to use the Internet.

Chapter 4 is designed to present and explain the research methods employed to answer the research questions. The online survey questionnaire findings are presented, which answer Research Question 5. The qualitative findings are presented and discussed in order to respond to Research Questions 2, 3, and 4. The research questions and their findings were designed to work concurrently and in an interrelated way between the quantitative and qualitative methods. The mixed method approach was the best suited to conduct the study, answer the research questions, and provide the triangulation of data in the mixed method design.

# Setting

The personal in-depth interviews were conducted with the participants as follows: four in their homes, two in my home office, and two on the telephone. The choice of the setting was left to the participants. The personal interviews lasted from 1 hour to over 2 hours. The researcher interview guide (Appendix H) was employed in order to facilitate research inquiry and influence the focus of the examination of the research questions. One interview participant became emotional at the beginning of the interview when asked what their experience had been in seeing that their child received adequate educational services within the public school. The participant was asked if they would like to stop and postpone until a later date, but they felt they could carry on. At the end of this particular interview, the participant was encouraged to seek the free counseling session with Carrie David, LCPC, but the participant did not feel that was necessary. During the course of another interview, the participant became distracted and being surrounded by their children, was asked if they would like to postpone until another time and they agreed to carry on. The participant had engaged in heavy manual labor earlier in the day and became tired

### **Demographics**

Eight individuals participated in the personal in-depth interviews. Their ethnic background included six European Americans, one African American, and one Mexican American. Five were married and three were divorced. One interview participant was male and seven were female. Two personal interviewees were grandmothers who

provided primary care of a child with autism and the remaining six individuals were the parents.

The survey participants' income levels included 18 individuals within the \$15,000-\$25,000 range, 15 within the \$25,000-\$35,000 range, four within the \$35,000-\$45,000 range, 30 within the \$45,000 and over range, and 11 preferred not to answer the question. The marital status showed 60 participants as being married, seven being single, 10 being divorced, and two as separated. The ethnic background of the online survey participants showed 42 European Americans, two Mexican Americans, five American Indians, four Asian Americans, two other, and 16 preferred not to answer.

## **Quantitative Research Purpose**

Quantitative findings were sought in order to illuminate in a numerical fashion for the purposes of validity the number of participant responses in each designated category regarding level of satisfaction with specific educational services. The quantitative findings were expected to further provide an understanding of the phenomenon for the parents and/or primary caregiver(s) of children with the autistic condition in the public school classroom.

#### **Research Ouestions**

## **Quantitative Research Questions**

Research Question 5: What is the parents and/or primary caregiver(s)' level of satisfaction with the educational services their child receives in the public school classroom in being one that contributes to positive classroom environmental health guided the quantitative portion of this study and examined the parents

and/or primary caregiver(s)' overall level of satisfaction with the educational services their child received in the public school classroom?

Environmental health in the public school classroom includes: (a) adequate academic growth through sensory supports; (b) overhead lighting; (c) noise level; (d) classroom structure; (e) educator knowledge and training about autism; (f) effective communication between the educator and parent and/or primary caregiver(s); (g) successful collaboration between the school administration and other autism service providers such as mental health, physician, occupational therapy, and speech therapy; (h) educator knowledge about resources for the parent(s) and/or primary caregivers; (i) parental participation in the IEP; (j) support from the educator for the child and parent and/or primary caregiver(s); (k) parental and/or primary caregiver(s)' input into their child's daily school routine; and (l) the educator's successful management of the behaviors associated with autism, including psychiatric conditions with accompanying behaviors in the school classroom.

## **Quantitative Procedures**

A 32-question survey questionnaire was administered online through Surveymonkey.com, and the responses were downloaded into the SPSS to analyze and create tables. Frequency distributions, which generated the percentages of the responses into a given category, was best suited to examine one dependent variable (level of satisfaction) by one or more between-subject factors (not at all satisfied, slightly satisfied, somewhat satisfied, very satisfied, or extremely satisfied

### **Quantitative Participants**

A total of 109 participants initially responded to the survey questionnaire on Surveymonkey.com. They consented to the Online Survey Questionnaire by agreeing to its terms (Appendix J). Not all 109 participants consistently responded to all 32 questions. Some agreed to the consent form, but went on to remark that they were not the parent and/or primary caregiver to a child with autism in the public school system, and their responses were eliminated. Some survey participants did not agree to the online consent form, and those surveys were eliminated. Some surveys were eliminated when the participant answered three survey questions or less. A total of 67 to 82 survey questionnaires were useful for the purposes of this study. Of the survey respondents, not all consistently responded to all the survey questions.

# **Quantitative Online Survey Questionnaire Findings**

The quantitative findings of the online survey questionnaire were examined and results are presented below. The questionnaire is in Appendix C. A discussion narrative and tables are used to present the data. The tables correspond to the survey questions. The criteria for participating in the online survey questionnaire was composed of being the parent and/or primary caregiver of a child diagnosed with autism and who was enrolled in a public school. The majority of the participants, 73.4% (*n*=109) of the participants agreed, and 26.6% of the participants did not complete Question 1, making all of the incomplete survey questionnaires ineligible for inclusion; however, the incomplete surveys were analyzed for incompleteness and/or did not respond to the question follow in order to reflect the rate of nonresponsiveness to the survey questions.

Table 1

Primary Care Giver

	Yes	Incomplete
%	73.4	26.6
Total	83	26

*Note*. The questionnaire participants provided 0 No responses.

Survey Question 2 asked participants what their level of overall satisfaction was with the autism educational services their child receives in the public school classroom making it one that contributes to a successful learning experience; 28.6% of the participants did not complete the survey and 3.1% did not respond to the question.

Table 2

Level of Satisfaction With Educational Services Received

	Not	Slightly	Somewhat	Very	Extremely
%	28.6	15.3	12.2	8.2	4.1
Count	28	15	12	8	4

Survey Question 3 explored the participant's level of satisfaction with different services; 36.7% did not respond to the question and/or had an incomplete survey.

Table 3

Extremely Satisfied

	Structure	Knowledge	Noise	Lighting	Communication	IEP	Support
%	7.3	2.8	1.8	6.4	5.5	27.5	11.9
Count	8	3	2	7	6	30	13

Survey Question 4 explored areas the participants felt that they were not at all satisfied with; 28.4% of the participants did not respond to the question and/or had an incomplete survey questionnaire.

Table 4

Not at all Satisfied

	Classroom Structure	Educator Knowledge	Noise Level	Lighting	Effective Communication	IEP on	Educator Support
%	5.5	24.8	6.4	8.3	5.5	11.9	9.2
Count	6	27	7	9	6	13	10

Survey Question 5 sought the participant's level of satisfaction regarding the amount of knowledge and understanding their child's educator had about the autistic disorder; 27.5% of the participants did not respond to the question and/or had an incomplete survey.

Table 5

Knowledge and Understanding Educator has About Autism

	Not at all	Slightly	Somewhat	Very	Extremely
%	32.1	12.8	15.6	5.5	6.4
Count	35	14	17	6	7

Survey Question 6 examined the level of satisfaction regarding the educator's successful management of the behavioral symptoms associated with autism in the public school classroom; 24.8% did not complete the survey.

Table 6

Educator's Successful Management of Symptoms

	Not at all	Slightly	Somewhat	Very	Extremely
%	38.5	7.3	13.8	10.1	3.7
Count	42	8	15	11	4

Participants were asked to answer Question 7 only if they chose the not at all satisfied option in the previous Survey Question 6; 26.6% of the participants had an incomplete survey.

Table 7

Lack of the Educator's Management of Behavioral Symptoms

	Yes	No	
%	43.1	2.8	
Count	47	3	

Survey Question 8 explored which behavioral symptoms participants felt were not well managed by the educator in the public school classroom; 33.7% did not respond to Question 8, and 1.2% did not respond as instructed.

Table 8
Which Behavioral Symptoms are not Well Managed

	Aggression	Easily Distracted	Behavioral Outbursts	Rocking	Self- Stimulation
%	10.5	22.1	25.6	1.2	3.5
Count	9	19	22	1	3

Survey Question 9 examined whether the primary caregiver and/or parent saw an increase in their child's behavioral symptoms since they began attending the public school; 25.7% had an incomplete survey or did not respond to the question.

Table 9

Increase in Child's Behavioral Symptoms

	Yes	No	
%	47.7	24.8	
Count	52	27	

Survey Question 10 examined participants' responses marked yes in Question 9, seeking which behavioral symptoms had increased; 29.2% had an incomplete survey, 1.0% did not answer the question, and 6.4% noted other behaviors not listed.

Table 10
Which Behavioral Symptoms have Increased

	Aggression	Easily	Self-	Behavioral	Rocking	Self-
		Distracted	Injurious	Outbursts		Stimulation
%	16.7	5.2	1.0	13.5	1.0	4.2
Count	16	5	1	13	1	4

Question 11 examined the participants' level of satisfaction with collaboration between the school and other autism service providers such as occupational therapy, speech therapy, medical, and mental health; 1.9% of the participants did not respond to the question, 27.8% had an incomplete survey.

Table 11

Level of Satisfaction With the Collaboration

	Not at all	Slightly	Somewhat	Very	Extremely
%	30.6	12.0	16.7	5.6	5.6
Count	33	13	18	6	6

Question 12 examined whether the participants believe the collaboration between the school and other autism service providers is an effective collaboration that benefits their child. Four participants did not respond (3.7% of the participants) and 26.6% had an incomplete survey.

Table 12

Collaboration is an Effective Collaboration one That Benefits Your Child

	Yes	No
%	37.6	32.1
Count	41	35

Participants were asked specifically in Question 13 which providers were the most effective in collaboration; 11.9% of the participants did not respond to the question, and 26.6% had an incomplete survey.

Table 13

Most Effective Service Provider in Collaboration

	Occupational	Speech	Medical	Mental Health
%	21.2	19.3	6.4	14.7
Count	23	21	7	16

Participants were asked which service provider they felt to be least effective in collaboration with the public school system in Question 14; 11.9% of the participants did not respond to the question, and 26.6% had an incomplete survey.

Table 14

Least Effective Service Provider in Collaboration

	Occupational	Speech	Medical	Mental Health
%	11.9	8.3	23.9	17.4
Count	13	9	26	19

Question 15 examined the participant's level of satisfaction with their ability to participate in their child's IEP; .9% of the participants did not respond to the question, and 27.5% had an incomplete survey.

Table 15

Level of Satisfaction in the Ability to Participate in IEP

	Not at all	Slightly	Somewhat	Very	Extremely
%	11.0	11.9	16.5	21.1	11.0
Count	12	13	18	23	12

Question 16 examined the participant's level of satisfaction with the noise level in the public school classroom; 29.4% had an incomplete survey.

Table 16

Level of Satisfaction With the Noise Level

	Not at all	Slightly	Somewhat	Very	Extremely
%	22.9	17.4	19.3	10.1	9.0
Count	25	19	21	11	1

Question 17 examined the participant's level of satisfaction with the overhead lighting in the public school classroom environment; 29.4% had an incomplete survey.

Table 17

Level of Satisfaction With Overhead Lighting

	Not at all	Slightly	Somewhat	Very	Extremely
%	20.2	16.5	18.3	13.8	1.8
Count	22	18	20	15	2

Question 18 examined a participant's level of satisfaction with the effective communication with their child's educator; 29.4% had an incomplete survey.

Table 18

Level of Satisfaction With the Effective Communication With Educator

	Not at all	Slightly	Somewhat	Very	Extremely
%	11.1	7.0	10.6	8.0	2.5
Count	22	14	21	16	5

Question 19 examined the participants' level of satisfaction with the public school classroom as being one that is positively structured and organized to meet the sensory needs of their child; 1.8% did not respond to the question, and 27.5% had an incomplete survey.

Table 19

Level of Satisfaction With the Classroom Being Positively Structured

	Not at all	Slightly	Somewhat	Very	Extremely
%	29.4	16.5	17.4	6.4	2.8
Count	32	18	19	7	3

Question 20 examined the participants' level of satisfaction with the recommendation suggested by their child's educator to participate in stress reduction activities; 1.8% of the participants did not respond to the question, and 26.6% had an incomplete survey.

Table 20

Level of Satisfaction With the Recommendation to Participate in Stress Reduction

	Not at all	Slightly	Somewhat	Very	Extremely	Not Recommend
%	11.9	11.0	6.4	5.5	2.8	33.9
Count	13	12	7	6	3	37

Question 21 examined the participants' level of satisfaction with the recommendation suggested by their child's educator to attend a parent support group; 1.8% of the participants did not respond to the question, and 27.5% had an incomplete survey.

Table 21

Level of Satisfaction With the Recommendation to Attend a Parent Support Group

	Not at all	Slightly	Somewhat	Very	Extremely	Not Recommend
%	12.8	2.8	3.7	.9	3.7	46.8
Count	14	3	4	1	45	51

Question 22 examined the participants' level of satisfaction with the recommendation suggested by their child's educator to attend classes for parental training in autism; 1.8% of the participants did not respond to the question, and 26.6% of the participants had an incomplete survey.

Table 22

Level of Satisfaction With the Recommendation to Attend Classes for Parental Training

	Not at all	Slightly	Somewhat	Very	Extremely	Not Recommend
%	17.4	9	3.7	1.8	1.8	47.7
Count	19	1	4	2	2	52

Question 23 examined the participants' level of satisfaction with the amount of educator support received by them and their child; 2.8% of the participants did not respond to the question, and 26.6% had an incomplete survey.

Table 23

Level of Satisfaction With Amount of Educator Support Received

	Not at all	Slightly	Somewhat	Very	Extremely
%	29.4	13.8	13.8	11.9	1.8
Count	32	15	15	13	2

Question 24 examined whether the participant's child has severe behavioral symptoms, and whether the participants observed a decrease in the educator's support of them and their child; 15.6% of the participants assumed the child had no severe behavioral symptoms and did not respond to the question for that reason, and 23.9% had an incomplete survey.

Table 24

Have you Observed a Decrease in the Educator's Support

	Yes	No	
%	29.4	31.2	
Count	32	34	

Question 25 examined whether the participants who had children with severe behavioral symptoms had an increase in educator support; 15.6% of the participants were assumed to have a child with no severe behavioral symptoms, and 23.9% had an incomplete survey.

Table 25

Have you Observed an Increase in the Educator's Support

	Yes	No	
%	19.3	42.2	
Count	21	46	

Question 26 examined whether the participant's child had been diagnosed with a psychiatric disorder; 28.3% did not have a complete survey. None of the participants chose schizophrenia which was an option and is not included in the table.

Table 26

Has Your Child Been Diagnosed With any of the Following Psychiatric Disorders

	Anxiety	Depression	Mood	Elimination	Bipolar	Sleep
%	27.3	4.0	1.0	1.0	1.0	1.0
Count	27	5	4	1	1	1

Question 27 examined the participant's level of satisfaction with the educator's management of psychiatric symptoms in the classroom if their child had a psychiatric disorder; 30.3% of the participants did not respond to the question, and 26.6% had an incomplete survey.

Table 27

Level of Satisfaction With the Educator's Management of Symptoms due to Psychiatric

Disorder

	Not at all	Slightly	Somewhat	Very	Extremely
%	23.9	8.3	7.3	1.8	1.8
Count	26	9	8	2	2

Question 28 examined the participants' level of satisfaction with the educational services their child receive in the public school classroom making it one that contributes to a successful learning experience; 3.1% of the participants did not respond to the question, and 28.6% had an incomplete survey.

Table 28

Level of Satisfaction With the Educational Services Making it one That Contributes to a

Successful Learning Experience

	Not at all	Slightly	Somewhat	Very	Extremely
%	28.6	15.3	12.2	8.2	4.1
Count	28	15	12	8	4

Question 29 examined the participants' level of satisfaction with the consistency of the educational services provided to their child in the public school classroom; 4.0% of

the participants did not respond to the survey question, and 27.0% had an incomplete survey.

Table 29

Level of Satisfaction With the Consistency of the Educational Services Provided

	Not at all	Slightly	Somewhat	Very	Extremely
%	24.0	21.0	8.0	12.0	4.0
Count	24	21	8	12	4

Demographic questions were asked of the participants and are contained in the following tables; 14.1% chose not to respond to the question.

Table 30

Yearly Income

	15, 000-25,000	25, 000-35,000	35, 000-45, 000	45, 000 and above	Prefer Not to Answer
%	23.1	19.2	5.1	38.5	14.1
Count	18	15	4	30	11

Table 31

Marital Status

	Married	Single	Divorced	Separated
%	75.9	8.9	12.7	2.5
Count	60	7	10	2

There was a question regarding ethnic background; 15.5% preferred not to answer the question and 33.0% did not respond to the question and/or had an incomplete survey.

Table 32

Ethnic Background

	European	Mexican	Indian	Asian	Prefer Not to Answer	Unknown
%	40.8	1.9	4.9	3.9	15.5	33.0
Count	42	2	5	4	16	34

## **Qualitative Research Purpose**

Qualitative personal in-depth interviews were conducted in order to explore parental and/or primary caregiver(s)' opinions regarding the educational services their child receives in the public school classroom. The mixed method design might afford the opportunity for triangulated data that either provided significant findings supporting the research question or did not support the research question.

# **Qualitative Research Procedure**

Specific research questions were administered to each participant who participated in the in-depth personal interview. The researcher interview guide was used to inform the participant of the following:

- Purpose of the study
- What personal information was being collected
- How the responses will be used
- Whether the responses will be disclosed to anyone else

## **Qualitative Interview Participants**

Interview participant 1 is a grandmother and primary caregiver to a 12 year old boy diagnosed on the ASD. Interviewee 1 has been an integral part of initiating

educational services for her grandson since he was diagnosed with autism between the ages of 2 to 3 years. Interviewee 1 emphasized that the entire family uses a team approach in his care and the team consists of the Mother, Grandmother, Grandfather and a sister who does not live locally. Interviewee 1 and her husband are retired and have been at home with their grandson since he was an infant which allows his Mother to maintain full-time employment. Mother was present at the interview and was able to interject some valuable information regarding her son. The family truly acts as a team in their care for their child. Interviewee 1 is very knowledgeable about autism and has consistently engaged in trainings to learn and constantly reads research and books about the condition which she shares with "the team." Interviewee 1stated that their grandson is very independent and intelligent and she swears he could read at the age of less than 1 year. She saw him pull out a Dell ad from their newspaper when he was sitting in his high chair and he picked it up. Interviewee 1 stated that most babies would put it in their mouth but her grandson picked it up and it appeared that he was reading it front to back as he flipped the ad over in his hands. Their grandson has limited verbal skills which they are working on in the public school classroom. Their experience has changed their lives.

Interviewee 2 is the Mother of a 5 year old girl diagnosed on the ASD.

Interviewee 2 is married and she and her husband have one other female child who is approximately 4 years older than her sibling with autism. Interviewee 2 stated that her daughter had normal development until between the ages of 18-24 months at which time she felt her daughter was behind on some developmental milestones. It was not until her daughter turned 2 that the developmental delays became extremely obvious. She and her

husband knew nothing about autism when their daughter was diagnosed and she immediately initiated action by going from speed 0 to 100 mph in order to read all she could about the disorder to help her daughter. Interviewee 2 has concerns about the lack of speech and occupational therapy needs in the rural community in which she lives. Interviewee 2 and her family are recipients of the services of the Montana Autism Waiver program and she states they have seen positive improvement in their daughter through that program. Interviewee 2 describes her daughter as requiring structure and purpose in her daily routine. Interviewee 2 stated, "In play therapy you come into their world and convince them to want to come into yours. They teach them to climb the ladder." The experience has changed their lives.

Interviewee 3 is a single divorced Mother with a 13 year old son diagnosed on the ASD at the age of 3. Interviewee 3 also has a daughter who is 3 years old. Interviewee 3 emphatically stated that her son was reading between the ages of 2-3 and had not been taught the skill. Interviewee 3 stated she knows this because he would pick up books and sit and go through the pages while other children would be playing with toys. Interviewee 3 stated she did not teach her son to read and he was reading doctor's manuals by the age of 5. Interviewee 3 has been solely responsible for seeing that her son's educational and academic needs are met since he started elementary school. Interviewee 3 struggles with her son in that he is only interested in learning about things that interest him which makes his academic progress a challenge, particularly math. Interviewee 3 has concerns about her son in his ability to succeed in life and feels that teachers let him slide through too much of the educational assignments because they don't want to deal with him or her.

Interviewee 3 expressed her frustration that her son is being bullied and nothing is being done to alleviate the problem at school. Interviewee 3 expressed concerns that due to her son's intelligence he should have been moved ahead in the classroom in order for his academic needs to be met. Her son suffers from a muscle condition that prevents him from engaging in exercise which has resulted in weight gain. This makes her son very self-conscious. Interviewee 3 expressed that the educators are not meeting her son's needs because they are "just passing him" and not challenging him academically and she fears how this will affect him in the future world of self-sufficiency and gainful employment.

Interviewee 4 is married and the primary caregiver for a 14 year old son with autism. When their son was diagnosed on the ASD at the age of 2 their first reaction was disbelief so they took him to a neo-neurologist in Billings, MT who confirmed the diagnosis. They had never heard of autism and knew nothing about the disorder. Their son never spoke a word until age 4 and would point to things he wanted. Interviewee 4 is an elementary school teacher and with the assistance of an aide, she pulled her son out of the public school he was in and she placed him in the school where she teaches. The aide stays with him during the school day. Interviewee 4's son wears specially made feet braces to counteract the effects of walking on his tip toes.

Interviewee 5 is the father of a 12 year old girl diagnosed on the ASD and currently attends the special education class in the public school. When Interviewee 5's daughter first began to attend the public school in California the school would send her home frequently rather than knowing what to do with her special needs. Interviewee 5

has two older daughters living at home and they are eager to participate in meeting their sister's unique needs. Interviewee 5 moved to the area a few years ago and found that the autism educational services in the community were backwards compared to those his daughter and he had received in California so he feels he has had to spend a large portion of his time educating them about autism. Interviewee 5 feels as a taxpayer he has the right to demand that the school system provide what they are legally obligated to in regards to meeting his daughter's educational needs.

Interviewee 6 is remarried and has a 14 year old son who was diagnosed on the ASD at the age of 5. Interviewee 6 and her son's father have been divorced since he was age 2. Interviewee 6's primary concern for her son is that he has no friends and was told he spends his time alone while at school which upset her and she felt this situation contributed to his diagnosis of depression. Interviewee 6 had requested the teachers begin to pay attention to this situation and attempt to engage him in activities. She reported that her son avoids teens his own age and prefers to spend time with those younger than he. Interviewee 6 fears there may be bullying going on and has concerns about her son isolating himself. Interviewee 6 stated there is familial depression and she and her son are both on antidepressants for the condition. There are also concerns about the educators providing her son with adequate schoolwork because the educator does not follow through on providing work he could be doing during study hall. He often sits in study hall with nothing to do. Interviewee 6 stated her son has a history of emotional problems for which he has been under the care of a mental health therapist.

Interviewee 7 is the grandmother and one of the primary care givers to her 6 year old grandson who was diagnosed on the ASD at the age of 16 months. Interviewee 7 reported that the boy's pediatrician felt something was not right at the age of 12 months and the official diagnosis arrived 4 months later after specialists were able to evaluate him. Interviewee 7 said she noticed it months earlier when the boy would not make eye contact with her when she would hold him and talk to him. Interviewee 7's daughter lived with her for a large portion of the boy's life as her daughter and son-in-law divorced when the boy was very young. Interviewee 7 reported that her grandson was nonverbal until the age of 3. Interviewee 7 stated she knew very little about autism when his parents received the diagnosis. Interviewee 7 reported that a diagnosis of autism and the aftermath created a strain on the couple and the marriage ended. Interviewee 7 reported that up until this past school year her grandson had received the service of an in classroom aide but that ended this year which upset Interviewee 7 as she felt her grandson could benefit from this service. Interviewee 7 discussed at length the supportive compared to nonsupportive educators during the course of her grandson's education.

Interviewee 8 is a single divorced Mother of a 13 year old son diagnosed on the ASD at the age of 18 months. Interviewee 8 noticed her son was not keeping up with his developmental milestones at age 12 months and she became fearful at the age of 18 months when it seemed "as if someone had pulled the shades and he became just dull, and retreated into a box." Interviewee 8 stated the diagnosis left her devastated as this was not what she had hoped for her son; she did not have the healthy baby she thought and stated she had all these great ideas about what great things her child would do and

what a great life her child was going to have. Interviewee 8 immediately wanted to know if there was a cure. Interviewee 8 discussed at length the demise of her marriage due to her husband's denial of their son's condition and the struggles she has had in seeing that his educational needs are met in the public school classroom.

## **Qualitative Personal Interview Findings**

The researcher interview guide was designed to facilitate the personal in-depth interviews with each participant. The guide contained pre-planned questions designed to foster discussion about the parent and/or primary caregiver's experience in seeing that their child received adequate autism educational services in the public school classroom. Upon completion, the interviews were transcribed and shared with each participant for member checking and then coded in the NVIVO software program to examine the content for any emerging themes and examined personally for emerging themes.

## **Interview Participant Crucial Comments and Emerging Themes**

Qualitative Interview Question 1 – What is the lived experience of the parents and the process they underwent regarding the adequacy of current educational services their child received in the public school classrooms? The first personal interview question asked the parent and/or primary caregiver(s) what the experience and process was like and what they underwent in having a child with autism in the public school system. While the theme of adapting to a diagnosis of autism was not as prevalent as others, this topic is important for the parents and/or caregivers of a child with autism because it is an emotionally charged experience in this life changing event. The forceful event affects the lifestyle of the entire family, including grandparents who are likely to be involved in the

future care. The insights gained by the parents and/or caregivers have the potential to contribute to ways that assist those with newly diagnosed children with autism.

One of the primary concerns expressed by more than one interview participant was what would happen to their child with a lifelong autistic condition. The interview participants expressed their concerns for their child when they reach adulthood and stated that it is important for their children to learn life skills in order to maintain a quality of life, whether they live on their own or in a group home. The emerging theme of a diagnosis of autism with its accompanying challenges and need for life changing adaptive skills is reflected in the following personal interview statements.

Interviewee 1: Well for one thing we found out that we have this autistic person. I have always loved education. Actually, I was on a school board for four years and it just really threw me into some new interest. I was still working and my husband was retired. We were trying to share all of the caregiving so I quit working. I retired but I was 67 so it was ok and I just started learning as much as I could about it personally. I had had four children and I have five grandchildren. I have three great grandchildren. This was just a different angle rather than a typical thing. It was interesting and has been interesting. We adore him so you know it just meant we had to change our lives but I think it is pretty good when you are older to have to adapt to something new.

Interviewee 2: Well, it has been life changing, obviously. My daughter developed pretty normally until about 18-24 months. We started to have some concerns but she was still in the realm of normalcy on the charts. We actually personally

expressed our concerns to her pediatrician but there just wasn't ... but nobody felt she was behind enough to really merit concern especially with being the second child. Our first child talked, talk, talk, talk, talk so, of course everyone thought that she was just talking for our daughter with autism and that is why she did not want to talk. Once she turned two, between the ages of two and three is when it became extremely obvious that there was something wrong. She was officially diagnosed. The pediatrician finally agreed something was wrong when she turned 3 and she wasn't speaking and it was obvious at that point that something was wrong. I had been researching it a ton because I was worried and that is the first thing that comes to mind is autism. They are not speaking. Well, the first thing that comes to mind is that they are deaf or something like that but it was obvious that she could hear. She just was not talking. At three is actually when she went through the testing and was diagnosed. At that point it went from 0 to 100 miles an hour.

Interviewee 4: DEAP first came to diagnose him with autism. He would sit at the fridge and bounce the ball off the fridge all the time. We went to two clinics over at the hospital and they diagnosed it but we didn't want to believe it so we went to the doctor, you know and the neurologist diagnosed him in Billings. He wouldn't speak at all. He wouldn't talk. He would point. We didn't know what it was. We had never heard of it and we were surprised. We didn't want to believe it. That is why we went and tried to get another diagnosis, doctor to doctor, you know. Yes, it was hard.

Interviewee 7: I noticed it mainly, I guess because I have so many children in my extended family (I was accustomed to more typical behavior). When I would talk to him I couldn't get him to make eye contact like you usually do when you are talking to infants and that they are just mesmerized by your face and your expressions and when I talked to my husband he told me I was nuts. I was reading too much into it that there might be something wrong. We didn't know it was autism. I just thought it was very odd that I couldn't get him to maintain eye contact with me.

Interveiwer: Did you know anything about autism at that time?

Interviewee 7: My sister has a niece who has Asperger's and so at that time I knew a little bit about Asperger's and I had heard a little about autism but knew very little, if anything.

The overall classroom structure is felt to be positive by parents and/or caregivers. The structure includes whether the classroom is designed to lend to the student's need for routine, incorporating things such as a cubicle for their belongings and a consistent routine from the time they arrive at school. Interview Question 2 examined the parent(s) and/or caregiver(s)' level of satisfaction regarding the following: (a) the quality of the classroom structure which included organization, classroom structure, overhead lighting; (b) management of behaviors associated with the autistic condition; (c) educator knowledge about the autistic condition; (d) noise level; (e) educator management of behavioral/psychiatric symptoms; (f) effective communication with educator; (g) participation in the IEP; (h) support from the educator for the parent and the child; (i)

satisfaction with the educator's level of training in autism; (j) satisfaction with the educator's knowledge about autism; (k) educator's knowledge of mental health issues common in autism, educator's knowledge of programs designed to reduce parental stress, support groups and training in autism for parents; (l) the availability of an integrated treatment approach consisting of mental health; (m) occupational and speech therapy; (n) and opportunities for expression of parental input into daily activities based on parental knowledge about their autistic child. Interview participants and those who commented in the online survey questionnaire are included and outlined.

Qualitative Interview Question 2 - What is the opinion of the parents regarding the quality of the classroom structure for their child?

The parents and/or primary caregivers who participated in the personal interviews expressed overall satisfaction with the classroom structure. Table 3 of the survey data showed eight (n=69, 7.3%) respondents are extremely satisfied with the classroom structure while Table 4 reveals six (n=78, 5.5%) respondents are not at all satisfied. Table 19 showed that 32 (n=79, 29.4%) survey questionnaire respondents are not at all satisfied with the public school classroom as being positively structured and organized to meet the unique sensory needs of the autistic student. The interview participants stated the following.

#### Classroom Structure.

Interviewee 1: It is so set up. They are the ones that are so good at cubicles. As he grew up he always had a little space of his own and we made sure those spaces existed. They still do; hither and you in the house where he can do his thing and

they have that at the school. They have the desks where they can sit and do their work like their spelling. They have their little computer and they have computer areas. They go into a little kiosk.

Interviewee 2: After the first hour she goes to a different classroom. Last year they actually did set up a whole classroom just for her. It was actually an old janitor's closet. It was big. She needed that. She was so distracted by everything else. Just a table and they had a curtain so they could hide all of the toys and stuff that they used for her.

Interviewer: So, it was real structured just for her?

Interviewee 2: (Nods head). She needed that. At this point now she is in the regular speech room and she goes after the first hour. K, who is the director of special ed., she takes her and they do more play-based activities. They virtually work on the same thing but not like the specific speech she has the first hour. In K's room they have coat hooks, all that. They still use thumb tack pictures. They have a board. They let her know what she is going to be doing.

Interviewer: Does she respond to all of that?

Interviewee 2: Yes, she likes it. She likes to know.

While the structure may have been suitable, the parents and/or primary caregivers stated that the overall organization of the classroom was in need of improvement. In survey Question 19, levels of satisfaction were sought for the combined structure and organization of the public school classroom and findings reveals 32 respondents (n=79, 29.4%) are not at all satisfied and 3 (2.8%) are extremely satisfied. The survey

respondents suggested that the need for a classroom aide is imperative in order for their child with the autistic condition to succeed academically in the classroom environment. In the following statements by the personal interview participants, some reflect on the issues they have with classroom aides as well as their opinions of the classroom organization. They went on to discuss those areas where they feel the aide would be beneficial for their autistic child.

### **Classroom Organization.**

Interviewee 1: The only thing that I can say is there is difficulty with some aides. Some of the aides have had problems. This year has been more difficult. Well, one's husband died and that has been emotional. He takes on emotions. We weren't really sure... He knows if something is wrong. The undercurrent of emotion; he reads that and he knows if somebody is unhappy and they are not having a good day. That makes him a basket case. He takes it on. It throws him off when they are not 100%. On the other hand, that throws the family off. Those types of things throw typical children off but it is that he has trouble expressing the sorrow or whatever is happening but I think it has been a bit of a problem everywhere having the continuity of their aides. He adapts better to some aides than to others and that is probably because of the extent of experience on the part of the aide, I would say. An area I always thought should be focused on is some aide training because it would really be helpful for them. Another thing is schools have their hands full.

Interviewee 3: Because they don't want to have to deal with the extra work. Is it really that much extra work? I mean, really? He has the worst organization problems and this has been an issue since kindergarten. Every year, every teacher, he cannot seem to keep himself organized. They cannot seem to trouble themselves to help him with that. The organization part; that is not happening at all and it frustrates me that they can't do anything about it. He is a special needs child and just because he looks normal and he acts normal and he is really smart doesn't mean he doesn't need help in certain areas. Organization is at the top of the list. I mean, it is way up there and I don't know what else I can do to do to get them to help him with that.

Interviewee 5: Yes, she has an aide. I told them M is just with her and that's it because I have a say so on that. I pay my taxes so I want what I want. They said, "No problem." She has been to every school with her. She is even going to go into the junior high with her and she is hoping she will be able to make it to high school with her. Her aide is really good always. I go in there and I stand in the door and I watch and they are doing all kinds of things. They shouldn't just pick up ones that say, "Well, she's an aide." She isn't just an aide to any kid, if that kid doesn't have any autism or Asperger's how are they going to know how to work with her? They (the aides) are going, "Why is he or she doing this?" I know. I don't understand. Why are they working with the kids with autism?

Interviewee 7: I mean, this year it seems to be doing much better but his first year after the first month the school couldn't handle him and so they would only let

him come to school one hour a day. After three or four weeks they would up it by a half hour and it wasn't until the last two weeks of school that he got to go full-time and that was only at my daughter's insistence. If my daughter hadn't called OPI he would not have had a full-time aide even though it was in his IEP. It was six weeks into school and she had to call OPI and the next day he had an aide and it was only because she called OPI and got them involved. The reason we were pushing for some kind of mainstreaming is when he is around other children, more typical children he acts like them, he talks like them.

Interviewee 8: I think it depends on the individual teacher. I have been in some classrooms where it is very organized. You know what is going to happen today because it is posted on the board and upcoming tests are on the wall. I think that people who are extremely organized and you can see how that benefits the children. Personally, I think teachers who can't find their own identification in their wallet and they are supposed to be the ones with the knowledge. They had to get organized because I told them. I said, "Listen, the key to my son's success is pure organization. He is autistic. It all has to make sense. It has to be consistent. It is like Ground Hog Day in some ways. It is like Ground Hog Day. We have a huge calendar on the wall and everything that B has to do is on that calendar. If it is not on the calendar it is not going to get done. If you can't plan for it, it is not going to happen so in order for me to put it on the calendar with some reasonable sense of getting it done we have to have some leeway on that so that's been really

great. It sort of bled over into their overall planning and helped their classroom in general.

Parents and/or caregivers whose child was not given a dedicated aide had the following to report:

Interviewee 1: I think it has been a bit of a problem everywhere having the continuity of their aides. He adapts better to some aides than to others and that is probably because of the extent of experience on the part of the aide, I would say. An area I always thought should be focused on is some aide training because it would really be helpful for them.

Interviewee 3: There is no organization which he is expected to do on his own which he cannot do on his own. He needs help. He needs hands-on supervision. He needs someone to do it for him literally. I know that the use of an aide would come in handy with him. Not only would it keep him on task since he is easily distracted because he would rather be doing something he wants to do than paying attention in the classroom. They don't have an aide available and if they do have one available it goes to somebody who is low functioning, not somebody who is high functioning. They consider him too high functioning to need an aide.

Interviewee 7: He got a new teacher and from what I understand there is only one aide and instead of having seven or eight kids in the classroom now there is 13 and the aide that was his aide was helping out part-time in the resource room and part-time in the classroom but now my understanding is that she works mostly in the resource room and there is just the one aide in the classroom. It makes me

pretty angry. I have to say that all the aides that were in that classroom were absolutely fantastic with the kids. He does not have his one-on-one aide. His other grandmother told me she feels he is being warehoused because there are not enough aides.

As suggested by Shore (n.d.), overhead lighting does affect students on the ASD. It has been included in this study to examine whether the parents and/or primary caregivers agree with Shore's statements on the overhead lighting in the public school classroom. Twenty-two (n=77, 20.2%) survey questionnaire respondents reported they are not at all satisfied with the overhead lighting in the public school classroom. Two (1.8%) survey questionnaire respondents are extremely satisfied.

# Overhead Lighting.

Interviewee 2: Now the elementary school has a different sort of lighting. The elementary school gym, she just loves to go in there, just loves, loves, loves it. It is the middle school gym that it just depends on the day. There are some days when she is having a good day she can handle it. There is no problem but she has had many a meltdown in that gym where she just freaks out. I know it is the lights. It is a horrible kind of lighting and does not do anything for you. I hate it. I don't think it handicaps her in any horrible way but I do think it certainly affects her. I can tell that it affects her.

Interviewee 4: I think it is. I know it used to affect him. He used to squint sometimes with the fluorescent. Well, his aide is amazing. She found these

yellow tinted glasses at the Dollar Store and she had him wear those for a while and those helped him.

Interviewee 8: I think as he has gotten older it has become more of an issue for him. There was a time I thought he had some vision problems because he was lethargic. He would come back from school and say, "I am lethargic." I would say, "Well, what happened today?" "Oh, it was just horrible at school. It's just murder." "Well, what's happening" I would say. Well, I came to find out after lots of questioning that the entire classroom setting was exhausting to him. In this particular school some of the classrooms do not even have a window. So the overhead lighting was even more of an issue because there was no natural lighting to go with it. I asked that he be placed in the library where there was lots of windows and better lighting so that he could better understand. He was just so tired when he came home from school and you know, I understand but I think it was a teacher's aide, not even a teacher that said to me, "Well, you know, it could be the lighting. A lot of kids in here get headaches. A lot of kids get eye strain. It could be that there is not enough natural light in here" so I think it is an issue. I think it is an issue not only in this school. I think it is an issue in a lot of places. People don't realize the impact it has on them.

As Schopler (as cited in ASA Advocate, 1994) pointed out, training professionals must understand that the comprehensive problems by autism had been raised regarding their own background in specialty training in order to address the whole child. Schopler felt it was necessary to include the views of parents in the educational planning for

autistic children. When it is understood by educators that sensory deficits are likely the cause of behavioral outbursts in the public school classroom those educators are likely to be aware of and utilize positive methods, such as the TEACCH program in order to reduce the occurrence.

The potential for accompanying behavioral/psychiatric symptoms is addressed separately in order that it is understood that the student with the autistic disorder often suffers from severe behavioral challenges which might be compounded by a psychiatric diagnosis, such as anxiety and depression. There were some parents and/or primary caregiver(s) who were not aware of the potential for psychiatric disorders. It is beneficial that educators, service providers, and parents and/or primary caregiver(s) are aware of the potential in order to provide a wide array of beneficial services in order to improve their quality of life.

At least half of the interview participants felt that improvement is needed in the educator classroom management of the behaviors associated with autism. The survey questionnaire findings revealed that 42 respondents (n=80, 38.5%) are not at all satisfied with the educator management of the behaviors associated with autism in the public school classroom while four respondents (3.7%) are extremely satisfied. This question was further explored in the survey questionnaire by inquiring whether the survey respondents feel the lack of successful management of the behavioral symptoms associated with autism are the result of a lack of training.

In Table 7, 47 (n=50, 43.1%) agree and three (2.8%) disagree. In Table 8, narrowing down precisely which behavioral symptoms are felt not to be well managed

includes easily distracted (n=56, 22.1%); 19 survey participants chose and 22 (25.6%) chose behavioral outbursts. Table 24 shows an additional question regarding whether the parents and/or primary caregivers observe a decrease in educator support when their child has severe behavioral symptoms. Thirty-two (n=66. 29.4%) responded yes and 34 (31.2%) respond no. Table 25 showed whether educator support increases if their child has severe behavioral symptoms. Twenty-one (n=67, 19.5%) respond yes and 46 (42.2%) respond no. The personal interview comments are as follows.

## **Educator Management of Behaviors.**

Interviewee 4: When there is someone screaming and hollering, it bothers him. He gets nervous. When he was younger it used to set him off. I think it would now if it happened all day, the screaming. I think that will set anybody off, you know if you had to go through that, you know. They have removed this kid from the room. They put him somewhere else with an aide. He doesn't know what to do right now. I think he is going to get goofy. That is kind of what he does. He gets silly when my Family Support Specialist comes from DEAP. He gets goofy because he doesn't know, "Are they going to work with me?" He doesn't know really what's going on so he just starts hollering and getting goofy.

Interviewee 5: Well, they take it a little easier with them. They make them sit on the floor, criss-cross their legs. Sometimes that isn't a good way to punish them more or less. When she licks, they will tell her, "sit on the floor, criss-cross your legs," well she is doing it for a reason. She is doing it because of her OCD. She

has that badly sometimes. I don't think it is really working. I would rather have them find a different alternative than put her on the floor.

Interviewee 6: I really don't feel they are managed at all. I mean I think kids with autism are labeled from the start. I mean, he doesn't have it as bad as some of the other kids because he is up a little higher but any kid that I have known with autism when they act out or whatever, out in the hall, it's out in the hall and sit in the hall by yourself. I understand autism, you need peace, you need quiet, you need to calm down but let's stick them in the hallway so all the kids that are going to the bathroom or are going from another classroom can see them and laugh at them? That just didn't make any sense to me. It's like, "Take them into the counseling center or take them," I mean, I have noticed kids with autism and some of them have it so bad they bang their heads or they try to hurt themselves. Interviewee 8: I feel that the teachers don't understand the behavior so a lot of teachers shy away from the behavior or they just simply ignore the student because they don't understand the behavior. They don't understand the echolalia. They don't understand the repetitive nature of conversations that you can have with autistic people.

The parents and/or primary caregivers feel the classroom noise levels are a likely contributor to the student's inability to comprehend the educator's academic demands. Since it falls within the sensory input it is important to have educators who are aware of how the noise levels affect students on the ASD. Twenty-five (n=77, 22.9%) of the survey participants are not at all satisfied with the noise level in the public school

classroom and nine (1%) survey questionnaire respondents are extremely satisfied. The personal interview participants stated the following.

#### **Classroom Noise Level.**

Interviewee 1: Noise level is something that a little autistic person is always going to have to deal with. You don't know. He could be sitting here listening to music and you could have it blasting and he isn't covering his ears or anything but you can walk into the school; it is the acoustics. They have had an experience at school when they were going to do the Christmas play and he jumped off the stage. I have had it explained in a book where it was suggested to visualize a room that is full of people and you are autistic and you are standing in the center. All of these people are talking and it is like someone else is trying to tell you something over the talking. It is absolutely excruciating. We understand and if I see a thing where he kind of wraps his arm up and over his head we try to avoid that. It can be excruciating for him. It can precipitate a rumble into a rage. Interviewee 3: (When asked about the classroom noise level and whether the noise levels affected her son, she gave the following response): Not much in the classroom but after watching my poor child have a meltdown at the Christmas program here this school year, I put my foot down. Last year he was sick so because while he is standing up on that stage and everybody is singing, it is so loud and it is so much he was bawling his head off but yet if he doesn't go, he doesn't get a grade for it. This year I made sure within his IEP that he not have to do that. Ok, granted some special needs children don't want to be left out. Well,

my son doesn't want to be put in that position. I mean, I feel sometimes that the parents don't want their children to be left out not so much the child doesn't want to not be there. You know, more power to them.

Interviewee 7: I think that there is room for growth there. The level of noise is much better this year and how that came to be was how they moved his classroom to where they did I am not sure but it is a much better situation. It is much quieter and they recognize the fact that sometimes they let him go into this other small area that they use as his classroom now so he can do that. This year it is much better. It is kind of off from all the other classrooms. They moved it behind the principal's office and the doors close on both ends of the hallway leading to it and the only other thing back there was a bathroom and a small conference room where we would do the IEP and now they get to use that conference room as part of the classroom. There is no distraction at all and less noise whereas his old classroom was right across the hall from the gym and by the doors coming into the building so I think the level of activity there because he hears everything; the kids in there I swear a mile away. I think that was a real distraction for him whereas now he is in a much quieter area.

Interviewee 8: I think it is too high. There are many classrooms where the kids are going awry. They are screaming and hollering, you know. The teacher is screaming and hollering at the kids. They are like shocked at a parent standing at the door. It's like an incubated environment. They don't ever expect a parent to appear in the middle of the day. They don't really know what is going on but yes,

I have seen some of the teachers screaming and hollering, "Sit down and shut up" and "Oh my, I don't even talk to my own kid like that at home." I think they need some classroom management skills.

The challenges that lie with professional caregivers and families are often overwhelming due to the severity of the behavioral symptoms. The behavioral symptoms are often accompanied by psychiatric symptoms, such as anxiety and depression and might present potential barriers to a quality of life consisting of social, behavioral, and educational factors. Some interview participants did not realize there is potential for a great deal of anxiety and/or depression for their child with autism.

The survey questionnaire data in Table 26 showed whether the parents and/or primary caregiver(s) had an autistic child who had been diagnosed with a particular psychiatric disorder. Twenty-seven (n=39, 27.3%) responded that their child has been diagnosed with anxiety and five (1%) responded that their child has depression. Table 27 shows the level of satisfaction with the educator's classroom management of those psychiatric symptoms in the public school classroom. Twenty-six (n=47, 23.9%) are not at all satisfied while two (1.8%) are extremely satisfied. Those parents and/or primary caregiver(s) who are aware of the potential for anxiety and depression, the most common psychiatric disorders among the population made the following comments.

### Educator Management of Behavioral/Psychiatric Symptoms.

Interviewee 3: Not with Mr. B and Mrs. W but Mr. Y has been his homeroom teacher for the last 2 years because he moved up with him, thank God. He has been really good for him as far as being laid back and not being too hard on him

for not conforming whereas, it could have been a lot worse because imagine him having Mrs. W for his homeroom teacher. She has no compassion, not empathy, no nothing. She is just hard as nails and really acidic, acerbic or whatever they call it. I got him in treatment. He has had it at mental health. They only offered him a chemical dependency counselor when he was only 6. I wanted him to be with a male because he has a way of wrapping women around his finger so I figured a male would be a better choice. Well, obviously there is not a lot of male psychologists in this town for whatever reason so since then he has been, we went with YDI because they had three of them (women) within a short span of time and that is hard on him. Kids do not like change so he has to sit there and start over and over again with a different person all the time and it is so hard on him. So, when he got in with this current one Darcy, she was going to have to discontinue because she found out she wasn't going to get paid because of whatever reason. She went to the mental health center and he is back with her because she said she had to go with a different agency and you will have to find someone else. He is like "if I can't have you, I am done with this. I am not going to go through another counselor." He said, "I am not doing this anymore."

Interviewer: So, he received treatment for social anxiety; what else?

Interviewee 3: Depression. I got him into therapy because at 6 years old the stresses at school were already making him suicidal.

Interviewer: So, did he have suicidal thoughts? Did he receive treatment for that as well? That is usually tied into the depression.

Interviewee 3: Well, yes they talked to him. I don't know what they talk about because it is confidential. I do know that I made the therapists aware that when he gets stressed out he gets anxious and he gets angry and the first thing that comes to his mind is to try to kill himself and I don't know how to deal with that because that is my coping mechanism. How do I nip that in the bud? I mean, I can't ignore it and at the same time I can't exacerbate it. A lot of people say, "Oh, just blow it off; don't give him attention on that issue because they are going to think that is a way to get what they want." At the time there has been enough suicide in my family that you can't just ignore it.

Interviewee 6: Yea, and I have got... well, and he is getting it double time with both parents with depression. I tried to kill myself and his Dad did and my Grandma and both my Mom have depression and so it was inevitable that he was going to get depression anyways which he does have. They are not managing it. They are not taking care of it. They know that he is in AWARE and he goes and sees P (counselor) so why can't the teachers say, "Go to P and say hey P we are a little concerned about R because he is sitting by himself at lunch. Do you, maybe you should talk to his Mom," you know? It's just like they push the kids through the school.

Interviewee 8: I think that there is a very small group of people in the public schools that are trained in behavioral therapy, in general and of course, they are a part of the parent team at the IEP. There is the behavioral therapist, speech therapist. They are sometimes referred to an outside psychiatrist or psychologist

but in the classroom I think those resources are lacking. I don't think there is enough of a focus on that for a lot of kids in a lot of situations and consequently, and again in a sort of square box approach to everything. If a kid does this then this is what happens but there is no overall analysis.

Much of the research outlined in Chapter 1 and 2 presents the need for an awareness of sensory issues among autistic students. Grandin (2008) and Shore (n.d.) emphasized the need for an understanding of this topic. Many of the research questions were designed to address this issue through examining the effects of noise, overhead lighting, and behavioral/psychiatric management of particular behaviors. The parents and/or primary caregiver(s) point out the importance of the topic in the following statements.

### **Need for Educator Understanding of Sensory Issues.**

Interviewee 4: He was in the part of the room but they eventually switched him to the basement because there was nobody down there. It was more quiet for him. It was less distracting.

Interviewee 8: there are not enough breaks built into the school space for an autistic person. My experience with my child has been he is thinking almost retrospective when he is exposed to something he has to think about how to process it and then he gets it but before that can happen they are on to the next thing. They are on to the next chapter. They are on to the next concept and I think that is a barrier for autistic kids in the classroom.

Interviewer: So, it is not enough reflecting time? Is that what you are saying?

Interviewee 8: It is not enough of a break. It is just nonstop, ongoing all day. It is not the best learning environment for someone with autism. They need breaks.

Interviewer: Do you think they need time to process it then?

Interviewee 8: Yes, particularly complex concepts. They need time to process it.

The school curriculum moves so quickly because it is tied to common core metrics and federal money or whatever. That time has to be taken at home. When he gets home it is only because I know what is going on in his classroom like the therapy, "How do you feel about that? Do you feel you understood that?" He will say yes or no. If he says no then I will review it with him then I will give him 15-20 minutes to think about it and then come back to me and tell me what his questions are but he doesn't have that kind of time in the school day. They are

pretty jam packed. It appears to other people like he is not getting it because he

hasn't had time to process it.

One of the interview participant's statements reveals the importance of an aide in matters of communication. The interview participants often referred to the fact that while they do not have direct contact with their child's educator, it is universal that they do with the child's aide. The level of satisfaction with the effective communication with the child's educator in Table 18 showed that 22 (n=78, 11.1%) survey questionnaire respondents are not at all satisfied with communication with their autistic child's educator and five (2.5%) are extremely satisfied. The parents and/or primary caregiver(s) stated in the following.

### **Effective Communication With Educator.**

Interviewee 1: Well, we see him about three times a day. We take him in the morning. We see that he gets in the classroom. The teacher is there. We go at noon. Now we are delivering his lunch and he eats his lunch there. Before we would pick him up for lunch and return him after lunch. That was three times. Then we would pick him up after school. We don't use the bus or anything. We can really keep track of things they need and what they have to have.

Interviewee 2: Yes, they try to accommodate me. I think that is one of the benefits of a small school. They know who I am. It's small and I can walk in and talk to the teacher or talk to whoever I need to talk to. They accommodate us in that way in that they let all the aides come into the school and they let us observe whenever we want.

Interviewee 4: I feel I have effective communication with the aide and I communicate through the aide to the teacher. A lot of times this year I have tried to call the teacher or, you know they won't answer the phone or they are stuck with some else right now. I just pretty much communicate through the aide. In the beginning I had a notebook and which I had at the other school too where the teacher could write things and I could write things too. No. He pretty much works with his aide and not much with the teacher so I don't think the teacher knew what to write. She didn't really work with him that day. For a while the notebook wasn't even in the...I think they just left it on the teacher's desk because there

was nothing to write. He is like an under the radar kid. If he doesn't freak out, if he doesn't whatever, he is fine.

Interviewee 6: Some of them I do. Some of them I feel like I can get through. Some of them I don't. Some of them just kind of listen to me and like, "Ok, we will take care of it," and then they never do. Mr. H and me butt heads when I was in junior high over there because he I skipped one of his classes and he found out that I skipped and I got detention for it so he didn't bring it up. He didn't say anything to my son about it or nothing but he goes, "I am pretty impressed as well of a mother you are, as an informed a mother as you are" and stuff and everything and it's kind of like, "My kid is my life." He knows when it comes to that he better get it right or he is going to see me in the classroom. So, I don't really have too many problems with him.

Interviewee 8: I do but it's not because of them. I feel I do because "I" make it a priority. "I" insist on them communicating to me. I feel if I did not communicate with them they would not communicate with me. Usually I will send out a blanket email on Monday to all the teachers "What's going on this week? Where are we? Any major tests coming up? Any projects coming up?" I have waited until late until late Monday afternoon just to see which teachers are going to e-mail me first. After 12-13 weeks of e-mail you should kind of get the drill, "Oh, where's the e-mail today?" A small, small percentage of teachers; I would say less than 1% actually get it and follow the pattern even if I don't email them at 8:00

Monday morning. They will e-mail me but that is rare. If I didn't communicate with some of these teachers they would not communicate with me.

The parents and/or caregivers have meaningful and positive statements to make about the IEP process. Parents and/or caregivers often have to remind the school staff about their child's goals in the IEP and have to push a little harder to make sure the way in which their child's educational goals are to be met are actually followed through. It was also determined that some of the interview participants are in need of advocacy efforts in educating them about the importance of the IEP developed for their child. Educators must abide by the educational steps in reaching a student's goals that are developed for children with disabilities. It appears that some parents are not aware of this.

An area of concern that was found was in the lack of the parents and/or primary caregiver knowing the power of an IEP has, as brought out by Interviewee 8 when she stated, "I don't know if you understand how an IEP works or what that means but that is the Bible. That is the Bible you have to follow whatever relates to my kid." Interviewee 8 brought up another valid issue regarding the ability of a parent and/or caregiver understanding their child's educational rights when she states the following.

I think there is a general lack of concern about the literacy of the parents. Again, I feel my child is very lucky because I am a very aware person but hey, they give you this handbook. It's like 1- or 15 pages of rules and regulations and policies they have put together and say; "Now you are going to check the box that I gave this to you." I check the box and thought, "What if I couldn't read and you just gave me 15 pages about what my child's educational IEP is and how we are going

to help my child be successful, but I can't read. I'm embarrassed and I can't tell you I can't read. How would I know what the heck this thing says?

Parents and/or primary caregivers who participated in the personal in-depth interviews and in the online survey questionnaire are generally pleased with their ability to participate in the development of their child's IEP. Table 15 showed that 23 (n=78, 21.1%) are very satisfied with the IEP process while 18 (16.5%) are somewhat satisfied. The challenge for the caregivers is felt to be whether the goals outlined in the IEP would be consistently implemented by the educators. The personal interview participants stated the following.

## Parental Participation in the IEP.

Interviewee 4: I tried to get them to do a picture schedule for him and after 6 months, maybe 6 weeks, we went to his IEP meeting to see how the picture schedule was going and how that came about. It was just on the file folder and that was all they were going to do and the teacher said that she didn't have time to do that. She said that after school is out that is her family time and that is the only time she would have had to do that so that never did happen. It was just a simple thing on the file folder that's all she had to do and she didn't have time.

Interviewer: And that was part of the IEP?

Interviewee 4: Yes. So, this other kid in the room, probably more than one, would set him off and I would have to leave my job and actually I had a kid in my room out in the country at that time that was a little bit wild and I didn't have an aide or anything and I would have to leave my regular school job; my regular classroom

and go to the self-contained room to get my kid because they couldn't handle him and so what I did on my own was took some of their aides on my own to some sensory/OT stuff in Billings, some workshops. I tried to help in the classroom and when I went to help in the classroom instead of the teacher going and helping the aid and showing her what to do with my son she went to the computer and did work she was behind on. So, I felt that I tried everything so I finally had to call in MAP (Montana Advocacy Program) and DD (MAP autism specialist) came twice to talk to the teachers and do some plans and to do some stuff with my son and write up some stuff. He came twice from Helena. They didn't know what to do with him. When they would take him out of the room he would run and laugh because I think being silly is his escape. He would run to a different classroom so eventually they put him in the boiler room with his aide. What he likes to do is bounce his little bouncy balls and that is what he did all day in the boiler room is bounce his bouncy balls.

Interviewer: You know, for him that is soothing.

Interviewee 4: Yes, for him it was good. It didn't seem like it was a big deal. It was brought up in the IEP meeting. The principal asked the teacher if he was in the boiler room and she said, "Yes, that is where they kept him, in the boiler room." So, it wasn't a secret or anything.

Interviewer: How did you feel about that?

Interviewee 4: I don't know. I felt kind of bad. I came one day to spend some time with him and I was told that he was in the boiler room.

Interviewer: You didn't know prior to this?

Interviewee 4: I didn't know and so I went and sat in the boiler room and he was just sitting there bouncing his balls. They weren't working or anything and the aide would just...I guess there was another girl in there too. She was in a wheelchair, you know and she can't talk or anything so they just had him in that room with the girl in the wheelchair. They couldn't talk or speak or anything and his aide would just talk to the other aide. They were just kind of hanging out. His aide was talking to the other aide and hanging out and I was kind of wondering what kind of work they did, if they did any academic things because it was a school.

Interviewee 6: He was in third grade by the time he got one. I had finally found out about TB (advocate) from PLUK. I got ahold of her and she is the one who got me the IEP because they would have kept pushing me off, pushing me off If I hadn't gotten her involved and that is when things started to turn around. She helps me because I don't understand a lot of it. I think they just blew me off a lot. One thing that frustrates me is that they say, "Well, we don't see that in the classroom. It doesn't apply." Like ok, how do you not see that in the classroom? I know my son and know he does this so why is it that he doesn't do it with you but he does it all the time with me?

Interviewer: Do you feel you were listened to at all?

Interviewee 6: Usually; to a certain extent. Whether they disregarded the information or not at least they listened.

Interviewer: But they didn't implement it?

Interviewee 6: They don't want to deal with the IEP. Yes, they still haven't because he has, it isn't necessarily a stutter but he repeats words and sentences, like when he gets really excited he says this part of the sentence over and over and over again before he can complete the thought. It can take four or five times of saying the first three words or the middle three words or whatever. They say they don't see that and I am saying, "How can you not see that?" He does it right in front of them.

Interviewer: I think they call it echolalia where they just keep repeating things.

Interviewee 6: I have no idea but anyway, the speech therapist was like "I don't see it, I am not going to treat it."

Interviewer: How did this all affect you and him?

Interviewee 6: Well, being able to speak your mind clearly is kind of important when you get older so I guess to me I want him to be able to speak clearly. He needs to because when he is excited about something and he becomes a scientist, how is he going to stand up in front of people and tell the world about his discoveries when he is constantly skipping like a record? They are going to look at him like, ok.

Interviewer: You want him to contribute to society.

Interviewee 6: Oh, most definitely. Whether he wants to know or not, I am trying to get him directed.

Interviewer: And you would like to see others do this as well.

Interviewee 6: Most definitely and that is another issue I come up with since he has gotten the IEP. A lot of the teachers seem to think I want him to get a free pass and that is not what I am asking for. I want him to have a level playing field. He cannot write with a pen and paper. He needs a typewriter or an iPad; something he can use to communicate his thoughts onto paper because they give him worksheets and he can't read them and he gets bad grades. He knows the material. He just can't write it out.

Interviewee 8: We developed an IEP with specific measures about how B should be learning and how he should be integrated into the classroom and over time teachers started to get not necessarily that my child was as able as anyone else but more that they just did not want to deal with me. Because of that they started to do the things that they needed to do. I even had teachers that would take classes on autism that the school offered them so they could get a better understanding of autism and how autistic children function and you know over time B started to do a little bit better. When he was in third grade we moved to Leander, TX and prior to moving there I did call the school system to let them know and find out if they were differently abled. I needed to know what services are available and I have an IEP that I am going to send to you in advance so you can take a look and see whether you can make these accommodations and you need to tell me where I need to go in the State of Texas to get the accommodations for my child and if we can do better than this, I am open to that too. Leander is in the school district just outside of Austin, TX so we went to the school and talked to them about the IEP.

I told them I don't want B to have a human shadow. I want him to be able to function on his own and so in order for him to ever be able to do that we have to start pulling back on some of these services that make him dependent upon other people. It was really in third grade when the inclusion started because first of all, for inclusion they did not have the human resources they said they are to have 24 hours a day and secondly, their resources were spread pretty thin and so, inclusion was sort of what their model was. What that required of me as a parent was more involvement and interaction with the school. He is included but what is he included in? What is he doing? What is he working on? What is your topic this week? What is he studying in science? What projects does he have coming up? He came in with this IEP where I require five days advance notice of any tests. They are a very disorganized bunch. You sometimes ask a teacher, "Well, what is your lesson plans five days from now?" They may not have that. "Well, do you have a study guide because B is going to need a study guide. That is in his IEP." "Ah well, it's going to be chapter 10.""Hmmm, you are going to have to be a little more specific about chapter 10." So what we are requiring is for teachers to do a lot more work. It requires them to do a lot more work than they did or wanted to do and some of them pushed back. "Well, I don't have to do this for other kids" and I am like, "Well, I'm sorry, I don't know if you understand how an IEP works or what that means but that is the Bible. That is the Bible you have to follow whatever relates to my kid. So what ended up happening is it was really helpful to all of the kids. Then we moved to Mississippi and what I found is that if you have

a good IEP in place it doesn't matter where you are. If you have that foundational IEP that you can share with the next school district it makes it a whole lot easier than starting over. They can just adopt those accommodations and go from there. Once they realize you are serious and that you will respond back to them and are interested in your child's education they will look for ways to help you and your child be successful. Like I said I think they rely on me as much as I rely on them. School districts and teachers have relied on me to tell them what he needs then they will work with me to make sure that he can get it; like the oral administration of a test or him listening to a book on tape as opposed to reading a book. They have been very receptive to that. Most school districts, the three that I have been in have made many accomplishments possible in that regard. I felt very involved in that process and what happens with him but again, it is because I choose to be that involved. I think if I didn't show up for the IEP meeting or whatever, they come up with whatever and that is what he gets.

Online survey comment 13: A lot of the IEP meetings were both sides pointing fingers at each other as to who was at fault...the laws need to change, especially for dual diagnosed kids.

The personal interview participants express that while the educator might appear to be supportive in educational areas, their actions dictate otherwise through examples of failure to follow through or being unavailable. The survey questionnaire data found in Table 23 showed that 32 (n=67, 29.4%) survey respondents are not at all satisfied while two (1.8%) are extremely satisfied. It was determined there is a need for advocacy and

education efforts for parents regarding understanding school policy, what their rights and the rights of their child are, and action steps they can take regarding the meeting the needs of their child with autism. Educator support for the parents and/or primary caregiver(s) were outlined earlier regarding whether there was educator support if their autistic child had an increase or a decrease in severe behavioral symptoms (p. 230). Some of the personal interviewees discuss areas of concern regarding educator support in the following statements.

#### **Educator's Support of Parent and Child.**

Interviewee 3: No. When I go to the IEP I am quite certain that I am the last person in the world they want to talk to.

Interviewee 4: No, not the educator's themselves because I can't ever get ahold of her. I call but...I do feel I could bring up something in the IEP and they would listen to what I have to say because now I can make them. I know I can make them do what they have to do.

Interviewer: You learned that from MAP?

Interviewee 4: Yes. They know I will do it because I did it before. I am sure they have his IEP highlighted with "don't cross this mother" highlighted or whatever. Interviewee 6: I feel some of them support me. Some of his teachers do, yea. Some of them just think I am a nut Mom who has nothing better to do than call the school and complain. I still think that sometimes I talk and talk and it doesn't do any good. She has so much going on that I understand. She expresses my concerns and she wants to help but I think because she has got so much going

on she puts it on the back burner and waits and waits and by that time it is like, well that's passed.

Interviewee 7: I would say the last couple of years it has been pretty much nonexistent. In preschool it was phenomenal. They were absolutely great. They would call and talk to the teacher. She could call them at any time. I mean it was really, really good but the last 2 years have been really poor. This year I know with B he has contact with the teacher because he will make comments that he will talk to M; her name is M and what she has said or different things. I think there is more support there this year for him. I don't know how much there is for the parents and grandparents.

Interviewee 8: Some of them, some of them. I also think the support comes from just their general unwillingness to have to deal with me in ways that they don't want to because I make it pretty clear that if we can't come to some mutual agreement then we are going to have some issues because this is what is required for my child and so I kind of feel like they are not necessarily vested in my child's education. They are more vested in oiling the squeaky wheel that they don't want to deal with. It's a lot of work, I will tell you that much. There is no built-in support system. There is no parent support and no guidance for parents in the school system. "Ok, here's an autistic child, here's the things that you need to know on what's available for your child." You have to dig all the information up. It's not coming through your front door. No one comes here and says, "Hey, did you know that if your child is autistic you can get state tests read to him? Did you

know that? Well, no I didn't know that." I had to pull that out of a school policy manual. Support on resources is very low. You have to dig it out and if you are not an aware person or if you don't even know what's possible I mean you don't even know what to ask for.

The interview participants had as many as 41 references over the course of the personal interviews that suggested the need for an educator to be more knowledgeable and training needed about autism. Table 5 showed that 35 (n=79), 32.1%) survey respondents are not at all satisfied and 7 (6.4%) are extremely satisfied. The personal interview participants had the following to report about educator knowledge.

### **Educator's Level of Knowledge about the Autistic Condition.**

Interviewee 2: There could be a major improvement. Improvement anywhere; in the classroom, with the kids, tolerance and education is what needs to be worked on. They just don't understand and I would not have until 3 years ago.

Interviewee 3: Given the fact that this town is so strange and they get off every Wednesday at 2:00 for PR, I don't think it should be too much to ask that they cover autism in one of these little classrooms. Apparently they get off at 2:00 on Wednesdays so they can do meetings every Wednesday at 2:00 for an hour. Well, autism should be covered in that meeting at some point. Another thing that is an issue is that they don't share the IEP knowledge with one another which is absolutely insane because at the beginning of the school year none of his teachers knew and I am like, "How can they not know, do you not share your information with one another?"

Interviewee 6: Absolutely not satisfied.

Interviewer: What do you feel can be done about that?

Interviewee 6: More training; lots more training instead of having these classes they go up to do their training to keep their license because V says they offer the same classes three or four times. Instead of offering those classes, offer classes on autism, offer classes on ADHD, you know.

Table 7 shows that the survey data found that lack of the successful management of the behavioral symptoms associated with the autistic condition are felt to be due to the lack of adequate educator knowledge about the autistic disorder. Lack of satisfaction among the personal interview participants is expressed as follows.

### **Educator's Level of Training in the Autistic Condition.**

Interviewee 4: At HP School I was not impressed with the teacher's level of knowledge about autism whatever and I would tell her about classes that were offered for autism in town and she said she didn't have time to go. She didn't go to any sensory workshops. She didn't go to anything because she didn't have time to go.

Interviewee 6: I don't think there is enough. I don't think there is enough training. I don't think there is enough knowledge and with all the research that is being done I mean there is never going to be knowledge because there is always going to be something new coming up but I think teachers need to have the basics of training in autism to know how to deal with it more because it just seems like most kids with autism if they continue to act out they get kicked out of school and

it isn't something they can help. It is not something they control. It's something that happens, you know?

Interviewee 8: I think it should be mandatory. I think it should be mandatory at the undergraduate level. I don't think they should be able to become a teacher without having some training on autism and what it means and how it works and how it affects the mind and the body and what you can expect from a student and how you can customize the curriculum to help an autistic student. I mean, I think it should be mandatory. I don't think you should be able to get a college degree, and a teaching certificate and say, "I am a teacher" and know nothing about autism. That is something that burns me up. Don't get me started on that one. On a scale of 1 to 10 I would say generally speaking about a 2. I think they definitely need more training. What I found in the public school system is that there are not very many teachers that know very much about autism. They have heard about it but they don't really know what autism is or how it affects a child in the learning environment. Even special education teachers are not always trained in autism. They have sort of a general special education background but you know they don't specialize in autism.

The area of mental health disorders among students with autism is one in need of further research in order to find ways to adjust the classroom environment to alleviate those symptoms which potentially exacerbate the behavioral symptoms common in autism. There appears to be a need to educate teaching professionals and the parents and/or primary caregivers that depression and anxiety may play a role in a student's

behaviors in their responses to their environment. Research is needed to address how mental health disorders might contribute to inadequate sensory responses due to overstimulation within the classroom environment. One interview participant was unaware that children with autism experience mental health disorders, such as depression and anxiety and is grateful for the information in the event that she observes either condition in her child. Table 26 shows the data survey results from parents and/or primary caregiver(s) who have a child who had a psychiatric diagnosis. Twenty-seven (n=39, 27.3%) are diagnosed with anxiety and five (5.1%) are diagnosed with depression. The survey data in Table 27 shows the level of satisfaction with the management of the psychiatric symptoms in the public school classroom. Twenty-six (n=47, 23.9%) are not at all satisfied and two (1.8%) are extremely satisfied.

## **Knowledge of Mental Health issues Common in the Autistic Condition.**

Interviewee 2: I think there needs to be more about mental illness, in general needs to be more understood, obviously. There needs to be more understanding. People have a hard time when a child has something physical wrong and they have so much more tolerance and empathy but when they see autism they think it is just a child with behavior problems. There definitely needs to be more awareness

Interviewee 3: No, not too much because when I brought up his depression at the latest IEP even though it has been an issue since he was 6 years old, they acted like it was the first they had ever heard of it. They never noticed that he had issues. It was like, "What?!"

Interviewee 8: Yes, their folks don't even know they have mental health disorders. It is funny you would say that because I actually work for a large insurer in Medicaid through the government actually. It is through ACA. It is pushing more mental health analysis and more behavioral mental health therapy for kids with special needs; all kinds of kids with all kinds of special needs. It is a big issue and the educators are undertrained. I don't think they know what to do.

Parental support, in light of this study addresses the need for educators to be aware of resources in the areas of available programs for parents and/or primary caregiver(s) in order to reduce parental stress associated with autism, parental training in autism, and knowledge of the availability of local autism support groups. Three questions on the survey questionnaire address the issue. The survey questionnaire posed these questions in order to determine whether the educators are knowledgeable enough to enquire whether the parents are aware of these resources. In presenting these three questions regarding educator knowledge of available programs, the outcome posed another need; parents and/or primary caregiver(s) are not aware of resources.

It is possible that the educator is not aware of these resources for parents. This suggests the need for advocacy and education efforts among the parents and/or primary caregiver(s). Online Survey participants agreed that they had not been informed of any of the resources available to them by their child's educator. Table 20 shows the level of satisfaction regarding the educator's recommendation to the parents and/or primary caregiver(s) for stress reduction programs. Thirteen (n=78, 11.9%) survey respondents are not at all satisfied and 37 (33.9%) stated that the educator did not recommend a stress

reduction program. The next two tables solely reflect the survey data as the questions were not presented to the interview participants, but are pertinent to addressing the need for educator knowledge about the options and need for education and advocacy with the parents and/or primary caregiver(s).

Table 21 shows the level of satisfaction with the educator recommendation to the parents and/or primary caregiver(s) that they attend a parental support group, 14 (*n*=79, 12.8%) are not at all satisfied, and 51 (46.8%) stated the educator did not recommend a parent support group. Table 22 shows the level of satisfaction with the recommendation that the parent and/or primary caregiver(s) attend parental training in autism, 19 (*n*=80, 17.4%) are not at all satisfied, and 52 (47.7%) stated the educator did not recommend parental training in autism. At least two interview participants expressed that it is solely their own responsibility to learn about stress reduction resources and did not feel it is the educator's responsibility to know and share this. The personal interview comments are as follows.

# **Educator's Knowledge of Programs Designed to Reduce Parental Stress.**

Interviewee 1: I feel that is my responsibility. I don't expect that from a teacher. If I am stressed, that is kind of my own problem. As far as alleviate it, she alleviates it just by having knowledge of what she is doing.

Interviewee 8: No. I would say that I have a loose knowledge of it but has anyone ever like in the school system come to me and say, "Hey, you know here's a program designed to help you, as a parent in coping with his condition," no. If

you are stressed out as a parent it is your responsibility and your health insurance's responsibility to pay for it.

Table 29 shows the level of satisfaction the parents and/or primary caregiver(s) have with the consistency of these services. Twenty-four (n=69, 24.0%) are not at all satisfied while four (4.0%) were extremely satisfied.

Table 11 shows the parents and/or primary caregiver(s) level of satisfaction with the collaboration and integrated services in the public school classroom. Thirty-three (n=76, 30.6%) were not at all satisfied while six (5.6%) were extremely satisfied. Table 12 shows whether the collaboration and integrated services are effective. Forty-one (n=76, 37.6%) respond yes while 35 (32.1%) respond no. In further examination of the topic, the survey data in Table 13 show which service provider is most effective in meeting the needs of the autistic student. Occupational therapy is chosen by 23 (n=69, 21.2%) as the most effective and speech therapy is chosen by 21 (19.3%). The educational service providers who are deemed the least effective are shown in Table 14. The medical provider, while not directly within the public school classroom, generally plays an active role in providing necessary services for the autistic student and medical care has the potential to play an active role in their overall well-being. Twenty-six (n=67, 23.9%) of the survey respondents felt the medical provider is the least effective. Mental health services providers were next, with 19 (17.4%) survey respondents.

While the availability of collaborative and integrated educational services for autistic students exists, service delivery appears to be inconsistent. It appears that mediation between the numerous service providers should be part of the plan to educate a

child with autism. Unless a parent is aware of what services their child is entitled to in the classroom through a well-planned IEP, there is less likely to be the chance to meet their unique educational needs. Included in the survey data is a question about the consistency of these services. The following comments were added from survey respondents.

Online survey comment 33: The service providers are experienced but have problems with the school understanding the need for interventions and following the Behavior Support Plan.

Online survey comment 42: There is no collaboration.

Online survey comment 52: The school is not collaborating with other providers.

Online survey comment 62: Nothing is being done in a collaborative manner by

our public school system. It's the school and that's it - they reach out to no one.

Online survey comment 108: There is very little collaboration. They operate in silos.

The personal interview participants stated the following.

## Availability of Collaboration and an Integrated Treatment Approach.

Interviewee 2: Yes, they do have that approach but it is just that there is not enough. There is not enough speech pathologists out here (rural eastern Montana) to give the kids what they need. The attempt is there. They get an E for effort, I guess.

Interviewee 6: They have all these structured things they have to do by law for kids and they are struck on doing those. They are not worried about the kids with autism and realizing they learn differently. That whole "No Child Left Behind

Act" doesn't take kids with autism into effect. It just doesn't. It's like they took one perfect kid is going to be the example we are going to follow. We don't care about these kids that have ADHD that learn differently. We don't care about these kids that have autism. They are going to follow these guidelines even though it may take them slower time but they are going to make sure they get this covered. I think they are more concerned about their guidelines. I really do because of the funding.

Parental input into daily activities falls in line with the topic of effective communication with the educator. This section of comments is broken down into areas where the interview participants were somewhat agreeable that communication was favorable with their child's educator. In moving down the list of comments, it becomes clear in the following comments that it is not the educator they are in communication with, but rather the aide. Some interview participants felt communication solely with their child's aide sufficed since that individual spends the greatest majority of time with their child and not the educator. It was not mentioned whether information that is communicated to the aide is passed on to the educator. The personal interview participants state the following.

#### Parental Input Into Daily Activities.

Interviewee 1: They rely on us and we rely on them. It is a total exchange because you just don't know if they are not feeling good.

Interviewee 2: I think that they listen. Like with her iPad, in her notes section, we write back and forth with the teachers and stuff like that. They are very open to me being there and being a part of it.

Interviewee 6: Oh, I feel comfortable expressing it but I don't think they listen to it. I can express my opinions and stuff but it's like, "Ok, yea whatever." Interviewee 7: I think as an overall district they are not very open to any involvement or input from outside. There are a few teachers that are the exception. We aren't asked for input and for my daughter and ex son-in-law their input comes through the back and forth book often after the fact.

In this section some of the personal interview participants refer to the aide as the individual with whom they primarily have effective communication. They stated the following.

Interviewee 4: I feel I have effective communication with the aide and I communicate through the aide to the teacher. A lot of times this year I have tried to call the teacher or, you know they won't answer the phone or they are stuck with some else right now. Yes, but I just pretty much communicate through the aide. In the beginning I had a notebook and which I had at Highland Park too where the teacher could write things and I could write things too.

Interviewer: Is she doing that?

Interviewee 4: No. He pretty much works with his aide and not much with the teacher so I don't think the teacher knew what to write. She didn't really work with him that day. For a while the notebook wasn't even in the...I think they just

left it on the teacher's desk because there was nothing to write. He is like an under the radar kid. If he doesn't freak out, if he doesn't whatever, he is fine.

Interviewee 5: Her aide really works for her a lot. That girl does anything. She is there with her. She has a concert; she is there with her. She goes out of her way to be with her to do anything and everything with her and I find that very respectful. She doesn't have to do all that. She really takes her teaching beyond.

One of the emerging themes found in the personal interviews is that of the need for parental advocacy. The interview participants universally suggested that their experience has been such that they had to learn to be an advocate in order for their child to succeed in the public school classroom. They often times solicited an advocate for assistance in working with the public school in seeing that their child's educational services were addressed adequately. Whether it was through repeated phone calls left unanswered by the educator causing them to personally go to the classroom, they appeared to take it very seriously. Most would not be left unheard which is tied to effective communication with their child's educator. One cannot assume that the aide communicates regularly with the educator about the children whose parents participate in the personal interviews.

The parents and/or caregivers of a child with autism were similar in acting as an advocate and this is primarily why they chose to participate in this study. With each of the interview participants it appears the effort at advocacy is one that is forced upon them in order to assist their child with autism to succeed. The parents and/or primary caregiver(s) appear to be unwilling to stand by and allow their child's education to be one

where their child is in a position to be unable to learn. The parents and/or primary caregiver(s) believe there are ways in which he or she can reach their full potential.

Interview participants have a chief concern about their child's ability to succeed in life and survive on their own, as suggested in the following statements:

## The Theme of the Importance of Parental Self-Advocacy.

Interviewee 3: By the time he got one (IEP) I had finally found out about TB from PLUK (advocacy agency), I got ahold of her and she is the one who got me the IEP because they would have kept pushing me off, pushing me off. If I hadn't gotten her involved and that is when things started to turn around.

Interviewee 4: I had to stop understanding and not understand anymore and say "That is not my problem anymore." In the beginning I understood but then I had to stop understanding. TB was a big help. I felt that I tried everything so I finally had to call in MAP (Montana Advocacy Program) and DD (autism specialist) came twice to talk to the teachers and do some plans and to do some stuff with my son and write up some stuff. He came twice. I don't know if he is the current one but I know he was the autism specialist for the State of Montana. He came down to offer his help.

Interviewee 6: Back then I was the Mom, I was calling the school every week. "Has my son been down there, has my son been doing stuff with Mr. H like he is supposed to?" I don't think they want to mess with me anymore because I'm pretty on top of things. Miss H complimented me because she said, "I have a lot of parents that really care about their kids but you're the only parent that is calling

at least every other week." At least once a month I would be calling to make sure that things were, you know and it is hard because I have a job. I was doing online school at the time so I was doing that plus trying to deal with what was going on with him and it was challenging.

Interview participant No. 8: It was a battle, you know so I met with this principal of this school he went to, the elementary school, JLM and met with her. I said, "Listen, this falls under the ADA, right? And so you have to make accommodations for my child and if you don't I don't think you are going to like what happens after that and that is not really a threat, it's just a promise because my child deserves an education like everyone else. You are required by law to make sure he has that even with the NCLB law." We came together and put together a plan and I will tell you for the first three years he literally had an adult shadow. There was a guy; his name was C that was assigned to basically babysit him all day. He was in a regular classroom but you know there were times that I would find out that while other kids were working on Math or reading or whatever, he was in the corner coloring and we were about to get ugly, I mean ugly with people. That is not acceptable behavior. "You will not measure my child by the lowest common denominator. You will present him with everything you present everyone else with or we will continue in court." I don't back down. Over time that message started to resonate. We developed an IEP with specific measures about how he should be learning and how he should be integrated into the classroom and over time teachers started to get not necessarily that my child

was as able as anyone else but more that they just did not want to deal with me. Because of that they started to do the things that they needed to do. I even had teachers that would take classes on autism that the school offered them so they could get a better understanding of autism and how autistic children function and you know over time he started to do a little bit better. they are like, "We don't have parents meeting with the principal when their does not do so well on their standardized test. We don't have parents researching, hey, you can read this test to my kid, he is an audio learner so that is what I want you to do is read this test to him because I think he will do better. You can do that so he doesn't blow it all together and just start checking the boxes. You want him to be successful you have to help him be successful and I am going to make sure that you do that. It's been a full time job; 24 hours a day, seven days a week. I wake up in the morning thinking, "Ok, what's going on, where is he? How close are we to where we need to be?" In that, I realize that teachers are not as organized as people think they are. They are a very disorganized bunch. You sometimes ask a teacher, "Well, what is your lesson plans five days from now?" They may not have that. "Well, do you have a study guide because B is going to need a study guide. That is in his IEP." "Ah well, it's going to be chapter 10.""Hmmm, you are going to have to be a little more specific about chapter 10." So what we are requiring is for teachers to do a lot more work.

#### The Theme of Genius Gone Awry.

A recurring theme was presented in that many parents commented on the high degree of intelligence that their child possesses and feel that the educators are not aware of how intelligent a child with autism is. The parents and/or primary caregiver(s) provide the following examples.

Interviewee 1: He has been on the honor roll because he knows that stuff. We have no idea so he goes to the next grade and he is able to do the stuff in the next grade so he is obviously improving academically or he already knows it. We don't know the difference. We think he knew how to read. I have pictures. He would be sitting in the high chair and he would never be playing with developmental toys. He would grab the Dell flyer and be studying it. I have a ton of books in my computer room and he would just come in and he would unload them around himself and then he would spend time going through them. These are words; not pictures and not kiddy books which he did not really care that much for. It was cute. One day he picked up a magnifying glass and he was sitting on the floor and he opened it up and ran it right down the page. I have a picture of it. How did he know how to do that? He was a tiny little guy. He has some sort of knowledge. He really likes books. I always had to guard my books. He is kind of hard on them. I would hide a book and it might be above the washer and dryer. I would feel real good he is not seeing this. You know that little stinker would come walking in with my book. They also think he is savant. It is because somehow they are born and they come in with all the technology/information. We can get something new

and I will hand it to J to read it and he is playing with it and has it going. He programmed the remote control to French. We had a hard time with that. We had to go find the manual as to how to put it back. We had to call our Internet provider a time or two because we ended up with different languages; Navajo. There is a hidden, close-captioning where you have your regular close-captioning on your remote and also the hidden menu. We did not know but he found this. He knew. It was a month before we got close-captioning off of the TV. We didn't know how to do it. J found the hidden menu thank God. It has really been a ride; it really has. It is a lot of fun.

Interviewee 2: When she was two whether she could read the words or not she knew, she would line books up and DVD's up. The words were correct. It was obvious she knew what they were supposed to look like. None of them were upside down. If you put a tote of blocks on the floor she can look at that and she usually has a favorite number or something and that she really likes and she can pick those numbers out of hundreds of blocks in about 2 seconds. She can just scan it all and she gets all the 9s is what she usually likes.

Interviewee 3: He taught himself to read by the time he was able to talk. So, he was very advanced. At first we thought he was doing recognition but then he started reading and we knew there was no way he could recognize what the words were. By the time he was 5 he could pick up a doctoral book and read the words whether or not he knew what they meant he could read them. He soaks things in. I mean, by the time he was 3 he had every toy train in the Thomas the Tank Engine

series. He could name every single one of them. He knew all of them. I don't know how he does it. We think he knew how to read. I have pictures. He would be sitting in the high chair and he would never be playing with developmental toys. He really likes books. I always had to guard my books. He is kind of hard on them. I would hide a book and it might be above the washer and dryer. I would feel real good he is not seeing this. You know that little stinker would come walking in with my book.

Interviewee 6: I keep saying, "He needs something else to work on. He needs something to work on at home. "They are like, "No, he is fine. He is doing good here at school. He's ok. He is getting his work done. If he has extras we will send it home with him. "I just don't think he is getting enough school work to do.

Interviewee 6: You know I was talking to MW the other day because MW has met him and she thinks he is smarter than the other kids.

Interviewer: Do you think he is ahead of the other kids?

Interviewer: That's what I am wondering. Just by what you are telling me and the fact that he doesn't have the work is he being challenged?

Interviewee 6: He is done with his homework before the rest of the kids. I mean, he goes through his ... and all these papers come home and there are a few little corrections here and there but it's not like the whole paper needs to be corrected. In sixth grade he was struggling with his Math but honestly, I think he was doing it on purpose because he wanted the attention.

Interviewer: Has he had his intelligence tested?

Interviewee 6: No, and that is the other thing I was going to talk to them about at the school this year to find out where I would go to get his IQ tested because I am really interested now to see where he is placing. I think he is not getting challenged enough and that's another thing that they are not challenging, you know. I don't think the school challenges these kids enough.

Interviewee 8: My experience has been if your child is different and I don't say disability. I say my child is differently abled because he is certainly able to do anything that I am not able to do and will never be able to do. He can listen to himself on the radio playing on four instruments. I can't even balance my checkbook so you know there are some things he is absolutely genius at. Then there are some places where he struggles but it has been my experience that when you have a differently abled child the bar automatically drops for that child in that expectations for that child become much, much lower and the general sense of that is, "Well, you know let's not push it too hard. We can't expect that much." From the very beginning I was adamantly opposed to anyone thinking of my child as "less than" and I wrote many notes to many school principals and met with many teachers and probably affected as many people and told them my expectations of my child are entirely different than yours. My child is differently abled and so you will have to learn so you will have to teach someone who doesn't follow the standard of toy box curriculum that you have followed for the last 25 years.

Mace (Mace, personal communication, October, 2010), written from the boy's perspective, and acting as his voice stated:

One day, Deligny was talking with a guest, a psychiatrist doctor. Suddenly he punctuates the conversation by tapping on the table. I was in the room with them: seeing Deligny tapping on the desk triggered in me the need to get on an errand: I went straight outside. Here I have to mention that usually I go through a certain "ritual" before going out of the room: I go to a pillar and smell it, go to the desk and smell it or touch it. Then and only then I can go out. Deligny sees me leaving, continues his discussion and forgets completely about it ... I come back 3 hours later with some unnamable, looking greasy stuff in my hands. I place it, as if I was proud of myself, on the desk where Deligny had tapped. "What is THAT?" thought Deligny! As they looked at it, they find that it is the remains of an ashtray Deligny had used 3 years before it got broken and then it was sent, de facto, to the compost pile!

Interviewee 8 stated that her son is "differently abled." Interviewee 1 comments that the family had been told that their son is a savant. Both examples have shown a large degree of enhanced ability and skill at particular skills that we who are "abled" may not possess, as confirmed by Mace's account. The hidden potential tapping such as this should be taken into consideration for the student and when these abilities are demonstrated, perhaps a focus on giving them ways to help that ability grow right within the public school classroom should be included in their educational planning and goals. Keston (2014) reported a story about Britain's "mini-Monet" Iris, who at the age of 5 has

the autistic condition and expresses herself through her paintings. The selling of Iris' paintings funds her much needed therapies to improve her ability to express herself.

Qualitative Interview Question 3 examined the parent(s) and/or caregiver's level of satisfaction regarding whether the current environmental health of the public classroom has the ability to promote a positive learning experience. A theme of satisfaction as well as suggestions for areas in need of improvement emerged when the interview participants responded to Research Question 3. The personal interview participants' stated the following.

Interviewee 1: I think that is building and it is just in its infancy and this is my estimation. I think there is really a will to build on that. There is a thing about why we don't sit over there. You know, you can visit or do whatever. He has us already categorized. They are teachers; he will learn from them. They can hardly do anything else. That's their role in his life. We all have our role. I don't know; he has them categorized for whatever and now he is learning to fluctuate as they tend to change but I really don't know. I think they are on top of trying to learn and as they are getting trained they are making changes and adjustments and it has always been a good thing.

Interviewee 2: I am happy with it, to be honest with you. In my opinion in my mind it goes directly back to the teacher. Any classroom can be inviting if you have a teacher who can make it that way. It doesn't cost a ton of money to have that. It is the attitude and the spirit in the room. Kids with autism are happy with a cup of water and a block, you know. Safety would be my main concern. The

playground is my concern. It has holes everywhere. There are areas they can get out of. It is not a completely closed playground. That is going to be an issue. Obviously, that is going to be an issue so we will have to see how E develops. There is a fence but there are holes; intentional holes so kids can get in everywhere from any part of the neighborhoods. To me it is just ludicrous. I have no idea why you would not have an enclosed playground. It is scary. She is always with somebody right now. She goes to the playground with the other kids at this point or her aide going out with her to play. At this point she is ok but at some point it will become a major, major concern when she goes to kindergarten. She is fast too. What people don't understand is she is not dumb. She will wait and if she wants to go out the fence she will watch you until you turn away. She is fast.

Interviewee 3: If they would just challenge him, you know? I mean, it is great the way they have got the system set up. They have low, middle, and advanced classes for each subject and he has been in the advanced on all of them except this year he dropped out of math because it was just too much given the stressful situation he had been doing through. But even still they are not challenging him enough. He is not stagnating but at the same time he is not flourishing because he is capable of much more.

Interviewee 6: They are not giving him his best educational experience. There is not enough training. The environment is not set up for a child with autism.

Interviewee 8: Emotionally, absolutely not. Academically, I think he has some support but we talked about how that has come about for him. Physically, I don't think that he, no and spiritually, absolutely not. I think if I had to rate it academically would be the strongest area but the other areas are really lacking and academic is weak. I have talked to the teachers; many of them about strategies for helping him with more abstract concepts but he still struggles with that to this day. I don't see any remarkable improvement in that area. It comes up at every IEP.

Qualitative Research Question 4 was asked to see what parents thought might be the environmental health barriers that exist in the public classroom, if any. The prevalent concerns were the lack of technological advances, such as the availability for individual student use of the iPad in the classroom, inadequate classroom aide presence in the public school classroom, inconsistency of educational services delivery, lack of educator knowledge about available resources such as stress reduction, parent support groups, and parental training for autism, lack of educator training and knowledge and awareness about autism, lack of the management of behavioral and/or psychiatric symptoms, lack of structure, and lack of adequate sensory supports.

The iPad is a positive tool for autistic students in the public school classroom (Family Center, 2012). The Family Center (2012) reported that many speech and language professionals are supportive of the use of the iPad as a therapeutic tool for students with autism. The personal interview participants stated the following.

Interviewee 1: They are going to be doing some changes at L School if the school bond thing passes. I got notice yesterday from Representative M that the bill is going to go before the governor's signature that includes their new boiler system. It is some \$100,000. It has passed so now I think it just needs Governor S's signature and he will probably sign it. That is a good thing and here is what I visualize. I think if they develop a technological room with a dedicated person to that. They are going to be doing some changes at Lincoln School if the school bond thing passes. I got notice yesterday from Representative M that the bill is going to go before the governor's signature that includes their new boiler system. It is some \$100,000. It has passed so now I think it just needs S's signature and he will probably sign it. That is a good thing and here is what I visualize. I think if they develop a technological room with a dedicated person to that. I really think there is a lot you can do for someone like our guy. You would get a lot more interest if it was that way.

Interviewee 2: That iPad has probably made a lot of difference, hasn't it? I haven't read extensively but I know they have started to use them and it is very positive for them. It brings out things we never knew she knew. If the iPad asks her to do it she will do it; not if we ask her to do it.

Interviewee 5: She does the iPad and they will have sentences and she will, ok, "The blank has to go for a walk or has to go to the bathroom." She takes the dog and brings it down and puts it there. I keep telling them she needs one for home. We can't afford it, or whatever." It's like, "Well you could afford to get her a

trailer for a bike which is just as much as an iPad." They don't have to get her an expensive one. She would be able to let me know if she wants juice but she knows how. She will go and bring the juice and give it to me, you know, or she will go grab a Capri Sun, stuff like that. I mean there are other things, like her stuff hurts. She doesn't know.

Interviewee 6: He goes off the handle if something isn't structured. The first week of school is mad chaos. In the summer it is not so bad because he just does whatever. I don't really control him. The first week of school it is just chaos. I just really think the lack of structure and the lack of training and knowledge and all of that stuff is a barrier.

Interviewee 8: The two top barriers would be I would say the lack of time and the lack of education of the educators. An autistic person in the public school is like trying to fit a square peg in a round hole. You are always trying to stuff it in there. The curriculum is absolutely not designed for someone with autism.

The interview participants had the following comments about the therapeutic use of the iPad for their children with autism.

Interviewee 1: They use the iPad for his spelling. They use it where he has to answer with his numbers. I mean, that is how they get all the information out of him.

Interviewee 2: She uses her iPad which is her means of communication.

Interviewer: That iPad has probably made a lot of difference, hasn't it? I haven't read extensively but I know they have started to use them and it is very positive

for them. Oh, it is just beyond. it brings out things we never knew she knew. If the iPad asks her to do it she will do it; not if we ask her to do it. There are other things like they got her an iPad. It's not just for her but the special ed. department has an iPad now. The children's autism waiver is what supplied hers.

Interviewee 5: She does the iPad and they will have sentences and she will, ok, "The blank has to go for a walk or has to go to the bathroom." She takes the dog and brings it down and puts it there.

Interviewer: Now, is that a special program on the iPad?

Interviewee 5: I don't know. I keep telling them she needs one for home so she can.

Interviewer: What do they tell you?

Interviewee 5: "We can't afford it, or whatever." It's like, "Well you could afford to get her a trailer for a bike which is just as much as an iPad." They don't have to get her an expensive one.

Interviewer: I think it would help her a lot.

Interviewee 5: She would be able to, uh.

Interviewer: She would be able to show you, "Here."

Interviewee 5: She would be able to let me know if she wants juice but she knows how. She will go and bring the juice and give it to me, you know, or she will go grab a Capri Sun, stuff like that. I mean there are other things, like her stuff hurts. She doesn't know.

#### **Summary**

The triangulation of the data obtained from the quantitative and qualitative portions of this study revealed similar themes. The online survey questionnaire responses were consistent with the responses from the personal interview participants. An example of this is that the data responses were favorable regarding the ability to participate in the IEP process and thus contributed to meaningful outcomes providing an idea of what the parent and/or primary caregiver finds satisfactory in the educational services their child receives in the public school classroom.

Overall, the responses were found to be significant in that the responses fell primarily within the not at all satisfied, slightly satisfied and somewhat satisfied levels, meaning effort must go into those areas in order to provide parents and/or primary caregivers' assurance that their child with the autistic condition receives educational services leading to successful educational outcomes. The small percentage of those participants who found the educational services very satisfactory and extremely satisfactory were in contradiction to those who felt education is necessary among service providers, including the medical and mental health provider.

Responses from the interview participants revealed the need for stronger parental self-advocacy efforts, including initial education in seeing that the needs of their child with autism are met in the public school system. The fact that 24 individuals agreed to a personal interview and 16 reneged further confirms the need to take action steps to engage the parents and/or primary caregiver(s) in the initial phases of a diagnosis of the autistic condition and entry into the public school system.

Common themes leading to areas in need of recommendations were found in the need for educator training in knowledge about autism in the following areas: (a) parental and child support efforts; (b) advocacy; (c) recognition of the potential for genius; (d) educator management and knowledge of the behaviors associated with autism and psychiatric disorders common among children with the autistic condition; (e) need for educator understanding of sensory issues; (f) more direct communication between the educator and/or primary caregiver; (g) and, (h) better collaboration between autism service providers, particularly the medical and mental health providers.

From a global perspective, the information contained within this study succinctly points out that the student with autism has the ability to succeed within the public school classroom and should be included in this system. Students with autism in its varying degrees from classic to high functioning are within the American public school system receiving an education and while it may be fraught with inadequacies, it is successful. As pointed out earlier, children with the autistic condition in France are encouraged to attend public schools only an hour a month or not at all and parents must seek an education for their child outside of France. Many mental health professionals within France adhere to outdated psychoanalytic theories, such as "freezer mothers" that have no evidentiary basis and exclude these children and their families from a deserved quality of life. This is an intolerable infringement of their basic human rights and unacceptable in that the founders of special education and those who brought societal awakening of meeting the needs of the developmentally disabled originated in France, such as the founder of what has come to be known as a man's first attempt at special education in the 1700s, Itard

with Viktor, the wild child of Aveyron. Other educators, such as Deligny followed suit but little has changed if parents must seek education in other countries, such as Belgium for their child with the autistic condition. Interpretations of the findings of this study will be discussed further in Chapter 5.

#### Chapter 5: Discussion, Conclusions, and Recommendations

#### Introduction

The purposes of this mixed method study were: (a) to examine the opinions of the parents and/or primary caregiver(s) of a child with the autistic condition in the public school classroom, and (b) to gain insights from their personal experiences in the process of seeing that their child received adequate educational services. The goal was to examine the findings and determine ways in which to improve the educational service delivery. Included in Chapter 5 is a discussion on the theoretical framework, interpretation of the findings, the implications for social change, recommendations for action, recommendations for further study, researcher's reflections on the research process, recommendations for public school administration, and summary and conclusions.

# **Interpretation of the Findings**

The quantitative study findings were upheld by the findings from the qualitative interviews in this study. The themes suggested a lower level of satisfaction on the part of the parent and/or primary caregiver(s) with the educational services for the autistic student in the following areas: (a) overall satisfaction with the educational services; (b) level of satisfaction with educator knowledge, training, and understanding of the autistic condition; (c) level of satisfaction with the successful management of behavioral symptoms associated with the autistic condition; (d) whether the lack of successful management of behavioral symptoms are due to a lack of educator training; (e) which behavioral symptoms are not well managed in the public school classroom; (f) whether the parent and/or primary caregiver(s) have seen an increase or decrease in behavioral

symptoms; (g) which behavioral symptoms have increased; (h) level of satisfaction with collaboration; (i) whether collaboration is successful; (j) which educational service provider was felt to be successful or not in collaboration; (k) level of satisfaction with the IEP; (1) level of satisfaction with the noise level in the public school classroom; (m) level of satisfaction with the overhead lighting in the public school classroom; (n) level of satisfaction with effective communication with the educator; (o) level of satisfaction with the public school classroom as positively structured and organized in order to meet sensory needs; (p) level of satisfaction with educator knowledge of available resources for the parents and/or primary caregiver(s) for stress reduction programs, parental support group, and parental training available in the autistic condition; (q) level of satisfaction with educator support for parent and/or primary caregiver(s) and student with the autistic condition; (r) whether the parent and/or primary caregiver(s) have observed an increase or decrease in educator support based on the behavioral symptoms displayed by the autistic student; (s) what psychiatric diagnosis, if any the autistic student might have; (t) if a psychiatric condition is diagnosed, the level of satisfaction with the educator management of the autistic student's psychiatric symptoms in the public school classroom; (u) level of satisfaction with the public school classroom in its ability to provide their child with a successful learning experience; and (v) level of satisfaction with the consistency in the delivery of autism educational services in the public school classroom. The interview participants and the survey respondents expressed overall satisfaction with the IEP process.

The qualitative findings reflect that the personal interview participants have similar opinions about the educational services provided in the public school classroom. There is agreement about satisfaction with the IEP process and comments were shared about the lack of consistency in following through the goals on the IEP. Difficulty arose in differentiating whether the parents and/or primary caregiver(s) interpret effective communication with the educator as that educator being the classroom aide or the actual educator

### **Implications for Social Change**

This study fills a gap suggested in previous research regarding the inclusion of parental and/or primary caregiver(s)'opinions regarding the educational planning and services their autistic child receives in the public school classroom (Arnini, 2007; ASA Advocate, 1994; Kutash et al. 2006; Mock et al., 2003; Spann et al., 2003). These findings reveal the need for improved educational planning and services with consistent delivery of those services to address the unique sensory needs and supports required for this population. Previous researchers on sensory supports had indicated the need for evidence-based classroom models, based on neuro-biomedical models (Happe, 1993; Just et al., 2006, 2009; Kana et al., 2006; Keller et al., 2007). The researchers pointed out the unique needs children with the autistic condition have and what they require in order to have a quality academic experience in the public school classroom. Collaborative efforts on the part of the various stakeholders in conjunction with involved parents and/or primary caregiver(s) might have an impact on the ways in which the public school

environment has the potential to contribute to changes that would enable children with the autistic condition to improve academically.

The parents and/or primary caregiver(s) repeated the need for the public school to engage more effectively in collaboration with other service providers. That is particularly clear in the comments made in the survey questionnaire. Historically, it has appeared that the public school systems have worked in a silo, likely due to a number of reasons. Many feel that their role is to educate students and due to the varied needs that exist with students on the ASD their role has changed. Based on findings from studies on the autistic condition, efforts to continue to engage the public school system are important. This might be achieved through adequate training for school administrators and educational professionals.

The findings from this study reveal important and meaningful knowledge about the opinions and experiences of the parents and/or primary caregiver(s) that have the potential to contribute to educational planning based on the insights they have gained from their personal experience in how they have managed their child's symptoms, what measures they have taken that have worked, and the effect the experience has had on the family as a whole. The knowledge that the parents and/or primary caregiver(s) are able to contribute provide meaningful insights into how educators can best incorporate parental knowledge into the public school classroom methods and development of a curriculum that has the potential to improve the academic quality of the classroom experience for those with the autistic condition.

Educational planning and programs based on these findings have the potential to reduce the classroom barriers the autistic condition might pose, reduce the daily stress experienced by parents and/or primary caregiver(s), students with the autistic condition, educators, and educational service providers. Previous researchers suggested that managing the autistic condition in a silo is not an effective outreach. Consistent collaborative efforts are necessary in order to act in the best interest of students with the autistic disorder and the challenges they present. The findings from this study have the potential to contribute to overall educational planning for the general and special education classroom milieu in order to reduce what one interview participant whose son is in a mainstream classroom could only describe as chaos.

The use of evidence based models within the classroom, such as ABA and TEACCH have the potential to reduce the stress experienced by educators, students, and caregivers of children with the autistic condition. Specific training for educators and staff in managing the autistic condition within the classroom might reduce behavioral outbursts due to the lack of adequate sensory input and necessary classroom organizational supports. Educators who are adequately trained in autism have shown effective management skills in the behavioral symptoms associated with autism in the classroom environment (Gregor & Campbell, 2001).

Awareness of the mental health issues and psychiatric symptoms among students diagnosed with the autistic condition must be recognized by educators in order to increase their potential for learning. Many public school administrations are working in conjunction with local mental health centers in providing mental health services in the

public schools in recognition of the mental health disorders, such as depression and anxiety among students with the autistic condition. Meeting the needs of students with the autistic condition is imperative in that it will likely improve their chances of academic success. Education for parents and/or primary caregiver(s) regarding mental health needs might provide skills to meet their child's needs. A few of the interview participants were not aware that researchers have found that there are a high number of autistic students who suffer from mental health disorders, such as anxiety and depression.

I sought firsthand knowledge from parents and/or primary caregiver(s). The intent was that the findings might contribute to ways to reduce stress for educators, student, and families and improve the ability of the student with the autistic condition to thrive, make academic strides in the public school classroom, and foster an overall improved quality of life at home and in the public domain.

## **Recommendations for Action**

The findings revealed common themes suggesting the need for the following changes in the educational planning for students on the ASD.

#### Need for Liaison/Coordinator Within the Public School

Many of the participants in the mixed methods study express the lack of collaboration on the part of the service providers. One way in which action steps potentially benefit parents and/or primary caregiver(s) and educators might be through support for an individual to facilitate collaboration/mediation efforts in order to bring educational service providers, public school educators, parents, and students together in recognizing the common goal of successful educational planning for autistic students.

The individual would have knowledge of the needs the student with the autistic condition has in regards to the needed supports that might provide academic success. The individual might bring awareness to parents regarding advocacy steps they can take to assure their child's success in their educational planning. A mediator/collaborator might be employed by the Office of Public Instruction, specializing in autism outreach coordination and familiarity with the specific research on adequate educational supports needed for this population within the public school system. It would be helpful if the individual were familiar with grant funding and legislative efforts in order to explore the funding of evidence-based outreach in the public school classroom.

The individual might have knowledge of local resources and programs designed to support parents and or primary caregiver(s) who have a newly diagnosed child attending the public school. The Montana Office of Public Instruction recently hired a school mental health coordinator. Considering the high number of students within the public school classroom with the autistic condition, a coordinator for autism outreach and services might be considered due to the pressing needs pointed out within this study.

Some parents and/or primary caregiver(s) suggested the need for the public school administration to understand the importance of implementing evidence based interventions and adherence to a behavioral support plan. Since there are a high number of students with the autistic disorder that suffer from anxiety and depression as well as the behavioral challenges the condition presents, a collaboration between an autism outreach coordinator and the school mental health coordinator might benefit students with the autistic condition.

The educator within the public school is not equipped to struggle with the number of issues this study found. Hiring a knowledgeable individual familiar with the needs of the autistic population within the public school system would benefit all educational service providers involved in the coordinated and integrated treatment needed to meet their educational goals. It would potentially benefit the parents and/or primary caregiver(s) through the individual's ability to provide needed resources and knowledge to them while acting as a liaison among the educational and other service providers, such as physicians and mental health professionals.

# Need to Effectively Address Behavioral Challenges and Accompanying Psychiatric Disorders

Sensory distractions potentially trigger behavioral challenges in the public school classroom. Ways in which challenges may be alleviated are through an adequately designed classroom sensitive to sensory issues inherent in students with the autistic condition. Training might inform educators of ways in which the dynamics of the classroom might be less of a distraction for the autistic students. Research had generated findings regarding the noise level, overhead lighting, classroom structure and organization, and use of technology as ways to ameliorate the sensory issues that are potentially exacerbated within the classroom environment.

#### **Need for Educator Training in the Autistic Condition**

The survey respondents and interview participants agreed that the lack of educator management of the behavioral symptoms associated with the autistic condition are the result of the lack of educator training in autism (Table 7). A school coordinator for autism

outreach may be able to provide available resources for educator training opportunities and have the ability to provide an awareness as well as support to educators when needed. The individual would be familiar with evidence based models in educational support for students with the autistic condition as well as knowledge of funding options to bring needed training programs to the educators in the public school system. The skilled coordinator would feel comfortable training within the classroom, if needed in order to eliminate environmental classroom barriers that prevent an autistic student from learning in a beneficial manner. The coordinator would feel comfortable in training a classroom aide in skill building with students with the autistic condition.

#### **Need for Classroom Aides Trained in the Autistic Condition**

The parents and/or primary caregiver(s) suggest that the classroom aide is essential for the student with the autistic condition. One on one support provided by a classroom aide trained in autism appears to contribute to improved behavior and increased learning within the classroom environment. The pair of educators trained in autism outreach might eliminate many of the barriers suggested that currently are within the public school classroom. As one of the interview participants notes regarding the placement of a classroom aide unfamiliar in the autistic condition was not helpful to the student.

## **Need for Educator Knowledge on Parental Support Programs**

Tables 20 through 23 showed findings on the level of satisfaction with the educator knowledge regarding resources for parents and/or primary caregiver(s). Earlier researchers pointed out that there is more parental stress than other groups for those

mothers of a child with the autistic condition due to the difficulties with adjustment, depression, and experienced overall increased stressors (Eisenhower, Baker, and Blacher, 2005). While some personal interviewees expressed that it is the responsibility of the parent and/or primary caregiver(s) to obtain resources for adequate stress management, the need remains and must be addressed.

The quantitative research findings revealed that a high percentage of participants are not informed by the educators that there are available stress reduction programs and activities designed to reduce parental stress. This might be due to a lack of educator training. Parental training regarding the autistic condition is not addressed by educators, as shown by the high number of survey responses. A parental support group was not suggested to the parents and/or primary caregiver(s) by the educator as shown in the findings. Kutash et al. (2006) stated that many children who received services through the SOC were in special education classrooms. At the heart of the SOC is its strategy to provide parental support while valuing parental input into decision-making plans for the child. Kutash et al. stated that the empirical evidence was growing that indicated the need for a comprehensive and integrated approach, and was available through a public health model.

Parental support in light of this study includes addressing the need for educators to be aware of resources in areas of programs and/or resources to reduce parental stress associated with the autistic condition, parental training in the autistic condition, and knowledge of local support groups available to parents in order to make helpful recommendations for parents and/or caregiver(s). The survey questionnaire posed these

questions in order to determine if the educators were knowledgeable enough to enquire whether the parents were even aware of methods that reduce parental stress associated with parenting an autistic child. An autism outreach coordinator within the public school system might contribute to knowledge about resources for parents and/or primary caregiver(s) and provide the educator the opportunity to teach.

### **Need for Classroom Design Based on Sensory Deficits**

While the classroom structure did not appear to be an issue, the interview participants expressed the opinion that the classroom organization could improve. This is likely directly related to other issues within the public school classroom, such as the lack of behavioral management, lack of educator training, and knowledge about the autistic condition. Architects are available to build a sensory supported classroom environment for students with the autistic condition and their goal was to provide proper care for this growing population beyond their home environments (Beaver, 2006). Autism News (2010) confirmed this in that the environmental design for students with the autistic condition must be one that meets their unique needs and contributed to reduced behavioral symptoms, promoted learning, and were organized in such a way that they felt secure, less distracted and overwhelmed, safe, and comfortable within their learning environment.

Continued support for the Montana Autism Waiver program is detrimental for the families of a child with the autistic condition. The program has had great success revealing data that some children who were previously diagnosed with the autistic condition no longer carry the diagnosis when they entered the public school system.

Efforts must be carried out to establish similar programs in states that do not have an autism waiver program and within the State of Montana the slots must be increased in order to meet the needs of those families on the waiting list for the program. Research into methods to assist older adolescents and adults with autism could lead to ways to improve communication and social skills.

## Need for Availability and Supported use of iPads in the Public School Classroom

Clinical trials are currently underway investigating the use of iPads for individuals with the autistic condition (Brasher, 2013). The interview participants suggested the importance of the use of iPads in the public school classroom. Some studies and articles discuss one way in which students with the autistic condition might have improved learning is through the use of supports, such as pictures. Grandin (2008) discussed her experience at length of thinking in pictures. iPads with the specialized programs designed for autistic students has been found to increase student interest in learning, as indicated by the personal interviewees. One benefit of the iPad for autistic students is its predictability with a consistent response to their inquiries when they touch it. Unlike the demand to pay attention to different voices and voice inflections, the iPad has the potential for verbal sameness and familiarity for the user.

Due to the constant barrage of sensory input inherent in the public school classroom environment the iPad has the potential to offer stability and a sense of control for the user with the autistic condition. The use of the iPad has the potential to offer the positive self-stimulation rather than the emission of challenging behaviors that are known to occur in the public school classroom, such as biting, rocking, or hand flapping. The

iPad has software applications that have the potential to contribute to an improvement in language acquisition skills as they speak when the iPad is touched. Some interview participants expressed frustration in keeping up with their child's schedule and the iPad might contribute to scheduling functions and reminders to assist them in developing independence. Due to its capabilities and contributions in assisting this population in the potential for academic achievement and life skills, the iPad might be an integral part of the educational curriculum and plan and a priority for adequate funding venues by the public school system.

## **Recommendations for Further Study**

## Improving Autism Educational Services Through Effective Collaboration

Comments were made by the survey questionnaire respondents that indicate that the public school systems are not willing to collaborate with the autism educational service providers. A proposed mixed methods study might be conducted with public school administrators to determine the degree of reluctance and what factors potentially contribute to potential reluctance. A similar study undertaken with the school administration seeking the opinions and level of satisfaction with autism educational services providers might be conducted. The findings might potentially illuminate areas that might be mediated in order to improve the educational services to the autistic student.

## Recognition of Mental Health Disorders Among Students With the Autistic Condition

Proposed researchers examining the level of knowledge educators, parents and/or primary caregiver(s) have regarding the potential for a mental health disorder among this population might provide awareness about the need for beneficial treatment options for the student with the autistic condition. The potential for anxiety and depression might go unnoticed due to behavioral challenges the student with the autistic condition might present in the public school classroom.

## An Educator's Opinion of Factors Contributing to Classroom Environmental Health

A study might be initiated in order to interview educators on what their specific needs might be in order to provide an environmentally healthy classroom for students with the autistic condition. Educators might be likely to express the nature of any potential barriers that might prevent them from providing beneficial educational services for the autistic student.

# Need for Language Acquisition Studies and Examination of Other Services With Older Children

Studies addressing the need for intervention programs for children on the ASD beyond the age of 3 are needed in order to examine the ability to gain or develop language acquisition and communication skills. At least one personal interview participant was interested in available resources to assist her child with learning more proficient language skills. Some researchers have indicated the need for language

acquisition skills training for the population beyond the age of 3. While early intervention is detrimental, it has been found that older children with the autistic condition were able to learn language skills. Tager-Flusberg and Kasari (2013) stated that the majority of studies had been completed with toddlers, preschoolers, and high-functioning older children with verbal skills due to compliancy of the subjects, there were approximately 30 per cent of children on the ASD with minimal verbal skills who remain to be examined. Tager-Flusberg and Kasari pointed out an intensive case study done by Gordon (2010) with a 12-year-old nonverbal boy on the ASD wherein the boy had progressed from using a one word vocabulary to several words and by the age of 22 was adept at the spoken vocabulary. Tager-Flusberg and Kasari emphasized the uniqueness of each individual with the autistic condition and noted that this may not be successful with everyone on the ASD. This particular case study was achieved through meeting the unique needs of the subject at hand.

Research might be carried out on ways to assist older children with a diagnosis of the autistic condition. Programs, such as the Montana Autism Waiver with its intensive services, had shown great success for the age group it serves; however, there are many children outside the age range who have never had intensive autism services and research could lead to ways in which to assist them in areas that could lead to a positive quality of life, including education and employment.

## **Involving Mental Health Professionals and Physicians**

Mental health providers and physicians are seen as being less involved and supportive in the survey data. Further studies might be undertaken in order to gain

insights into areas of concern and lack of collaboration in the educational services received by students with the autistic condition.

#### **Need for Parental Education and Awareness in the IEP Process**

More education and awareness might benefit parents and/or primary caregiver(s) in understanding the importance of the IEP process and planning for their child's educational goals and in self-advocacy efforts with their children in the public school system. One interview participant stated that the IEP is "the Bible" when it came to seeing that her child's educational goals were met in a consistent manner. Other interview participants commented that the IEP goals are not being consistently met. While overall satisfaction was expressed with the IEP process there are some areas that might be examined in order to determine whether the consistency of delivery is an issue with other parents and/or primary caregiver(s).

## Sensory Integrated Public Classroom vs. a Nonsensory Sensitive Classroom

More studies might be beneficial examining the benefits of a classroom designed specifically for meeting the unique sensory needs of students with the autistic condition. The CDC (2014) reported that one in 68 children suffered from the autistic condition and it would behoove professionals to provide them with classroom environmental health which is likely to benefit all students.

## **Examination of the Educator's Level of Training in the Autistic Condition**

Researchers examining an educator's level of training and knowledge about the autistic condition and how classrooms differ with the educator who is trained compared to the educator who is not trained as the findings might potentially lead to improved

educational services. Examining an educator's areas of frustration in attempting to meet the many needs this population presents could provide ways to improve the environmental health of the students in the public school classroom.

# The Manner in Which Occupational Therapy Provides Services Compared to Other Educational Service Providers

A study addressing the success factors associated with OT service delivery compared to other service providers and what makes the OT services being provided unique and favored by parents and/or primary caregiver(s) might be examined in order to provide findings that might be potentially adapted in order to educate those educational service providers who might be less helpful as suggested in the survey findings.

## **Examining Less Conventional Methods to Reach Students With the Autistic**Condition

More investigation is needed regarding the potential for unique creative capabilities among the autistic individuals who excel in a given craft, such as music, art, or math in order to apply the findings to ways to improve educator awareness and training. It is important to nurture the gifts the student might have and exert less emphasis on what is required by teaching professionals who are likely being responsible but yet intent on meeting educational program goals for funding purposes. How an autistic student learns through methods yet to be examined in regard to music, art, or math might lend to positive learning skills and experiences when applied to other subjects.

#### Benefits of a One-on-One Aide in the Public School Classroom

Research initiated into the benefits of a one on one aide for each student with the autistic condition in the classroom might be undertaken in order to determine whether this is an effective method to support the students and the educator within the public school classroom. If it is found to be an effective approach, the factors that lead to success might be examined in order to provide a universal skills training set designed for assisting students with the autistic condition. This might have the potential to provide data that is supportive of this method. This might enable school districts to gain needed funding towards classroom aides in that it might provide a beneficial learning and environmentally healthy classroom for the autistic students.

## **Student Safety Concerns**

During the course of engaging in this study, there have been numerous media reports concerning autistic students wandering away from the public schools and who met a tragic end. At least one interview participant expressed safety concerns for her child where she felt that the public school has not taken adequate measures to prevent a similar tragedy. It was clear from the interview that this topic weighed heavily upon the mother's mind. Parents and/or primary caregivers might be supported through efforts extended to keep the autistic student safe inside and on the public school property grounds. This issue might be due to the lack of awareness, education, and training regarding the autistic condition. Efforts have been undertaken to recommend a GPS device to track a child with the autistic condition and studies might reveal data that examines its effectiveness.

## Availability and the Supported Use of the iPad

A study examining the potentially beneficial use of the iPad among this population might reveal positive contributions to the autistic student's learning experience with its consistent use. A study might garner needed funding for the school districts in order to provide each student with their own iPad. At least two of the interviewees, parents of children with the classic autistic condition state that the use of the iPad enhances their child's communication skills. Improved communication skill is felt to be one of the needs for individuals with the autistic condition and the iPad is one way to further communication skills. Brasher (2013) found that children ages 5 to 8 years old with the autistic condition developed more proficient language skills, even acquiring the ability to utter full sentences when using speech-generating devices. Clinical trials are currently underway by Kasari, Kaiser, and Landa and results will be available in 2017 (Brasher, 2013).

Lastly, the final proposal will be shared with Heurtevent, an advocate for autistic individuals residing in France. Heurtevent is concerned about the lack of human rights for this population for the reasons outlined in Chapter 2 and has requested international assistance in addressing what he describes as discrimination.

#### Researcher's Reflections on the Research Process

Playing an active role in the development and implementation of the online survey questionnaire brings a great deal of satisfaction. There was constant monitoring and frequent distribution of the availability of the online survey to key stakeholders. It culminated in 109 responses; 79-82 which were repeatedly useful in data analysis.

Controlling the survey outcome and initiating the involvement of key participants in the personal in-depth interviews proved to be rewarding and frustrating at the same time. The incident of having 16 people renege in completing the personal interviews is something that was not initially anticipated.

The initial hope was that the personal interviews would be with more than ten people and would be achieved within a few months. After a year and only seven individuals who had been willing to participate and 16 failing to follow through, I counted myself blessed if I could reach eight and was satisfied with that number. The very first interviewee mentioned that it had been her experience that it was very difficult to find parents and/or primary caregiver(s) who are involved with their children with the autistic condition. I believe I was biased in that I expected the parents and/or primary caregiver(s) to follow through and was disappointed when that failed to materialize. The experience slowed me down precisely 1 year, which was something I had not anticipated and at times did feel discouragement.

My attitude was adjusted after each of the failed encounters and decided this endeavor was a challenge and I wanted only those who were dedicated enough to follow through so dismissed any negative emotions I might have carried with me. With the final interview participant, one gleaned through the Walden Participant Pool, I was elated and the interview turned out to be interesting, informative, and well worth the wait. I did not expect such a high degree of failure to follow through on the part of the parents. My bias was that most parents and/or primary caregiver(s) would be strong advocates for their child. What I found was that few followed through on agreements to participate in the

interview which is their right. Feeling overwhelmed could possibly account for this response. That does not mean they will not be willing to participate in future projects at some point in the future.

I was gratified that I had developed forms (i.e., researcher interview guide and participant interview guide) as it created a focused and well-developed format for the personal interviews. The researcher interview guide was useful in keeping the interview on track when it began to drift into topics other than the study's original investigation. The interview participants knew precisely the purpose and intent of the study and had the opportunity to formulate opinions about what they were being asked. Most were well prepared and more than one made the comment that some of the topics were something they had not thought about or did not initially know, such as the sensory needs within the classroom and mental health issues common to those with the autistic condition such as anxiety and depression. They expressed appreciation in knowing what to look for and be aware of when their children might display symptoms they do not understand.

The interview participants had the opportunity to express what they felt was wrong and what they felt was being done right within the public school classroom. I believe the experience of participating in a personal in-depth interview brought them a measure of knowledge and awareness they would not have gained otherwise. Each interview participant expressed their gratitude for the opportunity to participate and what they learned through the interview process. Some have contacted me post interview to inform me of more things they have learned based on what they initially learned through

the interview process. To date, I keep in touch with several of them as they await the outcome and to reading the final proposal.

#### **Recommendations for Public School Administration**

With the emergence of evidence based studies and ensuing models whose foundation is in biomedical research, it changes the face of education and requires specialized educator training specific to the autistic condition. Since one in 68-80 children are diagnosed with the autistic condition, it means that each educator must be trained whether they are interested in autism or not. There is a high probability that a number of their students will have a diagnosis of the autistic condition requiring a specialized approach. With the specialized training is the need for peer support from seasoned professionals which will contribute to their success with the student population in the public school classroom. Parents and/or primary caregiver(s) suggest that the public school employees do not feel they have to work with other educational service providers.

The strategy best suited to overcome this challenge lies in concerted efforts to address the needs of autistic students through having a dedicated outreach coordinator within the public school system to foster collaboration between educators, educational services providers, and parents and/or primary caregiver(s). Efforts to address the needs of autistic students would likely entail the need for budgetary changes to provide necessary training, programs, and equipment to meet the needs of this population. The area of required adherence to goals based on funding from state or federal levels would

likely create legislative and federal change in order to act in the best interest of the students with the autistic condition in the public school system.

### **Summary and Conclusions**

The mixed method approach to this study attempts to address gaps in the research discussed in Chapter 2. A gap existed in examining the parents' and/or primary caregivers' experiences and opinions regarding the educational services their child receives in the public school classroom. I attempted to fill that void through providing the parents and/or primary caregivers a voice in expressing how their experience of educating their child has affected the quality of their lives and that of their child. I sought to determine those areas of educational services that might be improved. This was achieved through an individual participant interview and an online survey conducted specifically to address some areas that were of concern as discussed in Chapter 2.

During the interview process some common themes arose and include: (a) student safety, (b) lack of adequate use of a classroom aide, (c) lack of educator training and knowledge about the autistic condition;, (d) lack of educator's management of behavioral and psychiatric symptoms associated with the autistic condition, (e) lack of educator knowledge of programs to support parents and/or primary caregivers, (f) the theme of genius gone awry and use of creative teaching strategies to assist the autistic child to succeed academically in the public school classroom, (g) lack of adequate use of the iPad for communication skills building, (h) lack of collaboration of educational service providers, and (i) inadequate mental health services available for those with the autistic

condition. When analyzing the survey data, the same areas were in need of improvement based on the responses provided by the parents and/or primary caregiver(s).

The findings are significant in that they provide insights into the importance of the need for consistent collaborative efforts from knowledgeable educators trained in autism in order to provide effective educational service delivery. A large number of the students have the potential to gain life skills and move on to successful life pursuits if given the educational supports they require. An evidence based approach might potentially reduce the stress for family members and educators in their attempts to deal with the day to day behavioral challenges brought on by a diagnosis of the autistic condition. It is imperative that a consistent and collaborative approach be implemented within the public school system in order to meet the needs of the one in 68-80 students who are diagnosed with the autistic condition. The fact that the Montana Autism Waiver recipients have data and at least one documented case of a child who no longer carries the diagnosis of autism is meaningful and reveals the necessity of addressing the points discussed in this study.

Addressing the global impact of the autistic condition, primarily for the individuals who are highly discriminated against in countries, such as France where they are not even allowed in the public schools for more than an hour a week deserves our attention. While the French psychoanalytic community repeats that they are working on evidence based studies, nothing has been produced. This study outlines alternative biomedical models with a solid foundation that sufficiently explain the origin of the autistic condition. The biological basis for the autistic condition does not include the

model of the refrigerator mother which has no basis in scientific exploration or in common sense. In the meantime, parents such as Roberts must send their children to Belgium or the United States in order to receive the education they deserve. It is ironic that from the French community emerged dedicated individuals, such as Itard and Deligny, who believed that the autistic individuals could succeed and left documentation of their approaches, efforts, and successful strides of those they served. The French community, particularly the professional community, must not forget the past contributions of their fellow countrymen who believed that the autistic individuals could succeed when provided the attention and supports they require.

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mental retardation, and normally developing individuals. *Psychological Bulletin*, *124*(3), 283-307. doi:10.1037/0033-2909.124.3.283

## Appendix A: IRB Approval

Subject: Notification of Approval to Conduct Research-Antonia Klein

Date: Thu, Mar 21, 2013 10:59 AM CDT

From: IRB <IRB@waldenu.edu>

To: Antonia Klein <antonia.klein@waldenu.edu>

Reply To: IRB <IRB@waldenu.edu>

CC: Sreeroopa Sarkar < Sreeroopa. Sarkar @email.waldenu.edu >, Walden University

Research research@waldenu.edu

Dear Ms. Klein,

This email is to serve as your notification that Walden University has approved BOTH your dissertation proposal and your application to the Institutional Review Board. As such, you are approved by Walden University to conduct research.

Please contact the Office of Student Research Administration at research@waldenu.edu if you have any questions.

Congratulations!

Jenny Sherer Associate Director, Office of Research Ethics and Compliance Leilani Endicott IRB Chair, Walden University Appendix B: IRB Approval Renewal

Original E-mail

From :IRB [IRB@waldenu.edu] Date :03/13/2014 11:37 AM

To:"'antonia.klein@waldenu.edu'" [antonia.klein@waldenu.edu] CC:Sreeroopa Sarkar [Sreeroopa.Sarkar@email.waldenu.edu]

Subject: Request for IRB Approval Extension

Dear Ms. Klein,

Subject: Request for IRB Approval Extension

Dear Ms. Klein,

This e-mail serves to inform you that your request to have an extension for the study # 03-21-13-0099018 has been approved. You thus have one year to gather the data for your study and your new expiration date is March 12, 2015. One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you need to collect data beyond the new approval expiration date. Also attached to this e-mail is the revised consent form which contains the new IRB expiration date. If this consent form is already in an on-line format it will need to be revised to reflect the new expiration date. Both students and faculty are invited to provide feedback on this IRB experience at the link below:

http://www.surveymonkey.com/s.aspx?sm=qHBJzkJMUx43pZegKlmdiQ\_3d\_3d Sincerely,

Jenny Sherer, M.Ed., CIP Associate Director Office of Research Ethics and Compliance irb@waldenu.edu Fax: 626-605-0472 Office address for Walden University: 100 Washington Avenue South, Suite 900 Minneapolis, MN 55401

## Appendix C: Survey Questionnaire

1.	Are you the primary caregiver of a child diagnosed with autism attending a		
	school?		
	•	Yes	
	•	No	
2.	What	is your level of satisfaction with the autism educational services your child	
	receives in the public school?		
	a)	Not at all satisfied	
	b)	Slightly satisfied	
	c)	Somewhat satisfied	
	d)	Very satisfied	
	e)	Extremely satisfied	
3.	Which	of the following are you extremely satisfied with?	
	a)	Classroom structure	
	b)	Educator knowledge about autism	
	c)	Noise level of the public classroom	
	d)	Overhead lighting	
	e)	Effective communication with educator	
	f)	Participation in Individual Education Plan (IEP)	

Support from your child's educator

g)

4. Which of the following are you not at all satisfied with? a) Classroom structure b) Educator knowledge about autism Noise level of the public classroom c) Overhead lighting d) e) Effective communication with educator f) Participation in Individual Education Plan (IEP) Support from your child's educator g) What is your level of satisfaction regarding the amount of knowledge and 5. understanding your educator has about the autistic disorder? Not at all satisfied a) b) Slightly satisfied Somewhat satisfied c) Very satisfied d) Extremely satisfied e) 6. What is your level of satisfaction regarding the educator's successful management of the behavioral symptoms associated with autism in the public school classroom? Not at all satisfied a) Slightly satisfied b) c) Somewhat satisfied

Very satisfied

d)

	e)	Extremely satisfied		
7.	Answe	er only if you chose Not at all satisfied in previous question. Do you believe		
	that th	e lack of the successful management of behavioral symptoms in the public		
	school	classroom is the result of a lack of educator training and knowledge about		
	autism	?		
	•	Yes		
	•	No		
8.	Which	of the following behavioral symptoms do you feel are not well-managed		
	by the educator in the public school classroom?			
	a)	Aggression		
	b)	Easily distracted		
	c)	Self-injurious behaviors, such as head-banging or biting self		
	d)	Behavioral outbursts		
	e)	Rocking		
	f)	Self-stimulation, such as rocking		
	g)	Other		
9.	Since	Since your child began attending the public school, have you seen an increase in		
	any of your child's behavioral symptoms?			
	•	Yes		
	•	No		

	10.	If the answer is yes to #9, which of the following behavioral symptoms have		
increased?			sed?	
<ul><li>a)</li><li>b)</li><li>c)</li><li>d)</li></ul>		a)	Aggression	
		b)	Easily distracted	
		c)	Self-injurious behaviors, such as head-banging or biting self	
		d)	Behavioral outbursts	
		e)	Rocking	
		f)	Self-stimulation, such as rocking	
Ş		g)	Other	
			is your level of satisfaction with the collaboration between the schools and	
			autism service providers (i.e., occupational therapy, speech therapy,	
medical, mental health)?		eal, mental health)?		
		a)	Not at all satisfied	
		b)	Slightly satisfied	
		c)	Somewhat satisfied	
		d)	Very satisfied	
		e)	Extremely satisfied	
If not at all satisfied, please explain what is not being done in a collaborative manner.				
12. Do you believe the collaboration between the schools and other au providers is an effective collaboration that benefits your child?		Do yo	ou believe the collaboration between the schools and other autism service	
		ders is an effective collaboration that benefits your child?		
		•	Yes	

	•	No	
13.	Whic	h service provider is the most effective in collaboration with the public	
	schoo	l system?	
	a)	Occupational therapy provider	
	b)	Speech therapy provider	
	c)	Medical provider	
	d)	Mental health provider	
14.	Which service provider is the least effective in collaboration with the public		
	schoo	l system?	
	a)	Occupational therapy provider	
	b)	Speech therapy provider	
	c)	Medical provider	
	d)	Mental health provider	
15.	What is your level of satisfaction with your ability to participate in your child's		
	Indivi	idual Education Plan (IEP)?	
	a)	Not at all satisfied	
	b)	Slightly satisfied	
	c)	Somewhat satisfied	

Very satisfied

Extremely satisfied

d)

e)

16.	What is your level of satisfaction with the noise level in the public classroom			
	enviro	environment?		
	a)	Not at all satisfied		
	b)	Slightly satisfied		
	c)	Somewhat satisfied		
	d)	Very satisfied		
	e)	Extremely satisfied		
17.	What is your level of satisfaction with the overhead lighting in the public			
	classroom environment?			
	a)	Not at all satisfied		
	b)	Slightly satisfied		
	c)	Somewhat satisfied		
	d)	Very satisfied		
	e)	Extremely satisfied		
18.	What is your level of satisfaction with effective communication with your child's			
educator?		or?		
	a)	Not at all satisfied		
	b)	Slightly satisfied		
	c)	Somewhat satisfied		
	d)	Very satisfied		
	e)	Extremely satisfied		

19. What is your level of satisfaction in the public classroom being positively structured and organized to meet the sensory needs of your child? a) Not at all satisfied Slightly satisfied b) Somewhat satisfied c) d) Very satisfied e) Extremely satisfied 20. What is your level of satisfaction with the recommendation suggested by your child's educator to participate in stress reduction activities? Not at all satisfied a) b) Slightly satisfied Somewhat satisfied c) d) Very satisfied e) Extremely satisfied f) Educator did not suggest stress reduction activities 21. What is your level of satisfaction with the recommendation suggested by your child's educator to attend a parent support group? Not at all satisfied a) Slightly satisfied b) Somewhat satisfied c) d) Very satisfied e) Extremely satisfied

- f) Educator did not suggest a parental support group

  22. What is your level of satisfaction with the recommendation suggested by your child's educator to attend classes for parental training in autism?

  a) Not at all satisfied

  b) Slightly satisfied

  c) Somewhat satisfied
  - d) Very satisfied
  - e) Extremely satisfied
  - f) Educator did not suggest parental training in autism
- 23. What is your level of satisfaction with the amount of educator support received by you and your child?
  - a) Not at all satisfied
  - b) Slightly satisfied
  - c) Somewhat satisfied
  - d) Very satisfied
  - e) Extremely satisfied
- 24. If your child has severe behavioral symptoms, have you observed a decrease in the educator's support of you and your child?
  - Yes
  - No

25.	If your child has severe behavioral symptoms, have you observed an increase in		
	the educator's support of you and your child?		
	•	Yes	
	•	No	
26.	Has your child been diagnosed with any of the following psychiatric disorders?		
	a)	Anxiety	
	b)	Depression	
	c)	Mood disorder	
	d)	Schizophrenia	
	e)	Bipolar disorder	
	f)	Sleep disorder	
	g)	Elimination disorder	
	h)	Other	
27.	If diagnosed with a psychiatric condition, what is your level of satisfaction with		
	the educator's classroom management of your child's symptoms due to their		
	psychiatric disorder?		
	a)	Not at all satisfied	
	b)	Slightly satisfied	
	c)	Somewhat satisfied	
	d)	Very satisfied	
	e)	Extremely satisfied	

- 28. What is your level of satisfaction with the educational services your child has received in the public school classroom making it one that contributes to a successful learning experience?
  - a) Not at all satisfied
  - b) Slightly satisfied
  - c) Somewhat satisfied
  - d) Very satisfied
  - e) Extremely satisfied

If yes, please discuss what factors you believe contribute to a successful learning experience for your child.

- 29. What is your level of satisfaction with the consistency of the educational services provided to your child in the public classroom?
  - a) Not at all satisfied
  - b) Slightly satisfied
  - c) Somewhat satisfied
  - d) Very satisfied
  - e) Extremely satisfied

If not at all satisfied, please explain what is not being done consistently.

- 30. What is your yearly income?
  - a) \$15,000-\$25,000
  - b) \$25,000 \$35,000
  - c) \$35,000 \$45,000

	d)	\$45,000 and over
	e)	Prefer not to answer
31.	What i	s your marital status?
	a)	Married
	b)	Single
	c)	Divorced
	d)	Separated
32.	What is your ethnic backgro	
	a)	European American
	b)	Mexican American
	c)	American Indian
	d)	African American
	e)	Asian American
	f)	Other
	g)	Prefer not to answer

#### Appendix D: Informed Consent Form

#### CONSENT FORM

You are invited to take part in a research study of the environmental health of the autistic student in the public school classroom. You were chosen for the study because you are the primary caregiver of a child with autism. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Antonia Klein, who is a doctoral student at Walden University.

### Background Information:

The purpose of this study is to examine the opinions and experiences of parents with an autistic child in the public school classroom regarding the overall classroom (e.g.,) lighting, structure and organization, educator's management of behavioral symptoms, educator's knowledge about autism, and other potential barriers contributing to a lack of academic progress. There is a gap in the literature regarding recommendations to include the primary caregiver and/or parent(s) in the educational planning for their autistic child who attends the public school.

#### Procedures:

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

 Participate in a personal in-depth interview in order to respond to four interview questions which should take approximately 1 hour 30 minutes.

- Participate in a 32-question survey which should take approximately 30 minutes.
- Confer with Ms. Klein for a transcript review and one additional check-in session after the interview regarding the accuracy and/or meaning of your experiences.

Voluntary Nature of the Study:

Your participation in this study is voluntary and there will be no penalty to excuse yourself from the study. This means that everyone will respect your decision of whether or not you want to be in the study. No one at Best Beginnings or David Counseling will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind during the study. If you feel stressed during the study you may stop at any time. You may skip any questions that you feel are too personal.

Risks and Benefits of Being in the Study:

Due to the potential risk that you may experience an increase in stress as you share your experiences in the interview Carrie David, a licensed professional counselor is available for one low cost counseling session in order to assist you in resolving any stress you may have after the interview. Carrie David's phone number is 406-852-0056. The benefits include having your voice heard which potentially lends to the development of ways to improve the public school classroom and reduce the stress for parents, educators, and the autistic student.

#### Compensation:

Compensation in the way of a \$10.00 Visa gift card will be presented to you upon completion of the personal in-depth interview and survey questionnaire.

#### Confidentiality:

The information you provide in the personal in-depth interview will be kept confidential and your responses to the survey questionnaire will be anonymous. The researcher will not use your information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in any reports of the study.

### Limits to Confidentiality:

Limits to confidentiality include the following:

- A reasonable suspicion that you are imminent risk of a suicide attempt or commission of a homicide, or if you describe yourself to the researcher as being at risk, steps will be taken to protect your safety and the safety of others. Situations such as described will require breaking confidentiality.
- If you report that you are abusing a child, I am mandated to notify the Department of Public Health and Human Services and/or local law enforcement.

In some instances, the courts may subpoen records. I would work with you and with the court to attempt to limit the release of information to only those documents that are necessary.

If you require emergency medical or mental health care, I will provide relevant information about you to those professionals involved in overseeing your care. Contacts and Questions: You may ask any questions you have now. Or if you have questions later, you may contact Antonia Klein, the researcher, via or Sreeroopa Sarkar, Ph.D. is the Chair of Ms. Klein's proposed research study and may be reached at Sreeroopa.sarkar@waldenu.edu. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is 1-800-925-3368, extension 1210. Walden University's approval number for this study is 03-21-13-0099018 and it expires on March 20, 2014. The researcher will give you a copy of this form to keep. Statement of Consent: I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below I am agreeing to the terms described above. Printed Name of Participant Date of consent Participant's Written or Electronic\* Signature

#### Antonia Klein

Researcher's Written or Electronic\* Signature

Electronic signatures are regulated by the Uniform Electronic Transactions Act. Legally, an "electronic signature" can be the person's typed name, their email address, or any other identifying marker. An electronic signature is just as valid as a written signature as long as both parties have agreed to conduct the transaction electronically.

#### Appendix E: Online Consent Form

#### CONSENT FORM FOR AN ONLINE SURVEY

The Environmental Health of the Autistic Student in the Public School Classroom
Informed Consent Form

You are invited to take part in this online survey questionnaire because you are the parent and/or primary caregiver of a autistic child who is a student in the public school system. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Antonia Klein, who is a doctoral student at Walden University. The purpose of this study is to examine the your level of satisfaction through your opinions and experiences as a parent and/or primary caregiver with an autistic child in the public school classroom regarding the overall classroom (e.g.,) lighting, structure and organization, educator's management of behavioral symptoms, educator's knowledge about autism, and other potential barriers contributing to a lack of academic progress.

#### Procedures:

If you agree to participate in this online survey questionnaire:

You will be asked to complete a 32-question survey which should take
approximately 30 minutes. Some of the questions ask for demographic
information (e.g., income, marital status, and ethnic background) in order
to describe the group of individuals who participate in the study

Voluntary Nature of the Study:

Your participation in this study is voluntary and you may stop at any time. You may skip any questions that you feel are too personal.

Benefits of Being in the Study:

The benefits include having your voice heard which potentially lends to the development of ways to improve the public school classroom and reduce the stress for parents, educators, and the autistic student.

Risks or Discomforts:

No risks or discomforts are anticipated from participating in this study. If a question makes you feel uncomfortable, skip that question. You are free to withdraw from the study at any time.

# Confidentiality:

The information you provide will be kept confidential. Your responses to the survey questionnaire will be anonymous and we will not collect any identifying information such as your IP address. All data will be stored in a password protected electronic format.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact Antonia Klein, researcher via \_\_\_\_\_\_ or zahmeirklein@gmail.com. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone

number is 1-800-925-3368, extension 1210. Walden University's approval number for this study is 03-21-0099018 and it expires on March 15, 2015.

Electronic Consent: Please select your choice below.

Clicking on the "agree" button below indicates that:

- You have read the above information
- You voluntarily agree to participate
- You are at least 18 years of age
- You are a parent and/or primary caregiver of an autistic child in the public school system.
- Agree
- Disagree

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Appendix F: Letters of Cooperation

Doctoral Dissertation Research Study Antonia Klein, Doctoral Candidate

Health Psychology Program Walden University

Community Research Partner Name: David Counseling

Contact Information: Carrie David,

Date: 11/9/2012 Dear Antonia Klein,

Based on my review of your research proposal, I give permission for you to conduct the

study entitled, "The Environmental Health of the Autistic Student in the Public School

Classroom" with Carrie A. David, and within David Counseling. As part of this study, I

authorize you to recruit and interview contacts we have referred to you for research

purposes. Individuals' participation will be voluntary and at their own discretion. We

reserve the right to withdraw from the study at any time if our circumstances change.

I confirm that I am authorized to approve research in this setting.

I understand that the data collected will remain entirely confidential and may not be

provided to anyone outside of the research team without permission from the Walden

University IRB.

Sincerely,

Electronically Signed: Carrie David, LCPC 11/9/12

Carrie David, LCPC David Counseling



Doctoral Dissertation Research Study

Antonia Klein, Doctoral Candidate Health Psychology Program Walden University

Community Research Partner Name: Best Beginnings

Contact Information: Kent Doughty, Molly Wendland,

Date: 10/27/2012

Dear Antonia Klein,

Based on my review of your research proposal, I give permission for you to conduct the study entitled, "The Environmental Health of the Autistic Student in the Public School Classroom" within Best Beginnings. As part of this study, I authorize you to recruit and interview contacts we have referred to you for research purposes. Individuals' participation will be voluntary and at their own discretion. We reserve the right to

I confirm that I am authorized to approve research in this setting.

withdraw from the study at any time if our circumstances change.

I understand that the data collected will remain entirely confidential and may not be provided to anyone outside of the research team without permission from the Walden University IRB.

Sincerely,

Electronically signed: Kent Doughty 10/27/2012 Authorization Official Best Beginnings

#### Appendix G: Participant Interview Guide

#### Antonia Klein doctoral dissertation research 2012

Antonia Klein, a doctoral student in the Health Psychology program at Walden University has developed this participant interview guide regarding the research study, "Environmental Health of the Autistic Student in the Public School Classroom" in order to inform participants about the proposed study. This research study is seeking parental and/or caregiver input on their level of satisfaction with the educational services provided to their autistic child within the public school classroom and whether those services promote positive classroom environmental health. Your contribution to this research is important as I attempt to identify potential barriers in the public school classroom for autistic students and seek ways to improve services in the classroom.

You are reading this information because you have been invited to participate in the research study. Before deciding to participate in this study it is important for you to understand why the research study is being conducted and what it will involve. The study consists of a personal interview regarding your level of satisfaction with the services your autistic child has received in the public school classroom. The interview is expected to last about 60 minutes. The researcher will use an IPAD audio/visual recording feature and/or cassette tape recording instrument, and personal notes. When the interview is completed you will be asked to participate in a 32-question survey questionnaire that will be available on the internet at surveymonkey.com. Please take your time in order to understand what is required of you in the study and please feel free to discuss the study with others if you desire. The researcher does not want you to feel pressured and carries

no preconceived ideas about your personal experience. You are encouraged to freely express your opinions about your experience in the in-depth interview with the researcher. While the interview questions are formatted, the free flow of your ideas is encouraged. Please do not hesitate to ask questions or if you feel you would like more information. Please do not hesitate to ask if you feel something is not clear. I have provided contact information below. The Chair of this dissertation proposal is Sreeroopa Sarkar, Ph.D and her contact information is provided below. The contact information for the Research Participant Advocate at Walden University is also provided below if you have any questions regarding your rights as a research participant.

The interview will take place in a location in which you feel entirely comfortable. You will be recorded during the course of the interview and the researcher will likely make notes during your response to specific questions that are asked of you. You may observe the researcher referring to a structured interview guide and employing the use of probes or further questions or comments that arise due to a certain interview topic. This is because the researcher may feel that the topic should be explored in greater detail. When the interview and survey questionnaire is completed, the researcher will keep you informed during the course of the remaining dissertation process. You will be given a rough draft of your portion of the interview to review in order to accurately reflect your contribution and changes will be made if you so desire them. You may be consulted regarding your meaning of certain statements in order to accurately reflect your experience and meaning to the information you contributed during the interview process.

Our contact following the interview and survey questionnaire completion will likely consist of a transcript review and one follow-up session.

Participation in the research study is entirely voluntary. You do not have to take part if you change your mind at any point in the process. You may withdraw without providing an explanation. Each individual who expresses an interest in participating in the study will be provided an informed consent form and an explanation of the parameters of the study including confidentiality issues, such as limits to confidentiality. Limits to confidentiality include the following:

- A reasonable suspicion that you are imminent risk of a suicide attempt or commission of a homicide, or if you describe yourself to the researcher as being at risk, steps will be taken to protect your safety and the safety of others. Situations such as described will require breaking confidentiality.
- If you report that you are abusing a child, I am mandated to notify the Department of Public Health and Human Services and/or local law enforcement.
- In some instances, the courts may subpoena records. I would work with you and with the court to attempt to limit the release of information to only those documents that are necessary.
- If you require emergency medical or mental health care, I will provide relevant information about you to those professionals involved in overseeing your care.

In recording the results of the findings of this study real names will not be used but real events are likely to be revealed excluding location and names of the school and other individuals who may be involved.

The data from the quantitative portion of the study will be collected from surveymonkey.com at the end of the survey, and based on convenience for participating organizations and individuals.

Upon completion of the personal interview your efforts will be reciprocated with a \$10 Visa gift card to thank you for your contribution. If you find that discussing your experience caused you to feel any stress, Carrie David, a licensed professional counselor is available for one low cost counseling session in order to assist you in resolving any stress you may have after the interview. Carrie David's phone number is My dissertation proposal has undergone an institutional review board (No. 03-21-13-0099018). The expiration date for the Institutional Review Board application is March 20, 12014. Thank you in advance for your participation and for reading the information and guidance sheet. At the conclusion of the study, I intend to meet the individual participants locally and with those participants whose personal interview will be conducted telephonically in order to wrap-up the study and debrief the participants and determine if they have any questions regarding the study.

consent grven.		
Name		
Date:		

Consent given:

# Contact information:

Antonia Klein, Ph.D. candidate

Sreeroopa Sarkar Sreeroopa.sarkar@waldenu.edu

# Appendix H: Researcher Interview Guide

# Antonia Klein Doctoral Dissertation, 2012 Structured Interview Guide

Welcome participant and thank them for their participation in this important study.

Discuss the purpose of the study.

The questions you will be asked will be asked of all participants who have agreed to participate in the personal, in-depth interview and in the survey questionnaire. There is no right or wrong answer. You should respond based on your experience and what it meant to you. Emphasize you are free to stop if you feel you must and leave anytime you wish. Privacy statement:

What personal information you are collecting: Inform participant whether you are collecting the responses anonymously or tracking by email address, ticket number, code, etc. Inform the participant the types of personal information the survey asks for (Ethnic background, yearly income, location, male or female).

How you plan to use the responses: Inform the participant why you are conducting the survey and what you plan to do with the results. After data collection and analysis the findings will be presented to you and to stakeholder agencies, Best Beginnings and Carrie David, LCPC.

Whether responses will be disclosed to anyone else: The results of the survey questionnaire will not be detected due to configuration on surveymonkey.com. The researcher will be the only individual with access to the data. Jeanette Prodgers, MSW

may be asked to review statistical data that has been analyzed for accuracy and that data is anonymous. Inform participants of the limits to confidentiality outlined in the Participant Interview Guide and Consent Form and the Research Consent Form.

Research interview questions:

1. What is the lived experience of the parents and the process they underwent regarding the adequacy of current educational services their child receives in the public classroom? Prompts: What has the experience been like for you in seeing that your child received adequate educational services in the classroom? Tell me the details about what you have gone through. Please share examples and background information of how the experience has affected you as well as your child. Please tell me the details about the relationship between you and your child's educator, if any regarding these issues.

2. What is the opinion of the parents regarding the quality of the classroom structure for their child? Go over each one.

Tell me your opinion about the quality of the:

Classroom structure for your child

Organization

Overhead lighting

Management of behaviors associated with autism

Educator knowledge about autism

Noise level

Educator management of behavioral /psychiatric symptoms

Effective communication with educator

Participation in Individual Education Plan (IEP)

Support from your child's educator for you and your child

Satisfaction with the educator's level of knowledge about autism

Satisfaction with the educator's level of training in autism

Knowledge of mental health issues common in autism

Knowledge of programs designed to reduce parental stress

Tell me whether your child has improved academically or not.

Whether there is the availability of an integrated treatment approach consisting of mental health, occupational therapy, speech therapy

Opportunities for expression of parental input into daily activities based on parental knowledge about their autistic child

- 3. What is the parents' opinions regarding the current environmental health of the public classroom in its ability to afford their child the best learning experience?
- 4. What do parents think might be the environmental health barriers that exist in the public classroom, if any?

Tell me what your opinion is regarding any environmental health barriers that might exist.

Appendix I: Stakeholder Agency Advertising Flyer

Environmental Health of the Autistic Student in the Public School Classroom Study

Be part of an important autism research study.

- Are you the parent or primary caregiver of an autistic student in the public school classroom?
- Do you want to express your opinions regarding the services your child receives in the public school classroom?

If you answered YES to these questions, you may be eligible to participate in a personal in-depth interview with the researcher and a 32-question survey questionnaire that is available on surveymonkey.com.

The purpose of this research study is to seek opinions of the parents and/or primary caregivers whose child is diagnosed with autism and receives services in the public school classroom. Your opinion will be asked regarding your level of satisfaction with teacher training and knowledge about autism, level of educator support you and your child receive, use of evidence-based programming in the classroom, level of satisfaction with sensory supports, behavioral management, overhead lighting, service provider collaboration, and noise level. These factors are being investigated in order to determine whether they contribute to a positive and healthy classroom environment and learning experience for the autistic student. Benefits include being a part of this exciting study and the opportunity to express your opinions through the survey now available on surveymonkey.com.

https://www.surveymonkey.com/s/8M96QH9

Please call Antonia Klein, Ph.D candidate, Walden University at information.

IRB 03-21-13-0099018 Expires 3/20/15

#### Appendix J: Online Survey Advertising Flyer

# Environmental Health of the Autistic Student in the Public School Classroom Study

Be part of an important autism research study.

- Are you the parent or primary caregiver of an autistic student in the public school classroom?
- Do you want to express your opinions regarding the services your child receives in the public school classroom?

If you answered YES to these questions, you may be eligible to participate in an online survey questionnaire that is part of an autism research study that will take about 30 minutes of your time.

The purpose of this research study is to seek opinions of the parents and/or primary caregivers whose child is diagnosed with autism and receives services in the public school classroom. Your opinion will be asked regarding your level of satisfaction with teacher training and knowledge about autism, level of educator support you and your child receive, use of evidence-based programming in the classroom, level of satisfaction with sensory supports, behavioral management, overhead lighting, and noise level. These factors are being investigated in order to determine whether they contribute to a positive and healthy classroom environment and learning experience for the autistic student. Benefits include being a part of this exciting study and the opportunity to express your opinions through the survey now available on surveymonkey.com.

https://www.surveymonkey.com/s/8M96QH9

Please call Antonia Klein, Ph.D candidate, Walden University at for more information.

IRB No. 03-21-13-0099018 Expires 3/20/2015 Appendix K: Sample Interview Transcript

Interview Transcript 8 (I-8)

March 22, 2014

AK: This is Antonia Klein and I am interviewing I-8?

I-8: That is correct.

AK: L, I have about four questions that I am going to ask you. They are asked of all of the participants who have agreed to participate. The first one is I want to know how your experience has been having a child with autism and you can start anywhere you want. You can start the minute you got the diagnosis or what you suspected beforehand or you can start with what your experience has been with the educational process with your child so it is up to you.

Question No. 1: What is the lived experience of the parents and the process they underwent regarding the adequacy of current educational services their child receives in the public classroom?

I-8: I will just kind of start at the beginning. I had my first child in 2000 and he was just trucking along. Now as a first time Mom I grabbed all of the books and I was marking all the milestones and he was doing just great and doing everything on time and even in some things a little advanced so I was not concerned. What I noticed at about maybe 12 months or so his interactive skills seemed to die down. He did less pointing. He just seemed to sort of withdraw a little bit and initially I wasn't concerned but as time went on and I noticed he wasn't hitting the milestones like he should be that is when I became concerned. Around 18 months or so is just seemed like someone just pulled down the

shades as he just kind of went into a box. I just could see it in his eyes. I could see it in his face. He just became dull and that was when I got really scared so I took him to a pediatrician and he did some tests and he said, "I want to test him on Fragile X Syndrome" and I said, "What's that?" He said, "Well, I don't want alarm you but it is a test to determine if your child may have autism or some other chromosomal disorder that caused him to start behaving the way that he is." I was a first time Mom and I didn't know anything about autism. That wasn't on my radar. Like every first time Mother or anytime Mother you expect to have a perfectly healthy child. You have all these great ideas about what your child is going to do and what a great life they are going to have and I was devastated. I was devastated and at the same time I was determined because I wanted to know everything I possibly could about autism. I wanted to know if it was curable. I wanted to know if there was anything I could do to help my son be functional in the world. The Fragile X Syndrome test came back negative. Then we were referred to a child psychiatrist. We took him to the best of the best in Washington, DC which is where we were living at the time. He was ultimately diagnosed with autism. My then husband absolutely refused to accept the diagnosis, you know. He said, "There's no way; you are over-reacting, you are just being paranoid, he is fine, he is going to be fine." Fortunately, I did not listen to him which is probably why we are divorced but I didn't listen to it. I got my son into speech therapy right away and into social situations where he was forced to interact with other people but I will tell you that from the time my child was 18 months old until he was nearly five he never spoke one word. He did not say anything. He would look. He would smile but he never spoke one word. I started to

believe that I would never even get the chance to hear him say Mom or I love you or anything but you know I trust God. I read to him every day. I bought the Bob books which is a series of starter books just to sort of help him start to look at words and put words together. I thought maybe it will change and everything I could think of and everything that made sense and something that didn't to try to get him to come out of that dark place where he had retreated to. I think about just before his fifth birthday I can't remember what I said to him but he said, "I love you, Mom."

AK: Wow.

I-8: I just lost it. I just lost it but in that moment I knew he is there, you know he is in there and I have to get him out so I will tell you what I have experienced with an autistic child has been humbling. It's been sad. It's been lonely and at the same time it has been one of the most amazing ordeals of my life because it has taught me so much about me and he has taught me about how to help someone which I thought I knew how to do until I met him; until he became a part of my life. My focus has been on helping him to receive. I have had many opportunities. I have had many services; taking anything and everything available to him to help him to get to a functional life where he can be independent and he can live on his own.

AK: How old is he now?

I-8: He is 14. He just turned 14 in January. It's been rewarding but it has also been very challenging. What I found in the public school system is that there are not very many teachers that know very much about autism. They have heard about it but they don't really know what autism is or how it affects a child in the learning environment. Even

Special Education teachers are not always trained in autism. They have sort of a general Special Education background but you know they don't specialize in autism. My experience has been if your child is different and I don't say disability. I say my child is differently abled because he is certainly able to do anything that I am not able to do and will never be able to do. He can listen to himself on the radio playing on four instruments. I can't even balance my checkbook so you know there are some things he is absolutely genius at. Then there are some places where he struggles but it has been my experience that when you have a differently abled child the bar automatically drops for that child in that expectations for that child become much, much lower and the general sense of that is, "Well, you know let's not push it too hard. We can't expect that much." From the very beginning I was adamantly opposed to anyone thinking of my child as "less than" and I wrote many notes to many school principals and met with many teachers and probably affected as many people and told them my expectations of my child are entirely different than yours. My child is differently abled and so you will have to learn so you will have to teach someone who doesn't follow the standard of toy box curriculum that you have followed for the last twenty five years. Along the way I have absolutely made some friends. I have enlightened some people and it looks like I have created a pathway for my child whereby he will be able to be independent and he will be able to be successful in whatever he chooses to do.

AK: Wonderful, wonderful. You have had experience in many different school systems, right?

I-8: Yes.

AK: Do you want to talk to me a little bit about that? Some details about what you went through you can use an example of any of those school systems. A common theme in this is the lack of educator training in autism.

I-8: Oh yes, absolutely. Let me tell you about my initial experience where my child was all set to go to school in Washington, DC. My very socially elite ex-husband said, "We will put him in a private school" so we interviewed with these private schools the private schools said, "We don't have the resources to manage a child with autism. We are structured around "normally abled children" ("Whatever that means, in quotations.") and "gifted children." (Again, in quotations because whatever that means.) I feel like my child is gifted in so many ways. They just didn't have the tools and resources to deal with a differently abled child so my ex-husband was very disappointed that we would have to put him in the public school but we looked at the school in the neighborhood, it was a couple of blocks up and we will see what happens. We put him in the neighborhood school and I will never forget this and my child's name is WB and all the forms when we had met with everyone we told them "he is autistic and here are some of the challenges we see but he is responsive and he is able" and you know, whatever so he goes to school the first day and of course he has the label of autism on his records which I wonder if that was a good thing or a bad thing, I don't know. I still wonder that sometimes but the teacher calls roll and she says, "W." Well, we have never called him W up to that point. I don't think he even recognizes that was his name. We always called him B. That is his middle name. B, B, B. So, when the teacher called him W, he didn't respond so a couple of days go by and the principal calls us up to the school and say, "Your child is not a high functioning autistic person. He is very severely disabled. This child does not even respond to his own name." We are like, "what are you talking about?" "Well, the teacher has been calling him W and he absolutely does not respond." I said, "Well yea because nobody calls him W. It is his formal name but nobody uses it. We all call him B. Try B and he may respond." The consensus was that, "You were talking about your child as differently abled, now I know and he shouldn't be in this classroom and I don't want to deal with it. Put him in a Special Education classroom." It was always my goal from the very beginning that my child would be in the regular classroom and that whatever it took for him to be in the regular classroom that is what is going to happen.

AK: L, how old was he at this time?

I-8: He was five years old.

AK: Ok.

I-8: It was a battle, you know so I met with this principal of this school he went to, the elementary school, JLM and met with her. I said, "Listen, this falls under the ADA, right? And so you have to make accommodations for my child and if you don't I don't think you are going to like what happens after that and that is not really a threat, it's just a promise because my child deserves an education like everyone else. You are required by law to make sure he has that even with the NCLB law." We came together and put together a plan and I will tell you for the first three years B literally had an adult shadow. There was a guy; his name was C that was assigned to basically babysit B all day. B was in a regular classroom but you know there were times that I would find out that while other kids were working on Math or reading or whatever, B was in the corner coloring

and we were about to get ugly, I mean ugly with people. That is not acceptable behavior. "You will not measure my child by the lowest common denominator. You will present him with everything you present everyone else with or we will continue in court." I don't back down. Over time that message started to resonate. We developed an IEP with specific measures about how B should be learning and how he should be integrated into the classroom and over time teachers started to get not necessarily that my child was as able as anyone else but more that they just did not want to deal with me. Because of that they started to do the things that they needed to do. I even had teachers that would take classes on autism that the school offered them so they could get a better understanding of autism and how autistic children function and you know over time B started to do a little bit better. Of course, he had a lot of echolalia. He was stuck on "Blue's Clues" for years, I mean he could recite every episode of "Blue's Clues" ever recorded and that is what changed his social engagement. "How are you, B?" and he would go into a script from "Blue's Clues." Getting those moments of clarity and between the scripting about "Blue's Clues," B was actually a very bright child and people started to see that "Oh, we give this child an opportunity and we give him some assistance he can do a little bit better." When he was in third grade we moved to Leander, TX and prior to moving there I did call the school system to let them know and find out if they were differently abled. I needed to know what services are available and I have an IEP that I am going to send to you in advance so you can take a look and see whether you can make these accommodations and you need to tell me where I need to go in the State of Texas to get the accommodations for my child and if we can do better than this, I am open to that too.

AK: Was that a public school, L?

I-8: Public schools, yea.

AK: Ok.

I-8: Leander is in the school district just outside of Austin, TX so we went to the school and talked to them about the IEP. I told them I don't want B to have a human shadow. I want him to be able to function on his own and so in order for him to ever be able to do that we have to start pulling back on some of these services that make him dependent upon other people. It was really in third grade when the inclusion started because first of all, for inclusion they did not have the human resources they said they are to have 24 hours a day and secondly, their resources were spread pretty thin and so, inclusion was sort of what their model was. What that required of me as a parent was more involvement and interaction with the school. He is included but what is he included in? What is he doing? What is he working on? What is your topic this week? What is he studying in science? What projects does he have coming up? He came in with this IEP where I require five days advance notice of any tests. I require at least72 hours before the test. In exchange for that I promised to communicate with each one of his teachers via email once a week and at the end of every week find out what he is doing, what he should be working on, what projects are due and generally checking in on his progress.

AK: Good.

I-8: He has never been a behavioral threat. He is very, very sweet, loving, kind, giving person so that was never the issue. The issue was that he got to a certain age where he

was unable to relate his fears because they had moved beyond Blue's Clues and because I could not sit in the classroom every day I needed to establish some way to understand what was going on at the school; how was he interacting? How was he doing socially? How was he doing academically? I didn't want any surprises. I didn't want to find out how he was doing when the report card came out so that having been said people seem to be impressed by that which was confusing for me because I didn't understand any other way to be. I mean, that is my child. I did get a lot of positive feedback in a kind of roundabout way because you know they were like, "Oh, we don't have parents that are involved in their special needs child's education. Most parents sort of just drop their kids off and expect us to do the rest."

AK: Right. That's true, L.

I-8: Yea, they are like, "We don't have parents meeting with the principal when their does not do so well on their standardized test. We don't have parents researching, hey, you can read this test to my kid, he is an audio learner so that is what I want you to do is read this test to him because I think he will do better. You can do that so he doesn't blow it all together and just start checking the boxes. You want him to be successful you have to help him be successful and I am going to make sure that you do that. It's been a full time job; 24 hours a day, seven days a week. I wake up in the morning thinking, "Ok, what's going on, where is he? How close are we to where we need to be?" In that, I realize that teachers are not as organized as people think they are. They are a very disorganized bunch. You sometimes ask a teacher, "Well, what is your lesson plans five days from now?" They may not have that. "Well, do you have a study guide because B is

going to need a study guide. That is in his IEP." "Ah well, it's going to be chapter 10.""Hmmm, you are going to have to be a little more specific about chapter 10." So what we are requiring is for teachers to do a lot more work.

AK: You bring up a very point. You are the first parent who has brought that up.

I-8: It requires them to do a lot more work than they did or wanted to do and some of them pushed back. "Well, I don't have to do this for other kids" and I am like, "Well, I'm sorry, I don't know if you understand how an IEP works or what that means but that is the Bible. That is the Bible you have to follow whatever relates to my kid. So what ended up happening is it was really helpful to all of the kids.

AK: Yes.

I-8: So, if they create a study guide for my kid but they would also get a study guide for all of the kids. Because they would have to tell me five days in advance, hey we are having a test. They would just make a class announcement so everybody got to know there would be a test.

AK: You know what else probably happened with that, you may not know this but it probably made their job a lot easier because they got organized.

I-8: They had to get organized because I told them. I said, "Listen, the key to B's success is pure organization. He is autistic. It all has to make sense. It has to be consistent. It is like Ground Hog Day in some ways. It is like Ground Hog Day. We have a huge calendar on the wall and everything that B has to do is on that calendar. If it is not on the calendar it is not going to get done. If you can't plan for it, it is not going to happen so in order for me to put it on the calendar with some reasonable sense of getting it done we have to

have some leeway on that so that's been really great. It sort of bled over into their overall planning and helped their classroom in general. For that I am grateful that I am a type A, anal retentive.

AK: It paid off, didn't it?

I-8: Yea.

AK: I described to someone the overall classroom and we will go into that a little bit and you will pick up on it. My focus is on the overall structure of the classroom, even the lighting in the classroom. That person said to me, "Well, you know that sounds like it would be good for all of the kids whether they have autism or not" and I said, "Yes." I-8: Then we moved to Mississippi and what I found is that if you have a good IEP in place it doesn't matter where you are. If you have that foundational IEP that you can share with the next school district it makes it a whole lot easier than starting over. They can just adopt those accommodations and go from there. Once they realize you are serious and that you will respond back to them and are interested in your child's education they will look for ways to help you and your child be successful.

AK: How old was B when you moved to Mississippi?

I-8: We moved to Mississippi in 2013.

AK: Is that where you are now?

I-8: We are actually leaving Mississippi. We are leaving in June to go to Houston.

AK: Ah, back to Texas.

I-8: Back to Texas and B is auditioning for the high school's visual and performing arts in Houston as a drummer.

AK: Great!

I-8: We will see how that goes.

AK: Great! So, your whole family, it sounds like you have had to be very adaptable.

I-8: Yea, well it's just my job and it's just me. I'm a single parent so we go where I got to

go. I mean, I actually think it has been very good because the change forces him to adapt.

AK: Absolutely. They have a lot of trouble with change so this is actually good for him

because he has the family support he needs.

I-8: That's right.

AK: You can pick anybody in the past; any educator but how do you feel about the relationship between you and your child's educator?

I-8: I feel like they are as reliant upon me as I am upon them. That is how I feel. I feel they need as much information about my child and what works for him for me as I need from them about what they are doing and how can I help them. It doesn't always work well because you have to really push some teachers but when it works well it becomes a very interdependent relationship, a team of people to work to get someone to a destination.

AK: That is a key word right there; team. Yea, you have to have that.

Question No. 2: What is the opinion of the parents regarding the quality of the following: AK: All right, I-8, I want to know your opinion regarding the quality of the classroom structure and I am going to go over these 15 topics and I want you to tell me what your opinion is, all right?

I-8: All right.

What is your opinion about the quality of the classroom structure?

AK: How do you feel about the classroom structure for your son?

I-8: I feel like the classroom structure is mostly chaotic. I have hopped into the classroom just kind of showing up at the school to check in on B and found that generally the classroom teacher on more than one occasion that the classroom teacher does not have control of the classroom. She is kind of overwhelmed. It's just been chaotic and so I am concerned. I have had concerns about that as it relates to B because he doesn't do well in chaos. Chaos is not his friend. When those situations have occurred I have certainly spoken to the administrative staff but I just don't find, in general that the classroom is a place for learning. There are too many distractions. There is too much stuff going on that have nothing to do with learning that make it difficult and challenging for any child. It certainly makes it hard for an autistic child to focus. Sometimes they will take B out of the classroom to a more secluded private setting so he can focus.

AK: Are there any aides in the regular classroom?

I-8: There is a floating aide; is what they call her here in Mississippi. They have the same kind of structure in Texas. The only time he had someone dedicated to him was in DC but there is a floating aide that is responsible for a group of children, maybe 10 to 15 kids of various different labels, conditions, and abilities. They just float from one classroom to the next and kind of hop in and check on them.

AK: Now is he a freshman?

I-8: He will be a freshman in high school next year.

What is your opinion regarding the quality of the organization in the school classroom?

AK: How do you feel about the organization of that classroom?

I-8: Again, I think it depends on the individual teacher. I have been in some classrooms where it is very organized. You know where the teacher what is going to happen today posted on the board, upcoming tests on the wall. I think that people who are extremely organized and you can see how that benefits the children. Personally, I think teachers who can't find their own identification in their wallet and they are supposed to be the ones with the knowledge.

AK: Let me ask you a question about that, L. I don't know if you know or not but the teachers that were more organized and had autistic students in the regular classroom were they trained in autism?

I-8: No. I can think of one teacher that in particular that was not trained in autism. She happened to be a type A; you know anal retentive organized person and that has served my child well. They are random though but like I said, most teachers are not trained in autism.

AK: I know.

What is your opinion regarding the quality of the overhead lighting in the school classroom?

AK: There have been articles written on the lighting in the classroom; the overhead lighting and the fluorescent lights in particular, has an adverse effect on students with autism. How is the overhead lighting? Does it bother him at all?

I-8: I think as he has gotten older it has become more of an issue for him. There was a time I thought he had some vision problems because he was lethargic. He would come

back from school and say, "I am lethargic." I would say, "Well, what happened today?" "Ohhh, it was just horrible at school. It's just murder." "Well, what's happening" I would say. Well, I came to find out after lots of questioning that the entire classroom setting was exhausting to him. In this particular school some of the classrooms do not even have a window. So the overhead lighting was even more of an issue because there was no natural lighting to go with it. I asked that B be placed in the library where there was lots of windows and better lighting so that he could better understanding. He was just so tired when he came home from school and you know, I understand but I think it was a teacher's aide, not even a teacher that said to me, "Well, you know, it could be the lighting. A lot of kids in here get headaches. A lot of kids get eye strain. It could be that there is not enough natural light in here" so I think it is an issue. I think it is an issue not only in this school. I think it is an issue in a lot of places. People don't realize the impact it has on them.

AK: I talked to an architect that was familiar with designing classrooms and spaces for autistic people and he said a lot of schools are switching to the LED lighting. Have you ever heard of Dr. Stephen Shores? He's a Ph.D and he has autism. He didn't speak until he was over three years old and his Mother was the one who really helped him. She used music but he was in a Special Education classroom. When he wrote his book he said he had a fellow classmate that when the fluorescent lights would start buzzing and his friend would start rocking back and forth, back and forth. That probably was pretty exhausting for him. The lights have a big effect on these kids and they need to do something about the lighting itself. Anyway, Stephen Shores went on to be a Ph.D and he helps parents.

He has written a couple of books for parents to try to help them. He is very knowledgeable and I would recommend picking up his book. He's great. He talks about the use of music and how music unlocked him, you know.

I-8: The music was transformative in B's life.

AK: I have talked to a lot of parents and it's music, you know.

What is your opinion regarding the quality of the educator's management of behaviors associated with autism in the school classroom?

I-8: I feel that the teachers don't understand the behavior so a lot of teachers shy away from the behavior or they just simply ignore the student because they don't understand the behavior. They don't understand the echolalia. They don't understand the repetitive nature of conversations that you can have with autistic people. You can say, "Go to your room and pick up your shoes." He will repeat that four times, "Mom, you want me to go to my room and pick up my shoes? Mom, you want me to go to my room and pick up my shoes?" "Yes son, go to your room and pick up your shoes." Over time I thought is that his way of confirming what is being asked of him? Is that confirming what he is hearing; his understanding of what is being said? I don't know the answer to that. I found AK:I have something that might help you with that. Have you ever read Carly Fleischman's book? Have you heard of her?

I-8: No, what is it called?

AK: It might be, "Carly" but she is a classic autistic, doesn't talk. What happened with her is they couldn't even send her to public schools. She would have such temper tantrums. She was a head banger, a biter; she was bad. What happened to her is they

brought a tutor into the home and he had a computer. This was when she was about 13 and her parents didn't know what to do with her. They took care of her at home and they gave her the best care they could. Frankly, they must have done a terrific job. They tried to teach her to spell and talk but it just didn't work. Unbeknownst to them this girl was bright. I think they knew that but what she did was absolutely incredible. She has been on television. She has written a book. The tutor brought in a computer and Carly sits down in front of the computer with the tutor there. The tutor didn't really have to tell her what to do. She started typing and she could spell. She wrote out exactly how she was feeling and just blew everybody away. She could spell. Her parents had taught her but they didn't know she had learned because there wasn't any way to tell them because all this girl did was run around the house all day, bang her head, and bite her hand. I mean, she was bad and you can look her up on the internet. She is absolutely incredible. She is actually in her first year of college now but it was the computer that gave her her voice. Temple Grandin kind of says the same thing because she knows about the brain. Well, Carly explains what we don't understand; that the mind and the body don't work together so when he is running, "go get your shoes" his brain is telling him "I have to go get my shoes" and he probably doesn't even realize he is repeating it but his body is going to get the shoes. I think it would give you some insight on what is going on with that. That might help.

I-8: Thank you so much. That might help. Being the parent of an autistic person is a lonely place to be. I used to do a lot of research about autism but once I started living it every day I have to be honest. I stopped reading about it because I was living it. I was just

trying to get to the next day, you know. I was just trying to figure out how to get to the next day. Man, it's more than a notion but anyway, I will. Thank you so much.

AK: If you do nothing else get that book because I think it will help you with that brain/body connection because it might explain some of his behaviors to help you understand what's going on.

I-8: Then I could explain it to other people. I can totally see, "Hey, is this person hearing me, does this person know what I am saying" and then something happens and oh my gosh this person is totally there with me the whole time.

AK: I think he understand you. His body and his brain just don't coordinate like they are supposed to.

I-8: Yea, I would have to agree with that.

What is your opinion regarding the educator's knowledge about autism?

AK: We talked a little bit; you actually talked a lot about this so I have the general idea about how you feel about this but this is the next topic. If you want to go into it a little more, go ahead.

I-8: Very low. I think it is something they have just head about and they don't know what it really means and they have no idea how it impacts people. They don't know how to deal with it so a lot of them just don't and that is why I said the best relationship you can have with teachers is one in which they rely on me to tell them about autism and my personal experiences as much as I rely on them to help me and tell me about what is going on in the classroom. I can only speak about my own experience, Other people probably have different experiences with autistic children so the gist of my conversation

is on what I know and what I have been through and what I have seen work but I think that generally people are not educated and are not aware of what autism is, what it means and more importantly, what autistic people are capable of. I think they put autistic people in the category of like mental retardation or something that the child has no capacity or no ability and that has been a big struggle in how people understand. Yes, he is autistic but he is brilliant. Let me show you all the ways he is brilliant. Give him a chance. He will get it. He may have to repeat it four times but he will get it.

AK: My opinion of autistic individuals is I can't help but feel it is genius gone awry.

I-8: Yes, that is exactly what it is.

AK: Do you think that some of the lack of educator knowledge about autism is financial problem for the schools in that they don't send them considering there is one in, while there is an argument about this; some say there is one in 50 while others say there are one in 80 children with autism? Don't you think there should be more of a focus on autism education?

I-8: I think it should be mandatory. I think it should be mandatory at the undergraduate level. I don't think they should be able to become a teacher without having some training on autism and what it means and how it works and how it affects the mind and the body and what you can expect from a student and how you can customize the curriculum to help an autistic student. I mean, I think it should be mandatory. I don't think you should be able to get a college degree, and a teaching certificate and say, "I am a teacher" and know nothing about autism. That is something that burns me up. Don't get me started on that one.

AK: Well, I don't think it should be confined to getting your Bachelors in Special Education. I think it is education period.

I-8: Period absolutely. It should be mandatory for anyone that is going into education and then there should be mandatory modules to follow in ongoing education if you have autistic kids in your school, classroom, community, anywhere that you are there should be mandatory modules of ongoing education. That's your profession. That's your job.

AK: Well, considering there are either one in 50 or one in 80 students with autism I think it should be mandatory for any educator.

I-8: Yes, I agree.

AK: If it is that high, which it is it should be mandatory because they are in the classroom and not all of them are in Special Education classes because they don't have to be. They are in regular classrooms so I agree with you. It should be mandatory for all of them.

I-8: It should be like a CEU credit for a doctor. None of them never take another class. It is ongoing education. I think it should be like that. It should be set up like a CEU credit so they get the knowledge and the tools to be able to help these kids. I always think about the kids who don't have a Mom like me. The ones whose parents are struggling too trying to figure things out but what about these poor kids who don't have that, you know? What about these poor kids whose parents just drop them off at school and say, "Good luck, little Johnny. I will pick you up at 3." It breaks my heart.

What is your opinion about the quality of the noise level in the school classroom?

AK: What do you think about the noise level in the classroom? What is your opinion?

I-8: I think it is too high. There are many classrooms where the kids are going awry. They are screaming and hollering, you know. The teacher is screaming and hollering at the kids. They are like shocked at a parent standing at the door. It's like an incubated environment. They don't ever expect a parent to appear in the middle of the day. They don't really know what is going on but yea, I have seen some of the teachers screaming and hollering, "Sit down and shut up" and "oh my, I don't even talk to my own kid like that at home." I think they need some classroom management skills.

AK: That is a good way to put it. I am going to write that down. You would think that would be part of their education, you know?

I-8: Absolutely.

AK: Some of these principles that I am writing about; they need to be incorporated into the classroom and it goes back to "it would be good for every kid."

I-8: Yes.

What is your opinion regarding the quality of the educator's management of behavioral/psychiatric symptoms in the school classroom?

I-8: Well, I think that there is a very small group of people in the public schools that are trained in behavioral therapy, in general and of course, they are a part of the parent team at the IEP. There is the behavioral therapist, speech therapist. They are sometimes referred to an outside psychiatrist or psychologist but in the classroom I think those resources are lacking. I don't think there is enough of a focus on that for a lot of kids in a lot of situations and consequently, and again in a sort of square box approach to everything. If a kid does this then this is what happens but there is no overall analysis.

Ok, "is this child differently abled? Is this child hungry? Does this child have electricity at home?" There are lots of reasons why children act out whether they have disabilities or are differently abled or whatever or not and I think there is not a focus on that. It is almost like everything else in this country. There is just a focus on the punitive aspect of it. There is not really a focus on the day, the condition or why something is happening. AK: You know there are a lot of kids that have psychiatric disorders, not just autistic kids. Right now they are bringing in a program of mental health into the schools where they have an actual mental health therapist right there in the school because for a long time the high school had their focus on the vocational skills and now they realize there are a lot of kids that have mental health disorders and are not being taken care of. I-8: Yes, their folks don't even know they have mental health disorders. It is funny you would say that because I actually work for a large insurer in Medicaid through the government actually. It is through ACA. It is pushing more mental health analysis and more behavioral mental health therapy for kids with special needs; all kinds of kids with all kinds of special needs. It is a big issue and the educators are undertrained. I don't think they know what to do.

AK: Well, I think it is going to help the educators to be aware of this. I was in Minneapolis at a residency just at the same time that they had the first elementary school that was going to have mental health therapists and now it has just mushroomed. Here where I live which is a small town in Montana, they have a program at the junior high and the high school that has a mental health therapist that goes back and forth. I think it is fantastic but not to get off subject. With children with autism there are three things that

are pretty high psychiatrically and a lot of parents don't understand. There is OCD, there is depression and anxiety and a lot of educators are not aware of it.

I-8: My son has a little bit of ADHD.

AK: That's pretty common. Teachers are not aware that they have these issues, you know.

I-8: I am very aware of the depression aspect. I am always wondering how is he interacting with people at school because he is autistic and he is different. Fortunately, he has a great personality so that most people who meet him love him and he hasn't met a stranger but I still wonder if he is aware that he has certain differences that other people now notice now that he is older and how that makes him feel inside and how does that impact him.

AK: I think Temple Grandin writes about that in some of her books. I think in her first book she talks about that; the one they made the movie off of.

What is your opinion regarding the quality of effective communication with the educator?

AK: We talked a little bit about this too. The fact that you have effective communication with the educator; whether you do or you don't.

I-8: I do but it's not because of them. I feel I do because "I" make it a priority. "I" insist on them communicating to me. I feel if I did not communicate with them they would not communicate with me. Usually I will send out a blanket email on Monday to all the teachers "What's going on this week? Where are we? Any major tests coming up? Any projects coming up?" I have waited until late until late Monday afternoon just to see which teachers are going to email me first. After 12-13 weeks of email you should kind

of get the drill, "Oh, where's the email today?" A small, small percentage of teachers; I would say less than one percent actually get it and follow the pattern even if I don't email them at 8:00 Monday morning. They will email me but that is rare. If I didn't communicate with some of these teachers they would not communicate with me.

AK: That's good. Do they actually follow through by emailing you back?

I-8: Yea, once they get in the habit of things. Again, I think it is less by me. If I don't hear from them, like his Math teacher, she is notoriously bad with communication I will say, "Hey, did you get my email? I am waiting for your feedback to show me what's going on this week and eventually she will but I figure it is totally because I approach them and I push them for communication.

AK: I think that is what it takes, you know.

I-8: Yea, but again, I think about the kids who don't have that. Who is standing up for them? Some parents don't have email which is very common and as socially disenfranchised as ever. Do you know what I mean? How are the parents getting information on what is going on at school?

AK: Well, you know, L, one of the first people I interviewed was a pretty energetic Grandmother who has primary care of her autistic grandson and she said it is not that often that you see a parent that is really an advocate for their autistic child. She said that because she couldn't even get the people, they would come to the support group; at least they did for two or three of them before they fell away but...

I-8: I can't believe you just said that! You know how many support groups not just for autistic kids but for all differently abled kids, how many times I have gone to a school

principal and said, "Hey, I think a support group would be good" and they said" If you want to put something together or a flyer or some kind of idea about how to do it, that's fine." We can't give you the names of differently abled children for privacy reasons but you know but people don't show up.

AK: Exactly. Well, here's what happened. With her they would come two or three times and all they would do was talk about their problems. They weren't focused on, which was ok but they weren't focused on solutions. They were focused on the problem and couldn't get them past that to do anything so ...

I-8: Well, she got them to show up.

AK: Yea and that happened in another small community not too far from where I live. It was the same kind of thing. It was just trying to get them involved. It is probably because they have so much going on.

I-8: We all do.

AK: I believe if you need to change something you have to take some action too.

I-8: It's the only way it is going to happen.

What is your opinion regarding your ability to participate in the IEP?

AK: I know that B has an IEP but how receptive have they been about including what you think he needs, being the parent?

LP: Very receptive, very receptive.

AK: Good.

I-8: Like I said I think they rely on me as much as I rely on them. School districts and teachers have relied on me to tell them what he needs then they will work with me to

make sure that he can get it; like the oral administration of a test or him listening to a book on tape as opposed to reading a book. They have been very receptive to that. Most school districts, the three that I have been in have made many accomplishments possible in that regard. I felt very involved in that process and what happens with him but again, it is because I choose to be that involved. I think if I didn't show up for the IEP meeting or whatever, they come up with whatever and that is what he gets.

AK:Right and that is probably the way it is for a lot of kids.

What is your opinion regarding the support received from your child's educator for you and for your child?

I-8: In what way?

AK: Overall support, do you get that from the educator? Accepting the fact that he does have autism and there has to be special ways to make the classroom successful for him? I-8: Some of them. Some of them are of the opinion, "why does he get special treatment?" "Um, because he is special; that is why he gets special treatment."

AK: That's right. He is unique.

I-8: Yea so I have had to educate some people in ways that they probably didn't want to be educated. Whether you think it is fair or not we don't think it is fair that he has autism but we are working with it so you have to work with the special accommodations that come with the IEP.

AK: Yea. Do you feel you yourself have support from your child's educator in what you are trying to do?

I-8: Some of them, some of them. I also think the support comes from just their general unwillingness to have to deal with me in ways that they don't want to because I make it pretty clear that if we can't come to some mutual agreement then we are going to have some issues because this is what is required for my child and so I kind of feel like they are not necessarily vested in my child's education. They are more vested in oiling the squeaky wheel that they don't want to deal with.

AK: Well, if that's working, that's good.

I-8: It's a lot of work, I will tell you that much. There is no built-in support system. There is no parent support and no guidance for parents in the school system. "Ok, here's an autistic child, here's the things that you need to know on what's available for your child." You have to dig all the information up. It's not coming through your front door.

AK: No one helps you with that then?

I-8: No. No one comes here and says, "Hey, did you know that if your child is autistic you can get state tests read to him? Did you know that? Well, no I didn't know that." I had to pull that out of a school policy manual.

AK: So, they don't give you any support on resources then?

I-8: No. Support on resources is very low. You have to dig it out and if you are not an aware person or if you don't even know what's possible I mean you don't even know what to ask for.

AK: Yea, I believe that. You have to have a beginning point. That is knowing what to ask for.

I-8: Right. I think there is a general lack of concern about the literacy of the parents. Again, I feel my child is very lucky because I am a very aware person but hey, they give you this handbook. It's like 1- or 15 pages of rules and regulations and policies they have put together and say; "Now you are going to check the box that I gave this to you." I check the box and thought, "What if I couldn't read and you just gave me 15 pages about what my child's educational IEP is and how we are going to help my child be successful,

but I can't read. I'm embarrassed and I can't tell you I can't read. How would I know

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what the heck this thing says?"

AK: Right. That's a good point.

What is your opinion regarding the educator's level of training in autism?

AK: Ok, we talked a little bit already about the training in autism. What is your level of satisfaction with the educator's training in autism?

I-8: On a scale of one to ten I would say generally speaking about a 2. I think they definitely need more training.

AK: Ok. I think it is fairly minimal. I know a lot of the educators around here...We are about 130 miles from Billings, MT which is a big city and all through the summer and once a month all year around they will have special classes for anybody whether it is an educator or not and there is a lot of parents that go to try to find out. They have learned a lot that way. They have educated themselves about it.

I-8: That is extremely important. Even in big cities I have not seen that.

AK: Well, Montana is pretty progressive when it comes to autism. We have an autism waiver here for children that are ages six months to three years. It is an early intervention

program and they are on it for 72 months and they have actually had a high percentage of kids because of their services that no longer carry a diagnosis of autism.

I-8: That's encouraging.

AK: It's amazing. They only have 50 slots and of course, they have a waiting list. They really need to increase the slots because there are a lot more people who have children that need it so there are a few options here.

I-8: They really need to use Montana as a national benchmark for the education of people with autism. I mean, I have never heard of that.

AK: You can look it up on the Montana Autism Waiver on the internet and it has the studies and how it did the first couple of years. There is some good information out there.

I-8: I will do it.

What is your opinion regarding whether the educator is knowledgeable of mental health issues common in autism?

I-8: No. I think teachers are taught to regard students in two ways; either they are good students or they are bad students. Bad students are the ones with behavioral problems. I think if my child had more behavioral problems he would have a totally different experience than another person because no one would understand where that is coming from. I think is so successful because he is so pleasant. He is a pleasant person to be around so it is easy to want to help him. If it were the opposite; if he were challenging or he were difficult with a horrible temper. No, I don't think there is an awareness.

What is your opinion regarding the quality of the educator's knowledge about programs designed to reduce parental stress?

AK: Were you aware of programs designed to reduce parental stress? These programs, the teachers know about these programs if they have some training in autism.

I-8: No.

AK: Were you aware there were programs designed to reduce parental stress?

I-8: I would say that I have a loose knowledge of it but has anyone ever like in the school system come to me and say, "Hey, you know here's a program designed to help you, as a parent in coping with his condition," no.

AK: Ok. I read a study where they talk about it and a lot of teachers have been trained to have resources and knowledge about parental stress and direct parents to support groups on that. I had one parent say to me that it is not the teacher's responsibility. "That's my responsibility to find out if there is anything for me like that."

I-8: I think that is true. That is the general consensus. I don't know whose responsibility it is but it is the general consensus that it is not the school's responsibility. If you are stressed out as a parent it is your responsibility and your health insurance's responsibility to pay for it.

What is your opinion regarding the availability of an integrated treatment approach consisting of mental health, occupational therapy, and speech therapy in your child's school?

AK: At his school is there the availability of an integrated treatment approach for autism consisting of mental health, occupational therapy, and speech therapy for B? Has that been available to him?

I-8: Yes.

AK: What is your opinion of it? Is it successful for him?

I-8: I think it helps him a lot, particularly the speech therapy. He didn't have occupational needs. He did have dexterity problems but those have been resolved. As for speech therapy and behavioral therapy, they have helped him a lot. He sees someone outside of the educational system once a quarter just to talk about his stress levels and how he is feeling and kind of keep an eye on him.

AK: That's great.

What is your opinion about the ability to participate in opportunities for expression of parental input into daily activities based on parental knowledge about their autistic child? I-8: I wouldn't say his daily activities, no. I think my interest is really focused around the schedule and the weekly email that goes out but do I know what he does on a daily basis and have input into that in each one of his classes? I only know what is reported by him when he comes back from school. He tells me about every class and he will follow through and tell me what happened which helps me identify areas where he is struggling and someone may not be paying attention so I can send out an email.

Question No. 3: What is the parents' opinion regarding the current environmental health of the public classroom in its ability to afford their child the best learning experience?

AK: All right, we are on question no. three.

AK: When I talk about the environmental health of the public classroom what I am talking about is environmental health as it has to do with how well they are doing emotionally, physically, and academically and in some instances spiritually. Does the current classroom afford B the ability to afford him his best learning experience?

I-8: No. I think it lacks because emotionally, spiritually, academically, and physically, right? Emotionally, absolutely not. Academically, I think he has some support but we talked about how that has come about for him. Physically, I don't think that he, no and spiritually, absolutely not. I think if I had to rate it academically would be the strongest area but the other areas are really lacking and academic is weak.

AK: Do you feel B has improved academically from the beginning?

I-8: No, interesting that you would say that; in some areas. I will give you an example. He has always struggled with reading comprehension. He still struggles with reading comprehension. I don't see any remarkable improvement in that area. Every school he has ever gone to, every teacher I have ever talked to it has been one of the first things I have ever said, "He is a very little person who is autistic. He is different so deductive analysis so what do you think is going to happen after the story is over? Nothing, it is the end of the story." I have talked to the teachers; many of them about strategies for helping him with more abstract concepts but he still struggles with that to this day. I don't see any remarkable improvement in that area. It comes up at every IEP.

AK: Yea, you would think there would be some improvement if that is an issue. It seems like it was ongoing because you talked about where he would be coloring while in Washington, DC, he would be coloring while the others would be going over reading lessons?

I-8: Yea, because they would ask him questions that you know they felt that they could ask him like for example, "What do you think happened at the end of the story? What do you think happened to Jack?" and B would just stand there with a blank stare, "What do

you mean? I don't know what happened to Jack and that is the end of the story." They kind of backed off of that. If I had to identify one area of concern in the public school system and I don't know if it would be any different in a private school, it would be that. AK: Is there any other area where he has a little issue with comprehension, maybe with some kind of instructions?

I-8: Yes, I would say written Math problems. They have always been a challenge. Some abstract concepts he didn't have, like solving an equation with a graph. Well, you have to come up with the coordinates and you plug them into an equation. Well, he struggled with where the coordinates comes from; do I just pull them out of the sky? Where do I get them from? Any concept that is abstract. There is not like a recipe for solving that he struggled with.

Question No. 4: What do parents think might be the environmental health barriers that exist in the public classroom, if any?

AK: Some of those we have talked about such as educator training about autism, their knowledge about autism, and the management of behaviors associated with autism, behavioral/psychiatric symptoms. What is your opinion on what the barriers are?

I-8: I think those are some of the more common barriers. I also think that there are not enough breaks built into the school space for an autistic person. My experience with my child has been he is thinking almost retrospective when he is exposed to something he has to think about how to process it and then he gets it but before that can happen they are on to the next thing. They are on to the next chapter. They are on to the next concept and I think that is a barrier for autistic kids in the classroom.

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AK: So, it is not enough reflecting time? Is that what you are saying?

I-8: It is not enough of a break. I will give you an example. When he does his homework

he may have three or four subjects. Well, between subjects I will give him a ten minute

break. "Just take a break. Take some down time. Get some water." It is just non-stop,

ongoing all day. It is not the best learning environment for someone with autism. They

need breaks.

AK: Do you think they need time to process it then?

I-8: Yes, particularly complex concepts. They need time to process it. The school

curriculum moves so quickly because it is tied to common core metrics and federal

money or whatever. That time has to be taken at home. When he gets home it is only

because I know what is going on in his classroom like the therapy, "How do you feel

about that? Do you feel you understood that?" He will say yes or no. If he says no then I

will review it with him then I will give him 15-20 minutes to think about it and then come

back to me and tell me what his questions are but he doesn't have that kind of time in the

school day. They are pretty jam packed. It appears to other people like he is not getting it

because he hasn't had time to process it.

AK: Right. I would agree with that. Do you feel that their curriculum is designed with

autistic students in mind?

I-8: No, absolutely not.

AK: So, that is a barrier, isn't it?

I-8: That is a barrier. An autistic person in the public school is like trying to fit a square peg in a round hole. You are always trying to stuff it in there. The curriculum is absolutely not designed for someone with autism.

AK: What would you say were probably the top two environmental barriers for B?

I-8: I would say the lack of time and the lack of education of the educators.

AK: Well, we are done, L. You gave me some valuable information. Do you have any questions?

I-8: No, but I am so glad we finally connected.

AK: Me too. I am really grateful because I know how busy you are and how busy you have been this week. I know you are trying to get ready for your trip and I just want you to know I really appreciate your time.

I-8: Oh, no problem.

## Appendix L: Personal Communication of Michel Mace

Even more awful, in their original environment, some of them were sometimes running head first against the walls, and biting their wrists to the bone, barking like dogs, hurting themselves very badly.

And they were entrusted to us? Who was this "us"? A total of around 15 grownups dispersed over 7 farms in the mountains. None of us was a health professional or psychiatrist. Thank God for that.

We had to wash them, to clothe them, to feed them, to do everything for them. We did not give them any medication, we were just trying to live with them, trying not to do anything directed toward them. Of course we did not speak to them nor tried to teach them to speak. In fact, our philosophy was to avoid making any of our actions depending on them. And after a few months these children were smiling, eating by themselves, washing themselves, walking, dressing themselves and doing so many other things.

Different themes stand out in this experience: the absolute nonuse of medication, the affirmed will of refusing to speak about them as someone would speak of a medical case, and of course much more the refusing of talking to them. Refusal to heal them: they are not sick, they just have a different way of life because of a handicap and as a consequence they have a different view of the world in which we live. I will never repeat it enough: we were not trying to make them speak.

The 1st idea was: we are here to live with them (with them 24/7/365) not to heal them. The 2nd idea coming out of the previous one was: we would try to weave a way of life between us and them, not trying to teach them to live like us because this would be like

taming them. What we wanted was really trying to find a common ground, trying to change the way we live so that we would really be living together like brothers and sisters and not being their caretakers, their nurses or their doctors!

The autistic children are very much attracted by water. They even find springs of water. And so we could say in a sense that our goal was to change our way of living to become water in their eyes, that they would be attracted to us as they were to water. To become water in the eyes of the autistic children... what a challenge! We succeeded in the sense that the children did not have any violent behavior anymore; even better, after a few months with us, they had initiatives of their own.

But the best part was that this had to be achieved without talking about them! Deligny was saying that talking about them who do not speak was an abuse of power on them.

And there is, I believe, a certain amount of truth in that. That's where Deligny "invented" what we were to call maps. A map was a drawing of one of the locations, during one day, with some ways of drawing the paths taken by the adults and the paths taken by the autistic children, with the different activities of each one of us.

Let me give an example of what I mean by "trying to change the way we live": let's take the dishwashing activity (did I say that it was where and when I learned to love washing dishes?).

We changed completely our way of... washing dishes! And I am NOT talking of buying a dishwasher here! Imagine a big flat rock in the courtyard on which we place an empty crate, and there is like a half circle of these flat rocks, one rock for one activity. When we are done eating we go place the dirty dishes inside the crate dedicated to dishwashing.

Later when we divide to go to diverse activities, we come to this half circle of rocks and, without speaking, one goes to one rock and start the activity this rock means. I go to the "dishwashing rock", I bring a wheelbarrow in which I put all the dirty dishes, plates, and pots and I go to a place nearby where the dishwashing will take place. I go fetch 2 empty basins, then warm water with 2 buckets and so on, like this I gather all the needed material for the activity. Then I start the activity.

When the child looks on, he sees the different steps of the activity, one after the other: the choice of the activity, the gathering of material needed and then the activity itself. At the dishwashing place there are 4 stations: 2 tables and 2 basins: one table and one basin for dirty stuff and one table and one basin for clean stuff. Each object goes through each station: first all the dirty stuff on the table, then one by one through the first basin, then through the second basin and then on the second table to dry.

When everything is washed and sundried we come with the wheelbarrow and bring back all these things to the places where they belong inside the house.

What you need to see is that the activity becomes visually "clear", very fragmented in time and space, step by step in the eyes of the autistic child. Therefore the child is not lost, he understands what's going on AND one day, he intervenes in any of the steps of the activity! It can be that he takes the crates without anybody "telling" him to do it and goes to the dishwashing place! Or he takes an object and washes it and rinses it. And finally he does the whole thing with us.

This is the main point and this we saw being repeated many, many times, in front of our eyes. These children were and are labeled incurable, unsociable, unsocial, but here they

are using their hands, doing any kind of activity, on their own, without any adult telling them even to start the activity: pure initiative from a child labeled irredeemable, incurable! I have seen them making bread (without bread machine!), knitting, sewing, washing, cleaning, and so on. This experience with the autistic children was really amazing.

So, I was now living in the mountain with a few goats and with the milk we made cheese which we were selling on the market. We also had an organic garden, and were selling a few vegetables. We were taking care of 2 autistic children and went working in the farms around to make some cash when needed. It was hard work but good healthy physical work. We lived with very little. I read books which show that our body's anatomy is for vegetarian diet and not for meat diet at all... Therefore I decided to become vegetarian. What we are doing is cool: helping these autistic children against all official ideas, all official programs, all psychiatric theories, and obtaining the best results in the whole world, much better than Bruno Bettelheim in the USA. The founder, Fernand Deligny, is a very good man.

We stay away from drugs and alcohol because we have the motivation of helping these kids against the establishment. And therefore we don't want to be arrested for secondary reasons like drugs and alcohol!

The first day a child came to my camp, he was staying about 50 feet from me watching every step, every action. I was thinking, "maybe I scare him, or I am not doing things right". The most scaring was when he was bringing his wrist to his mouth as if to bite it!

The following day he was staying 15 feet from me, still watching everything happening. The third day he was near me, putting his hands in the basin to wash the dishes, and the next day he was peeling the potatoes. I remember he was dropping the pieces of potatoes one by one in the frying pan! He did this, of course, without me asking him anything... or him asking me anything either!

As I mentioned earlier, Renaud started to make a movie of this experience for the public. One day as I was helping him at the video camera, we were walking backward holding the video camera and other material while filming the children that were coming toward us. Suddenly the cameraman hurt against a stone (never walk backward with a heavy video camera in your hands, especially on an uneven mountain slope!). On the stone was an object, which fell from the stone. Even before we could replace the object, one of the children who was 30 feet away actually jumped, reached the object and placed the object back on the stone!

I learned that the Department of Health of the French government watched the movie many times because they were so amazed to what they saw and could not understand what we were doing. They did not understand how we could have such wonderful results with children that had never used their arms, their hands, their legs, that had never eaten by themselves, or get dressed by themselves!

Why not simply relax and look at this documentary for what it is: the description of the daily life of a community of people living together in harmony.

In that experience I learned some invaluable lessons, the first one, as I said earlier, was humility. I am not saying here that I am proud today to have learned to be humble (!),

what I mean is that to be confronted with the autistic children made me realize that I was really nothing, that all my years in school, my years in college studying Mathematics and Sciences, of all these years of study of which I was so proud, didn't prepare me to live! They didn't prepare me to help those who need help! They were just smoke, vapor: "Vapor of vapors, all is vapor." Ecclesiastes Chapter 1, verse 2. There, I also learned to live with simplicity and good education principles such as country living, agriculture, economy and so on.

Yes, "open your mouth for the speech-less, in the cause of all who are appointed to die." (Proverb 31:8) (M. Mace, personal communication, October, 2010).