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Parents' Perception of a School-Based Inclusion Program for their Children with Autism

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Abstract

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MA, Norfolk State University, 2005

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

As the number of students diagnosed with Autism Spectrum Disorder (ASD) increases, many classrooms are turning to an inclusion model of learning. To gain the perspective of program users rather than providers, this study explored parents' perceptions of the inclusion model. Pearlin's stress process model served as the theoretical framework for this study. Ten parents in Pennsylvania were recruited via snowball sampling for participation, and 7 completed the study. Parents completed a short demographic questionnaire and then participated in individual interviews. The research questions were concerned with the lived experiences of parents of children with autism enrolled in inclusion programs or who have participated in inclusion programs within the past 5 years, their perceived roles, and the stresses they felt in those roles. Transcripts were iteratively reviewed to identify consistent themes across interviews. Findings from this study showed: (a) the inclusion model of education had both positive and negative effects on different children diagnosed with autism, (b) the development of emotional skills of children with autism enriched their participation and social relationships with other people, and (c) a strengthened support system for children with autism must be advocated through accessible information and services. These findings support available literature, which is largely against the inclusion model. Findings suggest that support systems for information dissemination should be strengthened, and educators should develop their emotional skills to help students with disabilities.

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Dedication

To God for granting me the tenacity to get through this project even when I did not think I would. In addition, I want to dedicate this dissertation to Ayric Bailey diagnosed (September 29, 2005). To my wonderful siblings who had to hear me complain every day about my fatigue and fears of not finishing. When I did not believe it would be over, they promised that it would all be over some day and that day is here. This dedication would not be complete without mentioning my parents, Foster and Cladine Ary. Although they never told me I could, they never told me I could not and pushed me when I did not want to continue. I thank them for giving me life and expecting the most of me even when I myself had doubt.

Acknowledgments

I would like to acknowledge all the instructors who assisted with guiding me through this dissertation process. I would also like to acknowledge the parents that participated in this research study. I thank them for allowing me to listen to their stories and for sharing their experiences. My hope is that my work will make a difference and shape the way that students with autism and their families receive assistance from the educational system. Lastly, I want to acknowledge my family and friends that have encouraged me throughout this process. Their kind and sometimes harsh words kept me going more than they know.

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Chapter 1: Introduction to the Study

Blumberg et al. (2013) defined autism spectrum disorder (ASD) as a set of complex neurodevelopment disorders that hinder—mildly to severely—a person's social interaction and communication with others. Some examples of ASD included autistic disorder, Asperger's disorder, and pervasive developmental disorder (Blumberg et al., 2013). Historically, children with ASD and other similar learning disabilities were treated as regular children who could not keep up with their peers, thus they fended for themselves in an educational system unsuited to their needs (Naraian, 2011). This issue could explain why researchers have historically found children with ASD to have poor postsecondary employment and education outcomes (Shattuck et al., 2012).

In recent decades, researchers have gained more information about these disorders, which led to more specialized educational policies, as mandated by the establishment of the Individuals with Disabilities Education Act (IDEA) in 1990. Leadership reauthorized the IDEA (1990) in 2004 to the IDEA Act of 2004. Government created IDEA (1990, 2004) to assist students with disabilities who might have experienced issues that hindered their academic progress in previous years (Solis, Vaughn, Swanson, & McCulley, 2012; U.S. Department of Education, 2011; White, 2009). Government used the IDEA (1990, 2004) to mandate that academic leadership must provide special education services for students with special needs. Based on this condition, leadership should design education services for the unique needs of students with learning disabilities, such as ASD, to provide them with the opportunity to learn the same content as their nondisabled peers in an environment suited to their special needs (Smith & Tyler, 2010).

The Center for Disease Control and Prevention (CDC, 2012, p. 11) found a 23% increase in the number of children diagnosed with an ASD in the United States between the years 2006 and 2008. While this increase would seem to heighten the need for more special education programs, a number of scholars have noted that, rather than separating students with ASD and other learning disabilities from the general student population, educators have started to follow the *inclusion model*. Leadership, following this model, place normally achieving students in the same classroom as their peers with learning disabilities (Solis et al., 2012). Friend (2007) defined *inclusion* as the integration of the disabled students into general education classroom with the appropriate assistance given to increase access to the general education curriculum. Researchers noted inclusion as a popular trend in educational reform, occurring since the 1980s (Friend, Cook, Hurley-Chamberlain, & Shamberger, 2010).

Leadership reauthorized the IDEA Act of 1990 in 2004; hence, the most recent version of the act is the IDEA Act of 2004, which revised the law to align better with the No Child Left Behind (NCLB) Act (2002). In the IDEA Act of 2004, leadership made the point that students with disabilities should be educated with their nondisabled peers, otherwise called the least restrictive environment (LRE) mandate (Solis et al., 2012). The mandate states:

> To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children

> who are not disabled , and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of the child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily (IDEA, 2004, p. 1).

Based on this mandate, the primary goal of special education programs involves reintegrating special education students back into the general student population, as much and as soon as possible. Leadership may offer supplemental aids and services separately to these disabled students to encourage their full inclusion in general education classrooms (Solis et al., 2012).

The government encouraged this view with the reauthorization of the NCLB Act (2002). The government increased the pressure on state policy makers and school administrators to integrate students with learning disabilities into general education classrooms as soon as possible (Allison, 2012). Researchers contended that the inclusion of students with learning disabilities with their nondisabled peers promoted heightened self-esteem and better social skills (Nutbrown & Clough, 2009; Sayeski, 2009). Accordingly, these insights have been instrumental in increasing the popularity of inclusion, with some advocates of this model have stated that all students with disabilities should experience inclusion with the general student population (Fuchs, Fuchs, & Stecker, 2010).

Due to the increase of students diagnosed with ASD—among other learning disabilities—and the current emphasis on the inclusion model, as mandated by the IDEA

Act (2004) and NCLB Act (2002), many educators currently face a shift in their classroom environment. Teachers, originally trained to work with general education students, now handle classes with students who might have faced placement in special education programs in previous years. As a result, leadership must provide support for the disabled students and for general education teachers who have not received any special training for dealing with students diagnosed with learning disabilities (Conderman & Johnston-Rodriguez; Friend et al., 2010). This lack of confidence derived from general education teachers who expressed that they did not have the requisite training and capabilities to guide disabled students to academic success (Nimante & Tubele, 2010).

Some researchers have noted their reservations about the inclusion model (Allison, 2012; Pasha, 2012; Rothstein, 2000). Rothstein (2000) pointed out that for certain students with disabilities, inclusion did not mean one must use the least restrictive environment for them. Allison (2012) further noted that some parents and educators might believe that some students' disabilities were too severe to integrate successfully into a general education classroom, thus requiring a separate educational setting. Pasha (2012) also revealed that certain factors were required for the inclusion model to be successful. These factors could include teachers having the will to commit to inclusion, teachers and administrators having developmental opportunities to learn about inclusion, and leadership providing supportive school policies (Pasha, 2012). Without these conditions, an inclusion model would likely fail. Pasha's (2012) findings coincided with the findings of Watnick and Sacks's (2006) study. Watnick and Sacks (2006) found that educators, who exhibited negative feelings toward inclusion, felt that way primarily due to the lack of staff and the proper training about ways in which to implement the model effectively.

This lack of understanding or concern about the level of aptitude that general education teachers might possess, regarding the handling of special education students, might also dissuade parents from responding positively to an inclusion model. Most disabled students cannot provide reliable assessments on the progress of their education not only because of their disability, but also due to them being students. Teachers should involve the parents of these students in the education process due to this issue coupled with the concern about the lack of appropriate training for general education teachers on how to handle such students.

For this study, I sought to gain an accurate assessment about the education that disabled students received under the inclusion model to determine its efficacy. This could not come from the teachers themselves, as a large number of them lacked the training to teach disabled students; therefore, they might have bias in that regard. Additionally, identifying a learning program's efficacy for disabled students might have more of an impact for the students themselves. Therefore, I developed a better inquiry by investigating the perceptions of the learning program users, rather than the learning program providers. As I could not investigate the students themselves, I chose the parents as the most convenient and useful population for this study. Teachers who struggle to educate those who have special needs could gain aid from this study by learning ways in which to ease the burden for general education and the students themselves by providing the opportunity for improvements in the students education.

The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design. The results of this study provided better insights into how these parents view the benefits and the shortcomings associated with the inclusion model, with regard to their children with ASD, and helped reveal what they feel should be given to their children with ASD to ensure their academic success. In turn, these insights might affect positive social change by providing both parents and educators with the necessary information to work together and allow the successful educational progression of students with ASD.

The rest of this chapter includes a background of autism and the learning programs developed to address the education of these students, the statement of the problem, the nature of the study, the purpose of the study, and research questions that served as a guide for the completion of this study. I also discuss the theoretical framework and give the definitions for the pertinent terms used in this study. I also present and explain the assumptions, scope, delimitations, and limitations of this study. I conclude with the significance of the study and a summary of this chapter.

Background of the Study

In 1943, Kanner first used the term *autism*. By giving name to a disability that had only been glimpsed at previously and often stigmatized, he provided an opening for research that aimed to help the individuals with the disorder. Kanner (1943) provided defining characteristics of autism over 60 years ago, and these characteristics have largely held up in current times. These characteristics include children with autism presenting difficulties in social situations, having a hard time communicating their needs and desires with others, and behaving in obsessive and repetitive patterns, manifested by extreme aloofness and indifference (Church, 2009; Kanner, 1943; National Institute of Mental Health, 2011).

Naraian (2011) stated that in the history of education, students classified as disabled were often taught in separate classrooms, away from their nondisabled peers, which may contribute to the decreased likelihood that they become reintegrated into a general education classroom in the future. This has led to the development of the inclusion model, where disabled students are placed in the least restrictive environment, with the goal of reintegration back into the general education populace as soon as possible (Solis et al., 2012). A shift in the way disabled students are educated has been affected in recent years, and the inclusion model has been argued to be the desired method for educating disabled students, according to Friedlander (2009).

In a full inclusion model, disabled students may no longer be separated from their nondisabled peers, thus making disabled students part of the general student population; the only difference being that they receive specific support services that have been tailored to their needs (Mastropieri & Scruggs, 2010). Instead of being separated from their nondisabled peers and being placed into a classroom comprised only of students with disabilities, leadership currently requires students to be placed according to the LRE mandate (McLeskey, Landers, Williamson, & Hoppey, 2010). Meaning, they are placed in general education classrooms, with certain supports for their individual needs provided separately.

It has been contended by some researchers that full inclusion may be able to help mitigate some characteristics of ASD by providing an environment wherein these students would be exposed to peers to interact with in a neutral environment, and expedite interventions on their social interaction and behavioral issues (Mazurik-Charles & Stefanou, 2010; Welsh, Park, Widaman, & O'Neil, 2001). With the passage of IDEA Act (1990, 2004), the presence of legislative support for the inclusion model made it into the predominant model for education students with disabilities (McLeskey, Landers et al., 2010; McLeskey, Landers, Williamson, & Hoppey, 2011; McLeskey, Rosenberg, & Westling, 2010).

While there have been concerns about the inclusion model of education, most advocates and educational professionals support the general intent of the LRE mandate (McLeskey et al., 2011). Given the increasing rates of children being diagnosed with ASD and their right to have a decent education, it is therefore important to ensure that they are given the same opportunity accorded to their nondisabled peers to be included in general education classrooms and achieve academic success there by placing accountability measures to make educational programs not just inclusive, but effective as well (McLeskey & Waldron, 2011a).

It would be beneficial to explore the perceptions of the parents of students with ASD to help teachers better understand the educational needs of these students. The perceptions of parents are important, given that the LRE mandate and its attendant programs were developed to address the education of students with autism and their right to have a decent education. The best way to determine such programs' efficacy would be to investigate the perceptions of the students themselves; as this is not possible, the next best thing would be to reveal the perceptions of the people who are most often closest to them and would have strong ideas about what benefits the children: these would be the parents. This assessment of the role of parents as co-therapists in the treatment and planning stages of their children with ASD has been supported by seminal works by Lowry and Whitman (1989) and Marcus and Schopler (1989).

Problem Statement

There is limited information on the parental perspective regarding children with ASD and their experiences with inclusion programs (McLeskey, Landers et al., 2010; McLeskey et al., 2011; McLeskey, Rosenberg et al., 2010). Much of the scholarly research on the inclusion model has focused on the perspectives of teachers and administrators. The perspectives of both the children and their parents have largely been ignored. I addressed this gap in research, as the inclusion model has become the predominant model for students with disabilities.

The role of the parents regarding their disabled children’s education has not been fully defined; given their role as the primary support system of their children, this is a significant gap in understanding. An implication of this gap is that, as the primary advocate of their children, parents of disabled students could provide certain insights that could deliver more effective tools and methods to help their children achieve academic success, especially providing insights about their behaviors outside school. The teachers of these students were likely not privy to these behaviors; therefore by revealing these behaviors, this study could better equip teachers on how best to manage disabled students and minimize the barriers between them and full inclusion.

Nature of the Study

I used a phenomenological research design in this study. Phenomenology in general originated from a philosophical perspective and is used as an approach for qualitative research (Trochim & Donnelly, 2006). I chose this design instead of a quantitative research design because it provides descriptive recordings of subjective lived experiences and perceptions, as opposed to the focus on quantifiable statistics and numbers offered in quantitative designs, as suggested by Vivilaki and Johnson's (2008) research. My goal in this phenomenological study was to explore the reality of the participants, in order to reveal common life experiences. This approach allowed me to comprehend a given phenomenon through a fresh perspective and conduct an in-depth exploration of a phenomenon that I could not achieved through applying a quantitative design. Researchers suggested that researchers use this method when studying a phenomenon (Leedy & Ormond, 2001; Moustakas, 1994).

Since a gap exists in scholarly literature about parental perspectives of the education of their disabled children (Trochim & Donnelly, 2006; Vivilaki & Johnson, 2008), I justified the use of a qualitative phenomenological research design, as it best accomplished the purpose of this study. The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design.

Purpose of the Study

The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design. To collect data, semistructured, open-ended interviews with the parents of children with ASD who are currently enrolled in a school with an inclusion program for disabled students or who have participated in the inclusion program within the past 5 years. Parents in the study resided in Pennsylvania. They were either the mother or the father of children; I included the parents as long as they self-identified as the primary caregiver to their child with ASD.

Research Questions

The research questions that guided this qualitative research were as follows:

RQ1. What are the lived experiences and perceptions of parents of students with ASD regarding the efficacy of the inclusion model of education on their children's academic success?

RQ2. What are the parents of students with ASD's lived experiences and perceptions regarding their role in the inclusion model of education?

RQ3. What are the parents of students with ASD's lived experiences and perceptions regarding the stressors that may result from their perceived roles in the inclusion model of education?

Theoretical Framework

The stress process model, first introduced by Pearlin, Morton, Lieberman, Menaghan, and Mullan (1981) and developed by Pearlin (1999), served as the theoretical framework for this study. After investigating the lived experiences and perceptions of parents of students with autism regarding the efficacy of the inclusion model of education and their role within it, I used the stress process model to analyze the stresses that resulted from their perceived roles in the inclusion model. In this model, three factors contribute to the stress process: *stressors*, *moderators* or *mediators*, and *stress outcomes* (Pearlin et al., 1981).

Stressors, stemming from external environmental factors, social factors, or internal factors (i.e., biology and psychology), include factors that force a specific individual to be exposed to certain events that would necessitate adaptation on their end (Pearlin, 1999). Moderators or mediators are the social or personal factors that modulate the effects of certain stressors, strengthening or weakening the effects based on individual factors. Hence, stress outcomes include the psychological, emotional, or physiological effects manifested by an individual after being filtered through specific moderators or mediators (Pearlin, 1989, 1999; Pearlin et al., 1981).

Definitions of Key Terms

Autism spectrum disorder: Autism spectrum disorder refers to a set of complex neurodevelopment disorders that hinder—mildly or severely—a person’s social interaction and communication with others. Some examples of ASD include autistic disorder, Asperger’s syndrome, and pervasive developmental disorder (Blumberg et al., 2013).

Inclusion: Inclusion refers to the integration of the disabled students into general education classroom, with the appropriate assistance given in order to increase their access to the general education curriculum (Solis et al., 2012).

Individuals with Disabilities Education Act: Leadership passed the IDEA (1990) to cater to students with disabilities that may prevent them from academic success (Solis et al., 2012; U.S. Department of Education, 2011; White, 2009). Leadership reauthorized this act in 2004 to the IDEA Act of 2004. Leadership designed the act for these education services to serve the unique needs of students with learning disabilities, such as ASD, to provide them the opportunity to learn the same as their nondisabled peers in an environment that is suited to their special needs (Smith & Tyler, 2010).

Least restrictive environment mandate: Least restrictive environment mandate consists of a mandate that states that the primary goal of special education programs is to reintegrate special education students back into the general student population as much and as soon as possible. Supplemental aids and services may be offered separately to these disabled students in order to hasten their full inclusion in general education classrooms (Solis et al., 2012).

Moderators/mediators. These are the social or personal factors that modulate the effects of certain stressors, strengthening or weakening their effects based on individual factors (Pearlin, 1989, 1999; Pearlin et al., 1981).

Stress Outcomes: Stress outcomes include the psychological, emotional, or physiological effects, as manifested by an individual after being filtered through their specific moderators or mediators (Pearlin, 1989, 1999; Pearlin et al., 1981).

Stressors: Stressors entail factors that stem from external (environmental, social) or internal (biology, psychology) factors that force a certain individual to face exposure to certain events that necessitate adaptations on their end (Pearlin, 1989, 1999; Pearlin et al., 1981).

Assumptions

Assumptions made for this study included the following:

- I assumed that all responses by these participants remained sincere and truthful to the best of their knowledge.
- Participants were knowledgeable about the inclusion model.
- Parents' understood the need for their children with autism to be in a special education program, including the inclusion model in a public school setting to support their children to achieve academic and behavioral success.
- Parents chose to have their children with autism attend a public school rather than a private school that might not have an inclusion program.
- The in-depth phone interviews were appropriate to explore parents' lived experiences of a school-based inclusion program for their children with autism; the parents' lived experiences and perceptions regarding the efficacy of the inclusion model of education for their children's academic success; the perceptions and lived experiences of parents about their role in the inclusion model of education; and the parents' lived experiences and perceptions regarding the stresses that may result from their perceived roles in the

inclusion model of education; parents' experiences with teachers and staff at their childrens' schools.

- The interview questions assisted in collecting the correct information for the research questions.
- The semi structured interview questions were phrased in such a way that parents understood what was being asked of them.
- The results of the study would lead to positive social change.

Scope and Delimitations

The scope of this qualitative phenomenological study was the parents of students with ASD, currently enrolled in a public school that used the inclusion model for its disabled students. These parents resided in Pennsylvania. By delimiting the participants of this study to a specific geographical location, the results of this study might not be generalizable to other parents of other children with disabilities that live in other areas. The final delimitation for this study was that the participants were the primary caregiver for the student with ASD and, as such, might be biased due to certain cultural or demographic factors inherent in lived experiences.

Limitations

The main limitation for this study was the honesty of the participants and their respective capabilities to articulate their lived experiences and perceptions regarding the phenomena of the inclusion model as it related to their children with ASD. Another limitation was the selection criteria for individuals to participate in the study. These participants were limited by the requirement that they lived within Pennsylvania. A final limitation of the study was the broad range of acceptable sample sizes within the context of phenomenological methodology. Marshall (1996) and Creswell (2013) argued that as few as 1 to 5, and as many as 50 to 100 participants, were acceptable; moreover, each range resulted in its own level of saturation. While I intended to recruit 12 parents for this study, seven parents completed the study, which remained within the acceptable range for phenomenological research, according to both Marshall (1996) and Creswell (2013). After continued attempts to reach 12 participants failed, I analyzed the seven interview transcripts. I achieved saturation when no new themes emerged that would offer further understanding.

Significance

The CDC (2012, p. 11) stated that a 23% increase occurred in the number of children diagnosed with an ASD in the United Status. Recently, educators have adopted the inclusion model, as required by the IDEA (2004) and the LRE mandate. This adoption meant that normally achieving students faced placement in the same classroom as their peers with learning disabilities, with the final goal being full reintegration for these disabled students back into the general student population (Solis et al., 2012).

This goal might be difficult to achieve given that, as more and more children with ASD faced placement in general classrooms, teachers who might not have received special training might find it difficult to educate these children. The continued prevalence of the inclusion model, coupled with the emphasis placed by scholarly literature on the perceptions of teachers and administrators, might not provide a complete picture of the actual efficacy of this learning program. As the children themselves could not provide their own perceptions, I required assistance from these children’s parents since they represented the primary support system for their children. By revealing the lived experiences and perceptions of these parents of students with ASD in an inclusion program, parents could help provide some insight on how teachers could best accommodate students with ASD. This accommodation could be shown through their knowledge of the behavior of their children outside of school. Through such insights, educators and policy makers could to ensure that inclusion programs deliver on the aims to ensure that these students were accorded the same opportunities for learning as their nondisabled peers.

Summary

Chapter 1 provided an introduction to the research topic and a description of the problem, purpose, and background of the study. The number of students with ASD who were educated by schools with an inclusion program rose dramatically throughout the years. For this educational model to be effective, teachers and parents must work closely together, given their respective roles in the life of the student with ASD. While researchers examined teachers’ perspectives and attitudes about the inclusion model, little research has focused on parents’ lived experiences and perceptions regarding the inclusion model as it relates to their child with ASD (Trochim & Donnelly, 2006; Vivilaki & Johnson, 2008).

The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design. By revealing these parents’ perceptions regarding inclusion, I gained insights on how best to foster healthy learning environments for children with ASD that could drastically improve the quality of education being provided within an inclusion setting. I chose a qualitative phenomenological research design to help gain better understanding the perceptions and lived experiences of the participants.

Chapter 2 will provide a review of relevant literature. Chapter 3 will present a further elaboration on the methodology and research design to be used for this study. Results and discussion are presented in Chapters 4 and 5.

Chapter 2: Review of Related Literature

Introduction

Although researchers once considered autism rare, it has gained an increased interest within the education setting due to its heightened prevalence in recent years. Within the last few years, the CDC (2012) found that the number of children diagnosed with ASD significantly increased, and when adults were included in the prevalence estimate, the number of individuals with autism equated to well over one million. The U.S. Government Accountability Office (2005) stated, “With the increase in the number of students with ASD, so did the need to understand the most effective way to provide services under IDEA” (p. 1). Currently, students with ASD receive as much of their education as deemed possible in the same classroom as their nondisabled peers.

Students with ASD could receive this inclusive learning largely due to the regulations set by IDEA (2004), which addressed the need to provide services in the LRE. The LRE is federally mandated and requires that children with disabilities receive as much of their educations as possible in the same environment as their nondisabled peers (Osgood, 2005).

In this study, I examined the perception of the inclusion model from parents who have an autistic child participating in the inclusion learning model. This chapter includes a literature review on the characteristics of autism spectrum disorders, the incidence and prevalence of autism, historical milestones in inclusion, and the IDEA (1990). The review will provide further insight into the challenges faced in implementing the inclusion model, parental views of inclusion, and studies supporting inclusion services for students with autism.

Literature Search Strategy

I conducted the literature search for this study using the internet, which included both peer-reviewed journals and primary data sources. All sources were published in the last 5 years, except for seminal literature on certain topics. I conducted the search for relevant literature using the following terms*: autism, ASD, inclusion, diagnosis, parents, parental stresses, stressors, motivators, mediators, learning disabilities, perception, special education, least restrictive environments, LRE, prevalence,* and *advocacy*. I used these terms because of the close relation to the current study.

I used the following databases within the Walden University library: EBSCOhost, ERIC, ProQuest, and ProQuest dissertation database. I chose these databases because these provided information closely related to the current study within the psychology/social service field and field of education. There was an abundance of information on the topic of inclusion of students with learning disabilities and those with mental retardation. However, there was a paucity of information that focused exclusively on students with autism or investigated the parents' perception of the inclusion model for their children (Trochim & Donnelly, 2006; Vivilaki & Johnson, 2008).

Theoretical Foundation

The stress process model, first introduced by Pearlin et al. (1981) and developed in greater detail by Pearlin (1999), served as the theoretical framework for this study.

This model includes three factors that describe the stress process: stressors, moderators or mediators, and stress outcomes (Pearlin et al., 1981).

Stressors include factors that arise from external aspects (e.g., an individual's immediate environment or social context) or factors that arise from internal aspects (e.g., an individual's biology and psychology) that force the individual to face exposure to certain events that necessitate adaptation on their end. Moderators or mediators include the social or personal factors that modulate the effects of certain stressors, strengthening or weakening the effects based on individual factors. Stress outcomes include the psychological, emotional, or physiological effects exhibited by an individual after considering the effects of their distinctive moderators or mediators (Pearlin, 1989, 1999; Pearlin et al., 1981).

There are two main categories of stressors: *event stressors* and *chronic stressors*. Event stressors are stressors that happen without the full expectation of the individual, often resulting in a stress outcome (Pearlin, 1999). Some examples of this are divorce or experiencing a hurricane. There are distinctions between the reasons or circumstances behind an event stressor as thee relate to an individual (Pearlin & Skaff, 1996). For instance, a divorce preceded by long periods of fighting and disagreements may have different results regarding stress compared to a divorce necessitated by a romantic partner having an extramarital affair. Furthermore, the reasoning behind an event stressor may affect whether it creates a stress outcome in an individual.

Chronic stressors are stressors that include many different kinds of strains, such as status strains, role strains, ambient strains, and quotidian strains (Pearlin & Skaff, 1996).

As opposed to event stressors that emerge at determinable points in time, chronic stressors arise stealthily or may be present over long periods of time without being perceived by the individual (Pearlin, 1995). These chronic stressors may be due to the consequences of rigid systems that promote inequality, such as class or institutionalized social roles and the various norms and activities contained therein, and also out of social networks, such as one's neighborhood, community, and larger social environment (Pearlin, 1995). These stressors, even without being perceived, may continue within a person, whether they verbalize the issue or not.

Status strains are problems that emerge primarily and clearly from an individual being ensconced within a rigid and hierarchical social structure (Pearlin, 1995). An obvious example of this would include abject poverty. The placement of an individual into the status of someone under poverty could increase the likelihood of them experiencing stressors. This would makes them more susceptible to these stressors by limiting their personal and social resources that could perhaps allow them to deal better with those stressors (Pearlin, 1995). This could lead to stronger and more lasting stress outcomes, resulting in individuals experiencing deeper states of stress (Pearlin, 1995). Other examples of this kind of strain would include strains from gender, age, race, and ethnicity (Pearlin, 1995). These factors are pervasive and often used to justify sweeping judgments on individuals, where society may use their status to marginalize them (Pearlin, 1995).

Role strains are problems that result from stressors in the major institutional roles, such as family and occupational roles (Pearlin, 1983). Some examples of this kind of strain include an individual facing certain demands beyond their physical capacity or stamina, or wide discrepancies between the completion of a job relative to the rewards the individual perceives that they get for that role. Moreover, Pearlin (1995) stated that if an individual worked a difficult job that involved lots of abstract thinking and specialized skills, it might result in some kind of role strain if that person was paid the same as an unskilled worker. Pearlin (1995) emphasized that this kind of strain could only be present given certain structures. Therefore, what happens during a role strain is that stressors influence more than just a single individual, but also other members in a given role set.

Pearlin (1995) provided an example of the gradual changing of roles within a family as time passes. For example, teenagers may feel role strain since they may perceive that they are treated similar to babies by their parents, in opposition to their own perceptions that they are fully grown adults. Years later, those same teenagers may help bring about that kind of role strain in their parents who, in their old age, are often treated similar to babies. Thus, “The actions and expectations guiding relationships with a role set normally undergo constant realignment and restructuring” (Pearlin, 1995, p. 8).

This may also be apparent in conflicts between incompatible demands of different roles. An example here may be a nurse who is not only responsible for the completion of their responsibilities to the hospital, but to the family members and loved ones of their patients as well. If a nurse chooses to commit fully to the role set up by their employing hospital, that specific role may involve completely different responsibilities, from the perspective of the patients or their family members (Pearlin, 1995).

In the parents' roles as primary caregivers and support systems for their disabled children, potential conflicts about their role may result in stress outcomes for parents of students with ASD, which may lead to stress outcomes, given certain perceptions and experiences. I designed this study to explore the lived experiences and perceptions of parents of children with ASD enrolled in a school with an inclusion program, in order to reveal if they perceive any stressors in the context of the inclusion program and its effect on their children and themselves (Pearlin, 1995).

Contextual strains include strains that arise from the interaction of an individual with the environment that surrounds them, such as their general community or neighborhood (Pearlin, 1995). Pearlin (1995) provided the following example: In the exploratory qualitative interviews he conducted, the elderly participants experienced trepidation and uncertainty, naming threats to security as salient strains to their well-being.

Lastly, quotidian strains include the kinds of strain that all individuals encounter and deal with in everyday life. Pearlin (1995) described these strains as arising from ordinary logistical activities at home or outside of the home. For instance, the responsibility to clean one's own room or house cannot be avoided if one wishes to live in a clean environment. However, for many individuals, this is not an activity that brings them happiness; rather, it strains them. Public transportation delays, slow-moving pedestrian traffic, and long waits for restaurant reservations are examples of this kind of strain.

The kind of strain most relevant to this study was Pearlin's (1999) conception of role conflict, wherein an individual is exposed to stressors derived from inconsistencies or discrepancies between their perceived roles. Researchers could use the stress process model to postulate that a role conflict exposes one to stressors, which would then result in the manifestation of stress outcomes (Pearlin, 1999).

Pearlin (1999) used this theoretical framework to purport that individuals were connected to social structures that heavily influenced their lives. The social structures that parents of students with ASD interacted with could be grouped according to the roles such people played in the inclusion model of education (i.e., both general and special education teachers), as well as according to age, race, ethnicity, or socio-economic class.

In this study, I focused on parents who were connected to the social structures of school personnel in the school. In addition to the parents' extraordinary amount of time and effort spent on the general and overall care of their child with autism, school personnel also play a huge role because of the amount of assistance and time provided in the success of the child's academic experience. However, I did not collect these data, as these were not of the purview of this study.

The stress process model is widely used in the medical field to examine the health and well-being of those who care for persons with disabilities or health problems (Pearlin, 1999). Specifically, it provides a framework for measuring the unique burden and risk factors of stress for family members in the position of caring for loved ones (Chronister & Chan, 2006; Dal Santo, Scharlach, & Nielson, 2007; Majerovitz, 2007). I decided that it was appropriate for this study as the roles of the caregivers for students with ASD fall primarily within two camps: their parents and their teachers. While their parents are considered the primary caregiver, their teachers are also likely to be influential in the caregiving process since they are the ones with whom disabled students spend the most time learning with outside of their home. The resulting conflicts that may ensue from this shared goal on the part of teachers and parents of students with ASD could hinder the academic progress of the disabled student. It may be easy for either caregiving role to slip into the other, causing role conflicts (e.g., teachers behaving similar to parents), if clear guidelines are not made.

The theory's components guided the data analysis in this qualitative research study. While research on similar populations has been completed, these studies were not applicable for this study, as the disabilities studied were different. Further researchers provided insights on how the teachers felt about including any individuals with disabilities, but there have been no studies specifically about teacher's feelings about including autistic children (Trochim & Donnelly, 2006; Vivilaki & Johnson, 2008). There is very limited primary researchers who accounted for how the parents of autistic children perceive the services provided (Trochim & Donnelly, 2006; Vivilaki & Johnson, 2008).

Autism

Kanner (1943) first used the term autism in the modern sense. He used the term to describe the markedly withdrawn and reserved behavior in the children that he studied, characterized by "extreme aloofness" and "total indifference" (Church, 2009, p. 524). There has yet to be a consensus among medical professionals regarding the cause or cure for ASD, which has led to continued gaps in understanding the full nature of the disorder

(Shattuck & Parish, 2008). Mazurik-Charles and Stefanou (2010) noted that the most important aspect in children with ASD involved their social interactions. This aspect would necessitate that students with ASD in inclusive classrooms must receive special services that would help them forge meaningful relationships with their classmates and learn along with their nondisabled peers. According to the DSM-5, to be diagnosed with an ASD, a child must meet, currently or by history, criteria A, B, C, and D:

1. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifested by all three of the following:
    - A. Deficits in social-emotional reciprocity,
    - B. Deficits in nonverbal communicative behaviors used for social interaction, and
    - C. Deficits in developing and maintaining relationships.
2. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following:
    - A. Stereotyped or repetitive speech, motor movements, or use of objects;
    - B. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change;
    - C. Highly restricted, fixated interests that are abnormal in intensity or focus; and
    - D. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment.

3. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities.

4. Symptoms together limit and impair everyday functioning.

(American Psychiatric Association, 2013, p. 20)

Although one may observe most of the criteria for autism in a number of children, one must identify this pervasive developmental disorder and confirm it with a medical diagnosis to determine accurately whether an individual truly has autism. This confirmation is important as an error in diagnosis may result in unwanted complexities and difficulties on the future life of the child (American Psychiatric Association, 2013). The age range in which autism develops varies from child to child, but it has been rarely found to show its effects before the age of three.

Some parents, guardians, or nonmedical professionals may be quick to misdiagnose a child with autism due to various factors. Church (2009) recommended that these individuals should pay close attention to certain factors that could help identify whether a specific child might have ASD:

- Does not smile or use other warm, joyful expression by 6 months.
- Does not engage in a back-and-forth sharing of sounds, smiles or other facial expressions by age 9 months.
- Does not babble, point or make meaningful gestures (such as waving or reaching) by age 1.
- Does not speak 1 word by age 16 months.
- Does not combine 2 words by age 2 years.

- Loses previously gained language or social skills.
- Has poor eye contact.
- Does not seem to understand how to play with toys, is attached to 1 specific toy or object, excessively lines up toys or other objects or a combination of these.
- Seems to be hearing impaired (e.g., a child may not respond to his name but mat instead overreact to small inconsequential sounds). (p. 527)

If such factors are found to exist in a specific child, Church (2009) made the recommendation that only then should parents contact medical professionals to test their child for a possible diagnosis of ASD.

Prevalence of Autism

According to the CDC (2012, p. 11), since 2009, a 23% increase occurred in the number of children diagnosed with an ASD in the United Status. Of the 11 sites that completed both the 2006 and 2008 surveillance years, seven exhibited a higher prevalence of ASDs in 2008 compared to the numbers in 2006. In addition, three sites exhibited a close amount of prevalence in 2006 and 2008, while only one site showed a decrease in the prevalence of ASDs (CDC, 2012, p. 11).

The percentage of increase in estimated ASD prevalence was similar for males and females, with 23% for the former and 21% for the latter (CDC, 2012, p. 11). The rates of estimated ASD prevalence also varied according to race, according to the data taken from individual sites, and when combined with data from all the other sites. It was observed that, between the years of 2006 and 2008, there was a 16% increase in ASD prevalence among non-Hispanic White children, a 42 %increase among non-Hispanic Black children, and a 29% increase among Hispanic children (CDC, 2012, p. 12).

If the results from 2008 were compared to the results of 2002, the numbers became even larger. Of the 13 sites that completed the 2002 and 2008 surveillance years by the CDC (2012, pp. 13-14), 12 showed a significantly higher prevalence of ASDs in 2008 compared with 2002. The combined data revealed that, the ASD prevalence estimates for children aged eight years increased 78% from 2002 to 2008, with an 82% increase for males, and a 63% for females; furthermore, a 70% increase was found among non-Hispanic White children, a 91% increase among non-Hispanic Black children, and a 110% increase among Hispanic children (CDC, 2012, p. 14).

While the definite reason for the prevalence of ASDs and its increase in rates over the years have yet to be found, the large numbers of children with ASD and the rate at which these diagnoses are increasing have made ASD a concern that must be addressed by various sectors in education and public health (CDC, 2012). As debate continues on whether this increase in the number of students with ASD are due to more actual cases of ASDs, better identification and diagnostic practices, or simply cases of intellectual disability, are now classified as autism (Autism Speaks, 2011; Mayo Clinic, 2013). The main issue of children with ASDs continues as a significant concern, especially for the educational community tasked by the initiatives, such as the IDEA Act (2004) and the LEA mandate, to provide services for these students.

History of Inclusion

PL 94-142

Congress passed the Education for All Handicapped Children Act (EHA; public law 94-142) in 1975, and this became effective on October 1, 1977. It required all states that received funds through PL 94-142 to provide free appropriate public education for all resident handicapped children, and protect the rights of parents and children in their claiming of these special education services (Jacobs & Walker, 1978). State and local educational agencies must therefore develop plans to identify, locate, and evaluate these prospective students and place them into suitable learning programs, ensuring that they are afforded full educational opportunities (Jacobs & Walker, 1978).

Segregation

The inclusion model is currently the ideal setting of choice for students with autism (Moore, 2011), but this has not always been the case. For instance, Stainback and Smith (2005, p. 12, claimed that it only occurred as recently as the early 1800s when the United States considered students with disabilities unworthy of free education. Because of the prevailing opinion at those times that students with disabilities simply could not learn, they were placed in group homes or state institutions, rather than schools. Furthermore, they received their educations in settings with populations comprised exclusively of individuals with disabilities (Stainback & Smith, 2005).

Hardman, Drew, and Egan (2008) also detailed the many difficulties individuals with disabilities have faced, such as infanticide, institutionalization, physical abuse, slavery, and forced sterilization. Students with disabilities continued to be treated in such horrible ways and receive their educations in secluded or segregated settings until the passing of the EHA (1975).

Special Education

The EHA (1975) was based on the landmark case *Brown v. Board of Education*, which received its ruling in the early 1950s. Although *Brown v. Board of Education* fought for equal education rights for different races, EHA (1975) expounded on this decision to include students with disabilities (Yell, 2006). The EHA (1975), now the IDEA (1990, 2004), required school districts to provide education to all students with disabilities, at no cost to the family (IDEA, 2004). Once the new laws passed, special education in the United States started to focus primarily on the kind of education where disabled students were educated with the goal of as much integration as possible in the soonest time (Osgood, 2005). This was when the term *mainstreaming* emerged, which described the practice of education disabled students, particularly those with mild disabilities, in the LRE (Alquiraini & Gut, 2012).

However, despite mainstreaming and its effects on affirming the rights of students with disabilities to be engaged in an education in the least restrictive environments, two limitations of mainstreaming were reported by scholars. The first type of limitation in mainstreaming was called *locational mainstreaming*, where students with disabilities faced placement in special classrooms, separate from their nondisabled peers (Alquiraini & Gut, 2012). The second type of limitation in mainstreaming, called *social mainstreaming*, was where students with disabilities could only interact with their nondisabled peers during art time, meal time, and other social activities, while leadership typically segregated them during other times (Osgood, 2005). With this in mind, leadership used to group children with autism with all other disabled students, although their characteristics were extremely different, thus making their education and future reintegration back into the general student population difficult.

These shortcomings have led to the development of inclusion, which developed out of the same philosophical grounding for the extension of civil rights (Alquiraini & Gut, 2012; Yell, 2006). The key difference between these two models is that while these both seek to allow students with disabilities to receive their education in the least restrictive environments, inclusion allows a more varied population of students with disabilities through integration (Alquiraini & Gut, 2012).

Inclusion

Leadership using the inclusion model, as defined by IDEA (2004), can educate all allowable children with physical, mental, and developmental disabilities in the same general education classroom. Osgood (2005) noted that inclusion represented a better educational model compared to mainstreaming, as it avoided the problems and inefficiencies found to emerge in segregating students with disabilities. Additionally, researchers claimed inclusion possibly reduced the stigma attached to students with disabilities and the isolation, both social and educational, that it might encourage (Alquiraini & Gut, 2012).

There are two kinds of inclusion: regular inclusion or partial inclusion, and full inclusion. According to Bowe (2005), inclusive practice is not always inclusive as it is normally understood; rather, it is a form of integration for students with disabilities, where they are educated with their nondisabled peers for most of their time in school but provided with specialized services that are specific to their needs outside the general education classroom. This may be viewed as quite similar to the mainstreaming process described earlier. While this leaders employing this process purportedly treat students with disabilities as full members of a general classroom, it also requires that they face treatment that varies from their nondisabled peers. Such specialized services mean that disabled students are occasionally taken out of their regular classes and placed in smaller classes that contain an intense focus on their special needs (Bowe, 2005).

In the full inclusion model, Zigmond, Kloo, and Volonino (2009) stated that disabled students should always receive education in general education classrooms alongside their nondisabled peers as the most desirable option, while continuing to provide special services to students with special needs. In this model, special education is not considered a place where students with disabilities are placed in isolation from their nondisabled peers; rather, it is treated as a service given to certain students, administered through the regular classroom (Feldman, 2008). Therefore, all special services must be taken to disabled students in their regular classrooms, where they are assigned to remain full-time regardless of their disability (Wisconsin Education Association Council, 2011).

What this means is that instead of taking disabled students away from general classrooms for their special needs, which may cause further social isolation and behavioral problems, the services that cater to their needs are brought to them with the minimum amount of disruption possible to their daily routines as regular students. This approach may best address the primary concerns raised by students with disabilities in special education classrooms. Namely, special students would face isolation from their peers, and this isolation might reduce the likelihood of them facing reintegration into the general student population (Feldman, 2008).

Researchers reported full inclusion as being the preferred method of service delivery in special education, although, researcher also mentioned co-teaching as a supplementary service (Zigmond et al., 2009, p. 196). Mazurik-Charles and Stefanou (2010) supported this claim, adding that fully inclusive classrooms might represent the best location for the services that would help students with disabilities deal with their problems regarding social interaction and behavior.

However, some scholars noted controversies regarding the implementation of full inclusion as the model of education for students with disabilities (Fuchs et al., 2010). With the advent of federal legislation that increases the accountability levels for students of all kinds, the standards these students must live up to achievement levels expected from them. Hence, the leadership amended these to reflect the same standards and achievement levels expected from nondisabled students (Fuchs et al., 2010).

As more and more students with disabilities are educated in general classrooms for most of their school days, it would therefore be important to ensure that the program is effective. McLeskey et al. (2011) discovered that the proportion of students with learning disabilities, currently being educated primarily in a general education classroom, rose to 80%. This increased amount necessitated that the educational system must not fail. The large stakes inherent in any discussion on the education of students with disabilities resulted in numerous diverging opinions on the topic of full inclusion. Some discussion of the scholarly literature on this topic follows, presenting both sides to the issue.

Scholarly Opinion on Full Inclusion

One may take the fact that the establishment and mandate of the IDEA Act (1990, 2004), NCLB Act (2002) and LRE resulted in higher standards for students with disabilities as a positive development in the continued search for the best method to approach disabled students. However, some scholars have disagreed that full inclusion was realistically possible for students with certain disabilities (McLeskey, 2007; Zigmond, 2003).

McLeskey (2007) and Zigmond (2003) articulated the controversy that surrounds full inclusion. They claimed that as schools continued to integrate students with disabilities with their nondisabled peers in an inclusive classroom, it could become the first and only consideration. This focus included disregarding the efficacy of the programs or the achievements levels attained by their students. McLeskey and Waldron (2011b) contended that it was necessary to determine whether some programs, which sought full inclusion of students with disabilities into general education classrooms, actually produced reasonable outcomes for their students in practice. As McLeskey and Waldron (2011b) have mentioned, inclusion cannot be the sole basis for the education of students with disabilities, especially if the emphasis on inclusion allows the efficacy of the programs or the achievement levels of the special students to be relegated to the background.

One may perceive the term inclusion as good in itself, without reference to the fact of whether it works best and most realistically for students with disabilities, which should be the main concern (McLeskey & Waldron, 2011b). Additionally, researchers discovered full inclusion was more difficult compared to simply enacting the policy. McCarthy, Wiener, and Soodak (2010) interviewed school administrators in 11 public schools who taught both disabled and nondisabled students in a general classroom. The researchers found that the experiences under the segregation system continued to permeate in their current policies. Some of these experiences with segregation consciously and unconsciously informed the school administrators' decisions regarding the inclusion model in their schools, thus undermining the goals of full inclusion (McCarthy et al., 2010). McCarthy et al. (2010) proposed that policies of inclusion in schools could not rely solely on legislation, as the personal and institutional factors that have been in place for long periods continued to exert influence on the school administrators. This resulted in a paradox where they espoused an overt goal of inclusion but might subscribe unconsciously to beliefs that reinforced a philosophy of difference (McCarthy et al., 2010).

Similarly, Lohrmann and Bambara (2006) gave this recommendation as well. They interviewed 14 general education teachers over an 18-month period to reveal teacher perceptions about inclusion to find ways in which it would work effectively. The authors found that the reflections offered by the participants focused on the creation of a culture within that school where the philosophy of inclusion was valued highly. Lohrmann and Bambara (2006) contended that without this overall school culture, legislation that mandates inclusion for students with disabilities might not help these students achieve their educational goals (Lohrmann & Bambara, 2006, p. 163). Meaning, mandated inclusion is not enough to compel teachers and education administrators to pursue an ideal of inclusion. Perhaps just as important is that these teachers and education administrators actually believe in the policy.

In a study of students with ASD, von der Embse, Brown, and Fortain (2011) claimed that researchers had yet to measure or evaluate inclusion systemically. The few studies that attempted to measure inclusion relied on subjective teacher reports or made implicit claims for the social aspects of inclusion with any explicit measurements, as in the study by Mancil, Haydon, and Whitby (2009). Teachers, interviewed by Mancil et al. (2009), reported inclusion as successful, without any explicit data being mentioned (von der Embse et al., 2011). Von der Embse et al. (2011) made the point that for inclusion to be possible, leadership must implement effective interventions to reduce the problem behaviors of students with disabilities who might distract nondisabled students.

Conversely, McLeskey and Waldron (2011b) have claimed that full-time inclusive programs did not work for all students with learning disabilities and that resource classes were often the same. In their research of elementary schools and the content areas of reading and mathematics, they found that elementary students with disabilities could make progress academically if they received high quality, intensive instruction in small, homogenous groups for limited periods (McLeskey & Waldron, 2011b). According to their previous research (McLeskey & Waldron, 2011a), the academic progress displayed by such students was significantly greater compared to the progress found in students with disabilities who have been educated in high quality inclusive settings (Waldron & McLeskey, 1998; Zigmond et al., 1995).

Most importantly, McLeskey and Waldron's (2011b) study bolstered the claims made by Torgensen (2009). Torgensen (2009) estimated that up to 50% of students with disabilities, placed in high quality, intensive instruction in small homogenous groups for limited amounts of time, could obtain the same levels of academic progress as their nondisabled peers. Moreover, these students could eventually handle reintegration into a general education classroom eventually. McLeskey and Waldron (2011b) further explained this kind of instruction by differentiating it from the traditional large, undifferentiated special education resource classrooms of the past. As opposed to such settings, high quality instruction was delivered to small groups with the similar special needs, with the instruction being provided more intensive and explicit than the instruction provided to their nondisabled peers (McLeskey & Waldron, 2011b).

The conclusion they make is that while inclusion remains to be an ideal to be attained, there have been too many shortcomings in the educational system to ensure that the programs for students with disabilities are both inclusive and effective, echoing the claim made in McLeskey and Waldron (2011a). Full inclusion programs were therefore found to be lacking in terms of being able to assist disabled students successfully to catch up with their nondisabled peers. The final stance offered by McLeskey and Waldron (2011b) emphasized the equal value on inclusion and program effectiveness, to best create schools that are not just fair to students with disabilities, but also allow them to attain academic excellence.

Teachers’ Views of Inclusion

The increasing number of students, who have ASD, combined with the policy of inclusion being put into place at schools, have resulted in general education teachers—who have traditionally taught only nondisabled children—now having the added responsibility of teaching students with disabilities, as well (Busby, Ingram, Bowron, Oliver, & Lyons, 2012). Along with the higher standards being placed on students with disabilities as mandated by the IDEA Act (1990, 2004), NCLB Act (2002), and LRE, teachers may find their jobs even more difficult than it had ever been. This may be argued to be a large contributing factor why teachers, despite agreeing with inclusion in theory, sometimes feel that they are not prepared for it (Uzair ul Hassan, Parveen, & Riffan-un-Nisa, 2010). Studies, as recent as Allison (2012), have continued to show that teachers still feel a lack of training and special support in their classrooms that include students with disabilities, causing them to feel ineffective and uncertain.

While change has always been constant, especially regarding the standards with which to hold students to, but the changes in education over the last two decades have been quick, complex, and wide-ranging, as governments have started to measure progress not just against the country’s own standards, but also against other country’s standards (Day, 2012). It is now much more common in teacher education programs to instruct their students on inclusive teaching methods and diversity-instruction models (Agran, Cavin, Wehmeyer, & Palmer, 2010; Voltz & Collins, 2010).

As a result, governments and policy makers may push for certain educational programs or standards to be put into place without considering the perceptions of teachers. The rhetoric such policy makers espouse about the children and how they should be given all the opportunities in the world often ignores the difficulties teachers face in enacting such changes quickly and sweepingly.

Day (2012) claimed that externally-imposed curricula, management innovations, and monitoring and performance assessment systems that teachers must implement have resulted in “periods of destabilization, increased workload, intensification of work, and a crisis of professional identity for many teachers” (p. 8). Since the number of students in any country would outnumber the number of teachers, government officials and policy makers might find it more expedient to appease students, rather than teachers. While this approach might not be wrong, it could marginalize teachers by essentially telling them how to do their jobs, which might demoralize them into perceiving that the general public did not believe in their capabilities to provide excellent service (Day, 2012).

One may observe the shifting nature of teacher responsibilities in the statistics published by the National Education Association (2010) about the trends currently in place regarding the teaching profession. The rate of teachers who work 40 or more hours a week increased from 14% in 1961 to 22% in 2006 (National Education Association, 2010, p. 48). The rankings of factors that teachers perceived as hindrances to their job were, in 1961, ordered from most to least:

> Lack of time to teach, classroom interruptions; lack of materials, resources, and facilities; discipline and negative attitudes of students; incompetent/uncooperative administrators; poor preparation of students, unsatisfactory remuneration; insufficient preparation for the field in which teaching (p. 93).This ranking of

> factors changed in 2006: heavy workload, extra responsibilities, paperwork, meetings; testing demands/teaching to the test; discipline and negative attitudes of students; incompetent/uncooperative administrators/lack of support from administrators; lack of preparation/planning time; lack of materials, resources, and facilities. (National Education Association, 2010, p. 93).

These changes have affected both the number and quality of teachers in our country. Teaching is one of the most difficult professions (Labaree, 2011), and the financial compensations offered for teachers pale in comparison to other professions, especially if one considers the impact of teachers on our country. Teachers would seem to be attracted to the profession for more than just the financial incentives, namely, the job of changing people's lives (Labaree, 2011). Therefore, as seen in the change in hindering factors for teachers above, educational policies that come from beyond the schools themselves are often perceived to limit the freedom of teachers to do their job to the best of their knowledge and abilities.

The external demands imposed by the government and policy makers (e.g., to teach to the test or to teach only the subjects and concepts included in national standardized tests) reduce the freedom of teachers. This reduction in freedom extends to their ability to make decisions about their own students, about whom they may have the best knowledge compared to the government policy makers. By disallowing teachers to make these kinds of decisions about what should be done to educate the students with disabilities, they may feel marginalized and unappreciated (Day, 2012).

As Labaree (2011) claimed, teaching is one of the most difficult professions, as it involves guiding people toward a life of learning, which can be a difficult proposition, especially for teachers of younger children. However, in the eyes of the public, teaching may seem to appear easy, given the fewer hours, the vacation time during summers, and other purported benefits. Labaree (2011) contended teachers were easy targets for "anyone selling a simple mechanism for distinguishing the good teacher from the bad" (p. 13). Thus, teachers might stay fearful of metrics and evaluations and could not do the job properly, according to their original training.

An example of this difficult situation is the dual emphasis on inclusion while, at the same time, pushing for a standards agenda that is based on narrow definitions of academic success under the umbrella of public accountability and government control (Avramidis, 2005). This in opposition to the perceptions of teachers, as revealed in a survey conducted by DeSimone and Parmer (2006). DeSimone and Parmer (2006) found that a majority of their participants supported the idea of inclusion. However, these participants also expressed that a general education classroom might not represent the most ideal place for students with disabilities. The participants cited that teachers might find it difficult to give these disabled students the attention and special services they require, while still covering the mandated curriculum.

Researchers have found out that, generally, that this state of affairs holds true: teachers have indicated that although they believe in the inclusion model, they continue to have some reservations when it comes to teaching a fully included classroom (Damore & Murray, 2009). This reluctance may stem from a limited knowledge about the disabled population being served, inadequate training to service the population, limited support staff for problems that may arise, and the idea that the students with disabilities will require more assistance and take time away from the regular education student (Daane, Beirne-Smith, & Latham, 2000; Gartin & Murdick, 2005; Goodman & Williams, 2007).

Soodak, Podell, and Lehman (1998) also provided insight on the dissatisfaction felt by educators regarding inclusion. The frustration and dissatisfaction would be reported again in an article provided by Davis (1989) who stated, “If inclusion is adopted too quickly on a widespread basis, it could bring serious harm to the very students it was designed to help” (p. 144). The frustration of the regular education teachers allowed for more collaboration between the special and regular education teacher.

The special education teachers seemed to welcome the inclusion model. Although the regular education teacher is invited to provide input on the students Individualized Education Plan (IEP), the special education teacher is the person held responsible for the monitoring of the goals and objectives of the program, and making sure those standards are maintained (Familia-Garcia, 2001, p. 6). An effective inclusion model requires clarification of roles of all those participating (Welch, 2000).

More recently, Dybvik (2004) conducted a qualitative study where he observed a young male student named Daniel. In this study, Daniel, a nonverbal student, was placed in a general education classroom. After observing Daniel, the researcher interviewed staff to obtain additional information about the services provided. Many staff members responded with frustration at the limited knowledge and training they had that was needed to assist the student. Staff members also noted their inability to deal with Daniel's behavioral disruptions, such as occasional verbal outbursts or meltdowns.

At the conclusion of this study, Dybvik (2004) described a disagreement between the education communities as to whether students with disabilities received any benefit from being placed in the regular education setting. Some educators have claimed that placing students with severe disabilities with nondisabled children may result in the opposite direction intended, in that they lose even more ground academically due to the lack of intense interventions on their behalf (Dybvik, 2004), as evidence by the occurrence of many instances presented by the teachers where the severity of autism made it impossible for some students to successfully participate in the inclusion model and, in the end, had to be placed in a self-contained classroom.

There have been reports of several obstacles for the special needs services necessitated by students with autism. Nickels (2010) named inadequate time, the innate traits associated with autism itself, and difficult teacher opinions as some of these obstacles. Again, while teachers generally have a positive conception of including disabled students with nondisabled students in general education classroom, it is very rare for teachers to advocate for inclusion without stipulating that there must be a wide range of supports available for the teachers, especially those who might feel they have been unprepared for such an undertaking (Idol, 2006).

Lerman, Vorndran, Addison, and Kuhn (2004) conducted a mixed method study. The researchers observed student growth in the areas of communication and correct task responses for six students with autism (Lerman et al., 2004). The teachers interviewed were provided training on the best practices for teaching autistic children. This training was seen to benefit the teachers who were responsible for conducting classes in an inclusive environment, in that they were not just ready to teach students with disabilities, but also felt confident about their readiness (Lerman et al., 2004). Concluding the study, the researchers noted the importance of that teachers being specially trained in the area of autism, as it can only help them more effectively in their goal to teach their autistic students, as mandated by policies of inclusion.

While it is important that teachers have appropriate training, Scheuermann, Webber, Boutot, and Goodwin (2003) examined the difficulties surrounding getting teachers trained appropriately and effectively to teach students with autism. The authors pointed out that the difficulty in training may have roots in the shortage of both regular and special educators. This shortage may be due to the rate at which teachers leave the field for any reason.

In the conclusion of the article, the authors stated that any solution to this issue must include the parents. They provided that it would also be beneficial to provide parents skills on effectively teaching their child. By assisting the parents, the authors believed that this would be a great benefit to the educators.

Parents' View of Inclusion

Just as autism and inclusion has posed various challenges to teachers, they also pose challenges for parents. For successful inclusion practices, it is important that parents be provided an opportunity to be a part of this decision. The input from parents may assure that all aspects of the disability are taken into consideration and appropriate accommodations are added in the students Individual Educational Plan (IEP). Although the IDEA (2004) has mandated that a disabled student’s parents must be allowed to participate in all aspects of the child’s IEP, a number of these parents have opted out of being involved, the reasons of which are still unclear (Leyser & Kirk, 2004).

Leyser and Kirk (2011) studied parents of children with disabilities; the researchers retained similar concerns as they did in their previous study (Leyser & Kirk, 2004). These concerns included lack of knowledge and training for general education teachers to educate the child properly, lack of resources on the part of the school to accommodate the special needs of their child, and fear that the child might be socially rejected and teased by peers in a general education classroom (Leyser & Kirk, 2011).

The lack of participation may be due to a lack of knowledge about autism and inclusion. Some researchers, as early as 1999 and 2000, have attempted to investigate the reasons for the lack of participation or dissatisfaction with the inclusion model (Kasari, Freeman, Bauminger, & Alkin, 1999; Yell, 2006). Moreover, these researchers have studied whether these parents remained fully aware of their children’s condition regarding their education. This unawareness extended to the positives and negatives that government mandates, such as IDEA (2004) and LRE, brought to their children’s education (Kasari et al., 1999; Yell, 2006).

Although these studies addressed possible dissatisfaction, there are some parents who agree with their child participating in the inclusion model, as revealed in an earlier study by Davey (2004). However, this study included all special needs students and was not limited just to autistic students, which may color the results. This distinction is important to make, as Leyser and Kirk (2004) found (i.e., inclusion was often perceived as a positive development by parents of students with milder disabilities compared to the parents of students with moderate to severe disabilities).

Parents of children with mild disabilities would more likely be inclined to pursue inclusion for their children, as it is reasonable for them to think that their children would learn to catch up to their nondisabled peers if given the appropriate opportunity. However, for parents of children with moderate to severe disabilities, they may fear that if their children were to be placed in a general education classroom, the difference between them and their nondisabled peers may be too glaring, which may result in social isolation, or a lack in intense small-group interventions to help them catch up. This could then lead these students to falling farther behind.

While these fears and reservations are indeed reasonable, a drive to educate these parents on what exactly constitutes an inclusion program must be made in order to help them make the correct decisions regarding their disabled child. Through such processes, perhaps parents may be more receptive to the idea of inclusion. The involvement of these parents in the education process could therefore be a key rallying point for education administrators and policy makers to assist in the goal of inclusion.

In a study that documents the impact of relative contexts on the long-term outcomes of these students with severe disabilities, Ryndak, Alper, Hughes, and McDonnell (2012) concentrated on the effectiveness of services in both inclusive education contexts and other educational contexts that had a more restrictive structure. They noted that currently, a policy of high accountability is the cornerstone of educational policies that dictates the provision of financial support for schools and salaries for teachers and administration to the levels these schools have achieved regarding student outcomes (Ryndak et al., 2012). This has resulted in the marginalization of social validity, which the authors have emphasized must be reinforced during high school for students with disabilities, to help them develop the social skills necessary to employment and other long-term incomes (Ryndak et al., 2012).

While testing well in standardized tests are no doubt important, a large part of what limits students with disabilities is the lack of genuine inclusion into the classroom that could result in the underdevelopment of social skills. Despite the presence of standard reading and arithmetic skills, such disabled students may still lack the requisite social skills their nondisabled peers have learned in the classroom to function well in their future. The authors provided recommendations for this reason (Ryndak et al., 2012). The recommendations might help increase the emphasis special education must give to social validity are threefold: consumer input must be sought out regarding curriculum goals, a reconsideration of teacher preparation must be made, and, finally, the context of instruction must be tailored to help students with disabilities master the technical and social skills needed for successful post-school outcomes (Ryndak et al., 2012, pp. 134-135).

They noted that general and special teachers, parents, and education administrators tend to disagree with each other, especially given the presence of legislative mandates and the state of the economy (Ryndak et al., 2012). Competing interests and goals may be present and, in the ensuing process, students with disabilities may be left up in the air in terms of their long-term outcomes, and may not be addressed until the time just before or after graduation, lessening its positive impacts. Additionally, the students themselves must be given the opportunity to speak out regarding their own desires and not be subject to the goals expected of them by their parents and teachers (Ryndak et al., 2012). The authors declared that there is a sore lack in cooperation and involvement between the many different support systems for the student with disability, such as their parents, teachers, students, families, administrators, and researchers, especially when it comes to thinking ahead to those students' post-school futures (Ryndak et al., 2012).

In a study of the assessments of 627 parents of students with disabilities on the importance of self-determination on their children, Carter et al. (2013) revealed that parents placed high value on all the self-determination skills that they measured, the data on the degree that their children were reported to display those skill were very low. The role that the parents play in the development process of their disabled children has, before this study, not been examined exhaustively. Based on the results of this study, there may be a disconnect in the main goals or purposes of the parents and the teachers of the students with disabilities. If parents did indeed rate self-determination skills as highly important, they may try to inculcate that viewpoint in their children. If so, the kind of education they are to receive at school must conform to this viewpoint if these students are to be truly self-determined. Without a confluence of goals between these support systems of the student, then it may be very difficult to lead these students to success, given the difference in what is being taught to them.

Teacher preparation must also be emphasized in order for this to happen, especially with the higher numbers of children with disabilities being placed into inclusive classrooms. General teachers must be better trained to adapt to their disabled students and learn how best to accommodate the mandated curriculum to those students, in recognition that not all disabled students can or should meet the same academic performance standards (Ryndak et al., 2012). A consequence of the emphasis on standardized testing has compelled teachers to focus more on the curricular content of academic subjects rather than endeavoring to identify the individual needs of all learners and coming up with methods that address those diverse needs, especially for students with significant disabilities (Ryndak et al., 2012). The authors have stated that there must be more preparation for these teachers than the current two to three hour credit course that focuses mostly on students with mild disabilities; having no contact and exposure to students with diverse disabilities and their special needs may leave the teacher unprepared to teach those students, and may negatively impact these students' post-school futures (Ryndak et al., 2012).

Lastly, the authors recommended that to help students with disabilities transition into adult life in the community, it is not enough to rely on the NCLB Act (2002), which only mandates schools to help students with disabilities meet general education academic standards (Ryndak et al., 2012). These students must instead be allowed to participate in community-based contexts such as employment sites or residential situations, to help acclimate them to their post-school future. This, they argued, would best serve students with disabilities in terms of their educational experiences, by ensuring that they perceive a linkage between their academic learning and their real life, as opposed to solely relying on standardized state and district assessments to measure success (Ryndak et al., 2012).

Researchers have echoed this need for the importance of including parents in the education process, as noted in the study conducted by Carothers & Taylor (2004). The authors also suggested that, with the collaborating between the parents and teachers, a greater trust among the participants might emerge, resulting in more productive dialogue and greater insights on how to help students with disabilities. The same point was made by Ryndak et al. (2012) who claimed that a model for determining relevant curriculum content would rely on the collaboration between special and general teachers, family members, and the students' social support network (p. 135).

This collaboration among parents and teachers, both of whom care about the education of the student with disabilities, may also help parents and teachers create a more comprehensive idea of how to educate students with disabilities, and assist them both in defining their respective appropriate roles (Carothers & Taylor, 2004). This could then result in less stress for both the parent and the teacher, which may be argued to help them perform more effectively in their prescribed roles. The authors also offered techniques to promote greater collaboration between teachers and parents, suggesting suggested that providing video tape modeling, pictorial schedules, and peer or sibling modeling could help improve parental collaboration (Carothers & Taylor, 2004).

Parental Involvement

For all parents with students receiving services under an Individualized Educational Plan (IEP), IDEA (2004) mandates that parent to be present in the meetings

(McCabe, 2007). The revisions in IDEA (2004) require that schools include families as members of the IEP team; provide prior notice for identification, evaluation, or the provision of free and appropriate public education (FAPE); and offer mediation when disputes cannot be resolved amicably (Muscott, 2002, p. 66).

Other researchers such as Trussell, Hammond, and Ingalls (2008) found in their research that parents participating in the inclusion model feel that do not serve an integral part in this relationship. Childre and Chambers (2005) and Stoner et al. (2005) found that parents of students with disabilities expressed frustrations regarding the process of how the Individualize Education Program was developed, and reported feeling a lack of respect and receptivity toward their views, being intimidated, and a lack of understanding or dismissal of their stated needs (Leyser & Kirk, 2011).

In research conducted by Mandlawitz (2002), research was compiled from court cases of parental complaints regarding the education of their children with disabilities. These complaints showed that parents felt their students were not receiving quality services (Mandlawitz, 2002). However, it has also been contended by some researchers that parents seemed to request services that may be unwarranted (Mandlawitz, 2002). As seen in Carter et al. (2013) it is imperative for both parents and teachers to have a confluence of goals regarding children with disabilities. Although parental involvement is undoubtedly a good thing given the importance they have as a support system, it must be the case that their goals are commensurate with the evidence.

If parents were to become involved, they must have the knowledge and capability to understand currently ongoing research on disabilities and education. This is to avoid any potential complaints and misunderstandings that could arise from mistaken assumptions or unrealistic expectations they might have. Martinez, Conroy, and Ceretto (2012) studied these parents' means of accessing information related to their predicament and the impact inclusive education has had on their children in the secondary level, and how this affects the parents' desires and expectations for their children to one day reach postsecondary education.

The authors found out that the levels of student inclusion were related to the levels of parental desire and expectations for their children to reach postsecondary education and those parents' involvement in the transition process that follows (Martinez et al., 2012). This appears to indicate that the more included students with disabilities are into general education classrooms, the more their parents expect them to reach postsecondary education, and the more that they involve themselves in that goal. This suggests the importance not just of including students with disabilities, but also the strengthening of the information process that allows the parents to know exactly what is going on with their child. Martinez et al. (2012) further suggested that the inclusion of information about postsecondary education options could strengthen teacher education programs.

Leyser and Kirk (2011) revealed some of the suggestions and advice that parents of children with a complex and severe disability called Angelman syndrome. While these parents would desire to get involved with the education of their children, they noted a need for better communication and partnership between the school and the home, emphasizing that needs to be better training for severe disabilities such as Angelman syndrome. Furthermore, they called on teachers to be more patient, to love and believe in their students, not to settle for low expectations just because their students are handicapped, and be open to the possibility of using different methods to teach their children, with an emphasis on a curriculum that teaches life skills, communication, and socialization, and not just teaching their children to pass standardized tests (Leyser & Kirk, 2011).

Role Conflicts

With the number of individuals working together to form a successful inclusion model, there is bound to be some lack of clarity in the roles being played by each individual. This lack of clarity may lead to a greater level of frustration for the parents who have limited knowledge about the inclusion model. Early researchers defined roles in the school system as “the structural and normative elements defining the behavior expected of role incumbents or actors, that is, their mutual rights and obligations” (Getzel, Lipham, & Campbel, 1968, p. 20). What this means is that certain individuals have well-defined roles based on their position in a system and their competence to engage in that role.

In a study of the cardiovascular implantable electronic device industry, Mueller, Ottenberg, Hayes, and Koenig (2013) found that employed professionals reported having feelings of work-related role conflicts and moral distress in the multiple roles they perceive they need to play in their job. The themes enumerated to contribute to these role conflicts are as follows: “(a) their relationships with their patients, (b) their relationships with clinicians, (c) role ambiguity, (d) customer service to clinicians, and (e) cardiovascular implantable electronic device (CIED) deactivation" (p. 1). The various roles they are expected to play outside of their own jobs were shown to generate considerable amounts of stress in the employed professionals.

For instance, these employed professionals were commonly requested to deactivate CIEDs, particular in cases where they were asked to deactivate the pacemakers of patients who depended on those pacemakers to live. The conflict that arises during such times was between their relationships with their patients, with their clinicians, and their responsibility to deactivate CIEDs. These employed professionals reported being treated as clinicians by patients and, as such, they get to know these patients, which make their responsibility to their responsibility to deactivate CIEDs difficult, sometimes even causing moral distress (Mueller et al., 2013).

Such problems may be avoided if and when roles are clarified, causing each individual to be absolutely clear on what is expected regarding what they are able or willing to perform in their respective roles, without engendering extreme conflict. Similarly, if there is an agreement on the behavioral expectations of a specific role, the role incumbent enjoys a well-defined role identity; however, if there if there is disagreement, a role conflict arises (Getzel et al., 1968).

In relation to special education and the specific both parents and teachers play in the education of a student with disabilities, role stress may arise if either party is unclear on what their role is in the system. Parents may experience this role conflict within the inclusion model when an expectation of their role or participation is inadequately defined or contradictory to their expectation. If the parent does not have adequate skills to resolve the conflict or participate as needed, due to other work or family obligations, the parent may experience and imbalance, frustration and stress as a result of this uncertainty. Similarly, if a teacher feels that their role is being undermined or contradicted by the parent, they may feel stress and demoralization. Both instances can be seen as frustration that stems from not being able to do what they perceive is their job.

Role conflict may lead to greater dissatisfaction. For example, Stoner et al. (2005) examined lack of parental trust and dissatisfaction of the current services being provided to their student. This study was conducted by examining the themes resulting from the interactions between parents of children with autism and teachers. The study concluded with a correlation between distrust and dissatisfaction. If the parents had a lack of trust and were dissatisfied, they were less likely to participate in their required IEP meetings or participate in their expected role.

Although there have been other studies conducted that identifies role conflict as the source of added stress for parents, the studies looked at all students with developmental disabilities not autism specifically. Nachshen and Minnes (2005) conducted a quantitative study. These researchers indicated that although additional support was added, the parents experienced a higher level of stress than parents of nondisabled students.

To assist with limiting role conflict, McCabe (2007) found that parents and teachers needed to communicate more for services to be effective. He further reported that, if respect from either side is not given, this might further foster conflict (McCabe, 2007). Teachers should be sensitive of the following issues that may arise within the family: educational, emotional and the need for additional outside resources (McCabe, 2007).

When educators are aware of the needs of the parents and families, McCabe (2007) found that a greater relationship was fostered. Teachers and parents must work together to assure that the needs of the child are met and effective understood, then addressed through appropriate services (Howland, Anderson, Smiley, & Abbott, 2006). If this is not ensured, then much of the hard work on both side of the parents and the educators can counteract each other and produce negative outcomes for the child with disabilities.

Working Together

Learning is a continual process, which has no limits as to where it may take place. The school, community, and home play a huge role in what and how students learn (Epstein, 2001). Further, in the research, Epstein (2001) found that parents felt that they lacked sufficient information from the school or community to be productively involved. With this lack of clarity; schools, communities and families, have a possibility of either positively or negatively affecting the child's learning environment. For instance, if a parent of a disabled child has specific ideas about how to educate and socialize their child, these ideas must be close to what is being taught in school, since a contradiction may confuse the child and cause them to not learn effectively. Similarly, the school must tailor its program to fit the needs of the parents. Given that parents also play a large role in the support of a child with disability, they may be more aware of certain personal factors that, if accounted for, could help a child overcome their disability and achieve academic success.

Epstein and Jansorn (2004) investigated how to effectively involve parents in the education of their student. Again, it is not enough to simply involve parents, their involvement must be productive and be informed by current research on the issues facing students with disabilities. Epstein and Jansorn (2004) found that schools need effective, purposeful, and planned partnership programs in place to involve parents in the education process. They concluded that parents were grateful when teachers took the time to show them how to be involved and provided examples of how they could be of assistance in the learning process (Epstein & Jansorn, 2004).

When the roles of the teacher, community, and the family are defined, this ultimately helps the student in obtaining further direction (Epstein & Jansorn, 2004). An even collaboration during educational planning may result in plans for students that are more effectively designed to meet the individual social, emotional, and educational needs of the child (Jivanjee, Kruzich, Friesen, & Robinson, 2007).

Jivanjee et al. (2007) surveyed 133 family members of students with emotional disorders. They reviewed the family members' perception of the educational planning provided to their child. When bringing parents and teachers together, teachers should understand that much of the jargon that is used in the educational field may be foreign to those outside. Because of this statement, Jivanjee et al. (2007) provided, "Families need to be aware of terminology, policies, and procedures that may surround educational planning" (p. 78).

To work together effectively, Hall, Vue, Koga, and Silva (2004) advised that ideas must be blended. Key players in the inclusion model should conduct the following steps to foster success: (a) define what support students need, who will provide them, and how they will be provided; (b) adapt general education curriculum or settings to suit student needs and abilities; (c) accommodate students physically; (d) evaluate student outcomes; and (e) enhance understanding among all who interact with students with disabilities (Hall et al., 2004, pp.10-11).

Titone (2005) supported the notion that working together was very important. In his study, parents of the focus group showed concern that all participants in their child's education were not working together (Titone, 2005). Within the focus groups, parents suggested that special education and regular education teachers should understand the scope of each person's participation. The parents emphasized the need for teachers to have a great understanding of the overall curriculum to "take it, diversify it, differentiate it, and make it more accessible to the student with special needs" (Titone, 2005, p. 21). In other words, these teachers must not just learn how to interact with and teach their students using information gleaned from a book, but they must also learn through experience and adapting to that experience.

In other research, teacher attitudes about inclusion clearly defined responsibilities between the special education teacher/general education teacher and successful inclusion of parents produce academic success, as well asimproved social skills for both the special needs students and nondisabled peers (Titone, 2005). This may serve to counteract the pessimistic contention that the problem with special education lies in any one specific support system. Rather, it is through the clear defining of the roles for each specific system that allows them to do their job, and do it well, leading to positive outcomes for students with disabilities.

Support for Inclusion

In the past few years, there has been increasing support for the inclusion learning model. For example, Nutbrown and Clough (2009) suggested that including special needs students with their regular education cohorts assisted in the showing of a heightened self-esteem and an increase in social skills. Other researchers have postulated that effective collaboration among the regular, special education teacher, and parents may increase classroom expectations (Sayeski, 2009). When regular education students are taught alongside those with special needs, a greater level of tolerance and understanding is fostered (Staub & Peck, 1995; Mastropieri, Scruggs, & Berkley, 2007; Newburn & Shiner, 2006). The findings of these studies showed that effective collaboration evolved in the inclusion process with benefits. All students are taught about equality, although in different ways. For example, students with disabilities are taught equality by showing them that they are not all that different from their nondisabled peers, while nondisabled students are taught equality by showing them that there are people different from them, who deserve the same kind of respect.

Summary and Conclusions

This study examined the lived experiences and perceptions of the parents of students who are currently participating in inclusion services or who have participated in inclusion programs within the past five years. A gap in the literature exists as the perceptions of parents of students with autism have yet to be explored, which may limit the overall efficacy of the intervention program. While the perceptions of teachers and administrators have been investigated previously, the end-users of the inclusion program have largely been ignored. As the students themselves may not provide data on this phenomenon, the perceptions of their primary caretakers may prove instrumental in ascertaining gaps or limitations in the inclusion model, and the roles and stresses those parents perceive because of the model. Chapter 2 provided information on the different categories of autism along with information on the history and prevalence of the disorder and the way in which the public education system has responded to children with autism.

There have been drastic changes in how education has been provided and Chapter 2 explained the changes that took place in forming the inclusion model. Inclusion itself, as it began in the early 1900s, has changed drastically. When inclusion first began, students were only allowed to participate with regular education students in resource classes such as music, physical education, and art. Later, due to changes in IDEA Act (1990) and NCLB Act (2002), school districts were mandated to place students with disabilities in classrooms that were based on their specific need. With this mandate, more students with special needs are being served in the regular education classroom. Although this change has taken place, there are still mixed feelings about the inclusion model. Preliminary research shows that some parents feel the inclusion model increases social skills of their children and allow the child to make great progress; other parents feel there may not be enough structure for the student to thrive. The way inclusion is viewed by teachers has been explored but not parents. This study examined more deeply the parental views of the inclusion model.

Chapter 3 provides an explanation of the research design and rationale, the role of the researcher, methodology, and issues of trustworthiness.

Chapter 3: Research Method

Introduction

The increasing trend of using the inclusion model in the education of students with disabilities in a regular education classroom, and the possibility of misunderstandings between the teachers and the parents of these students, indicates the need to understand better how parents perceive this model of learning for their autistic child. Previous researchers (Carothers & Taylor, 2004; Leyser & Kirk, 2004; Stoner et al., 2005) showed that the parents of autistic children, participating in the inclusion model, had varying views on the reasons for their own level of satisfaction with the inclusion model. Research that focused on parental reasons of dissatisfaction with the inclusion model revealed that over half of the parents of autistic children participating in an inclusion model of education commented that their child's educational needs were not adequately met in an inclusion program. Given the prevalence of the inclusion model of special education, there was a need for revealing any concerns these parents might have so that one could remedy any shortcomings in the programs. To address this issue, Chapter 3 includes the research design and the rationale for the study, the role of the researcher, the methodology employed, the instrumentation, the data analysis plan, and a discussion on researcher trustworthiness and ethics.

Research Design and Rationale

The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design. The goal of this study was to answer the following research questions:

RQ1. What are the lived experiences and perceptions of parents of students with ASD regarding the efficacy of the inclusion model of education on their children's academic success?

RQ2. What are the parents of students with ASD's lived experiences and perceptions regarding their role in the inclusion model of education?

RQ3. What are the parents of students with ASD's lived experiences and perceptions regarding the stressors that may result from their perceived roles in the inclusion model of education?

In conducting the research, I utilized the modified van Kaam method by Moustakas (1994). Using this method, researchers conduct "semistructured, audio taped, and transcribed interviews" (Moustakas, 1994). The goal of a qualitative phenomenological study is to explore beyond what seems obvious and dig deeper into reality to reveal common life experiences. This approach allows the researcher to apprehend a given phenomenon through a fresh perspective and allows an in-depth exploration of a phenomenon that cannot be achieved through a quantitative design (Leedy & Ormond, 2001; Moustakas, 1994). I further organized this study around Pearlin's (1999) stress process model as a way to understand the different stresses associated with being a parent of a child with ASD and their role in educating their child.

Role of the Researcher

For qualitative research, the researcher is the primary data collection tool. It is also important for the researcher, if conducting interviews, to locate adequate space to perform interviews. In determining a location, Creswell (2013) stated that the researcher should seek out neutral, noise-free environments to reduce distractions and undue stress.

I did not have any relationships with the participants. I previously worked as a special education teacher, but I had not worked in the field for over 8 years, and I had no contacts or acquaintances from that time. I selected participants from outside of the school district where I had previously worked. Since the inclusion model was new to the district where I worked, I had no preconceived notions about the results of the study. The participants were volunteers, and I contacted the participants by phone for interviewing purposes only.

Methodology

The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design. In qualitative research, Creswell (2013) stated that the sample size for phenomenological studies might be as low as one and as high as 100. For this qualitative study and based on this information, I planned to reveal deep and meaningful data by conducting interviews with 12 participants. I assumed that a small number of interviews would allow for longer, in-depth interactions that could develop more complex aspects of the experience of being a parent of a student with ASD by providing more space and time for the participants to speak their minds.

However, I failed to collect 12 participants, as only seven participants met the desired criteria.

I requested assistance from a personal contact to begin the recruitment process with 12 parents of students with ASD, currently enrolled in an inclusion setting or had participated in the inclusion model within the last 5 years. In this study, I utilized a snowball recruitment strategy, as suggested by Creswell (2013). I began by identifying a participant who knew others with similar situations. The contact introduced me to one parent who fit the criteria for inclusion in the study. The first parent then referred more parents to the study until no more parents met the research criteria. Seven participants ultimately participated in the study.

To collect data, I conducted semistructured, open-ended interviews with the parents of children with ASD currently enrolled in a school with an inclusion program for disabled students. These parents resided in Pennsylvania and were either mothers or fathers; I included them as long as they self-identified as the primary caregiver to their child with ASD. The parents did not have to be a biological parent; however, they had to be the child’s primary care provider. Participants volunteered to participate in the study based on their desire to share their stories and perceptions of having an autistic child in inclusion services. I contacted the participants through email or telephone to screen and recruit them, and then scheduled their interviews. I conducted interviews in a secure area, via telephone conference.

Several problems occurred that prevented the successful recruitment of 12 parents. The first main issue occurred right after I obtained permission from the institutional review board (IRB). Parent recruitment had to take place in a facility in Louisiana. Shortly before recruitment began, the selected facility decided not to be involved in the study. To overcome this issue, I requested that the IRB allow observation of an alternate population/area. The Walden IRB approved the request to allow me to survey parents of students with ASD in Pennsylvania.

The second issue occurred because the snowball technique for parent recruitment yielded a smaller number of parents than I expected. The set of parents interviewed for this study asked friends and acquaintances if they would be interested in participating in a study on autism. Two additional parents expressed interest, but I excluded them because they did not meet the criteria. Other parents at the public schools, where their children were in the inclusion model, were not eligible because their child had been out of the inclusion program for more than 5 years. I excluded another participant because their child attended a facility for students with ASD. To address the second hurdle, I revisited the contact who recommended participants; however, no one else expressed interest in participating.

Instrumentation

I developed the interview guideline prior to data collection to solicit answers using open-ended questions. Open-ended questions allow answers that are "unconstrained by any perspective of the researcher or past findings" (Creswell, 2005, p. 214). In this study, participants responded to semistructured, open-ended questions about their lived experiences of when their child received services in the inclusion model. One-on-one interviews are “ideal for interviewing participants who are not hesitant to speak, are articulate, and who can share ideas comfortably” (Creswell, 2005, p. 215).

The interviews took approximately 45 minutes, although the exact time varied depending on the participant’s answers. The participants completed a short demographic questionnaire before interviews began. I audiotaped and transcribed the interviews. Because I used a semistructured format with a series of open-ended questions, I could not anticipate potential responses. This allowed for unexpected responses, as stated by Bernard (2013).

Ideally, one should conduct interviews through face-to-face interactions and in quiet, neutral locations, as convenient to both parties. In this study, this option was not available because I lived in Texas, and the participants lived in Pennsylvania. I considered flying to Philadelphia to conduct face-to-face interviews with parents over a 4-day period. However, this consideration did not work because it was difficult to organize interviews with all parents during such a minor period. Therefore, all interviews took place by telephone.

I successfully recruited 10 parents. However, two parents lived outside the designated region; therefore, I excluded their data from the study. One parent dropped out of the study, leaving seven parents. Data collection ended at this point because I reached the end of the time for data collection and the number of participants fell within the acceptable range for phenomenological research, as based on Creswell (2013) and Marshall (1996). I reached saturation with seven participants when no new themes emerged during interviews.

The intent of this phenomenological study was to explore what parents perceived as issues with the inclusion model for their autistic children. This research method allowed participants to explain their experiences in a way that allowed me to understand their thoughts on the inclusion model. Because the parents could fully tell their stories using this method, thus potentially revealing new insights, I believed it was the most appropriate method for this study.

Data Analysis

I used multiple data sources during data analysis. Data analysis consisted of typical data preparation activities related to qualitative data. I transcribed the data from the audio-recorded interviews. Once I completed the transcription, I reviewed data to identify general themes that emerged. In addition, I analyzed data using a similar procedure. I examined the responses to the interview questions, along with any notes from journaling, to see what themes emerged within the context of the model. I then compared the themes with the concepts of the model to identify consistencies and differences. For this research project, the most important task was to assure that the research truly expressed the interpretations of the data in a manner that closely represented the intended meanings and experiences of the participants, as suggest by Bernard (2013).

I used a coding process for this study; this allowed me to discover and develop common themes. The coding process consisted of reading all transcripts to acquire a general feel and extract specific statements, phrases, and descriptions regarding the phenomenon. I then recorded responses in a journal. I also encoded the quotes, phrases, and notes in a Word document.

I took three steps to reveal the lived experiences and perceptions of parents of children with ASD in inclusion programs. These steps included (a) a close reading of the interviews, (b) an organized breaking down of the data from the text into smaller units of meaning, in order to reveal discrete meaning units, and (c) an investigation of those meaning units to isolate and find invariant constituents of experience, as suggested by Matthews, Smith, MacMillan, and Gilbert (2012).

I examined the units of relevant meaning so that redundancies were eliminated. I organized the emergent themes by the interview questions. I placed numbers by codes and phrases most stated to indicate the importance of the concern (Marsh & White, 2006). In addition, I discarded vague or insignificants codes that did not assist with the description of the research phenomenon. After data collection ended, I followed Moustakas' (1994) modified van Kaam method of phenomenological analysis.

Issues of Trustworthiness

Regarding qualitative research, Creswell (2013, p. 250) used the term *validation* to reference trustworthiness. Earlier researchers, such as Lincoln and Guba (2005), used terms, including "credibility, authenticity, transferability, and dependability" (Creswell, 2013, p. 250), to describe trustworthiness. Lincoln and Guba (2005) added that one could establish trustworthiness by adding *confirmability*.

I reviewed the data of this study multiple times. I began by reading transcribed data from Participant 7 and continued to Participant 2. Once reviewed, I analyzed data from Participant 1. This process aligned with referential adequacy and increased credibility because I set aside one set of data, returning later to review, as suggested by Lincoln and Guba (2005). The final participants' data produced themes closely related to other participants. Reflexive journaling provides for multiple data sources, which can also increase the credibility of a phenomenological study (Lincoln & Guba, 2005). The additional data sources that I used included a demographic questionnaire, which also increased credibility. I provided a *thick description* that enhanced transferability, as suggested by Lincoln and Guba (2005). I established dependability through continued chair/committee review. Overall, I allowed the participants statements to guide the study. To assure trustworthiness further, I remained honest about my previous background as a special education teacher explained this to participants.

Ethical Procedures

Prior to beginning data collection for this research, I obtained approval from Walden University's IRB. Participation in this research study remained purely voluntary. I provided participants with an informed consent document that outlined any benefits or consequences associated with the study. The informed consent document provided the reason for the research and provided clear insight on any foreseeable ethical issues related to confidentiality of identity and material.

I placed all data in a password-protected flash drive, and I placed all printed materials in a secure location; no real names were used for the participants. No other person other than the researcher had access to this data. After 5 years, I will delete the data. I advised participants of contact information should they have any further questions or concerns regarding the information provided during or after this study. Participants signed and dated consent documents to assure understanding.

Summary

Chapter 3 presented a detailed explanation of the significance of the proposed research. The presentation of the research methodology included (a) role of the researcher, (b) instrumentation, (c) methodology, (d) data analysis plan, (e) issues of trustworthiness, and (f) ethical procedures. Chapter 4 will provide detailed findings of the research.

Chapter 4: Analysis

Introduction

Chapter 4 includes the data analysis for this study, including the data that I collected and organized regarding the three research questions of the study. The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design. To collect data, I conducted seven semistructured, open-ended interviews with the parents of children with ASD currently enrolled in a school with an inclusion program for disabled students. These parents resided in Pennsylvania. The parents included mothers and fathers who were the primary caregivers to their children with ASD.

The research questions that guided this qualitative research were as follows:

RQ1. What are the lived experiences and perceptions of parents of students with ASD regarding the efficacy of the inclusion model of education on their children's academic success?

RQ2. What are the parents of students with ASD's lived experiences and perceptions regarding their role in the inclusion model of education?

RQ3. What are the parents of students with ASD's lived experiences and perceptions regarding the stressors that may result from their perceived roles in the inclusion model of education?

Setting

A phenomenological approach is an attempt to explore and understand people's perceptions, perspectives, and understandings of a particular situation (Creswell, 2013). In this study, I examined the perception and lived experiences of the parents with students with ASD. Creswell (2013) stated that one must understand common experiences of people to develop practices, policies, or a deeper understanding about the features of the phenomenon under study. Patton (2002) agreed that one should use qualitative methods to discover how people deal with certain issues in everyday life or institutional practices. Therefore, I explored, analyzed, and interpreted common experiences of the parents. The experiences of the parents were evident from the semistructured interviews.

Patton (2002) defined qualitative research as an attempt to understand unique interactions in a particular situation. The purpose of understanding did not necessarily include predicting what might occur, rather it included in-depth understanding of the characteristics of the situation and the meaning brought by participants about their experiences. Based on this purpose of understanding, I conducted personal interviews that illuminated the struggles of parents who advocate for the welfare of their children with ASD.

Derived from the German philosophy of phenomenology, phenomenology typically involves in-depth interviews with individuals who have experienced the phenomenon of interest (Marshall, 1996). In-depth interviews capture a deeper level of understanding, which opens the lived experiences of the parent participants available for data collection and data analysis (Marshall, 1996). For this reason, I used in-depth interviews in this study.

The phenomenological approach uses a relatively small sample group to generate theme and pattern analysis with which to provide insights and information about a given phenomenon (Marshall, 1996). In this study, I intended to obtain a small group of 12 parents for this study; however, I obtained an even small number of seven participants. Based on the criteria from Marshall (1996) regarding sample size, the smaller number of seven participants remained acceptable for this research. After obtaining seven participants, no more participants met the criteria.

In a phenomenological study, one may obtain data collection through a variety of methods, such as using action research and focus groups, participant self-reporting through narratives or artistic expression, and observation and the use of interviewing (Marshall, 1996). These data collection processes allow the participants to offer descriptions, as opposed to explanations, of their phenomenal experiences without bias or preconceptions. In this study, the small set of participants allowed a deeper overall comprehension of the lived experiences of the parents. Moreover, seven participants is not an unusual sample size within the phenomenological research paradigm (Creswell, 2013; Marshall, 1996).

Demographics

I requested assistance from my personal contact via telephone for the recruitment of 12 parents of students with ASD currently enrolled in an inclusion program. Seven participants participated in the study. I conducted semistructured, open-ended interviews with the parents of children with ASD currently enrolled in a school with an inclusion program for disabled students. These parents resided in Pennsylvania and were primary caregivers to their child with ASD. The parents did not have to be a biological parent but were the child's primary care provider.

Participant 1 was 44 years old, female, Caucasian, and a mother to two male children diagnosed with ASD. Her children were 18 years old and 16 years old. Participant 2 was 41 years old, male, Caucasian, and a father to a male child diagnosed with ASD who was 15 years old. Participant 3 was 53, male, Caucasian, and a father to a male child aged 19 years old. Participant 4 was 52 years old, Caucasian, female, and a father to a male child diagnosed with ASD aged 17 years old. Participant 5 was 45 years old, female, Caucasian, and a mother to a male child who was 15 years old. Participant 6 was 38 years old, female, Caucasian, and mother to a male child who was 15 years old. Participant 7 was 41 years old, male, Caucasian, and a father to a male child who was 15 years old. Table 1 shows the demographics of the participants:

Table 1

Demographics of the Participants

Participant No.	Age	Gender	Ethnicity	Relationship	No. of Child with ASD	Age of Child	Gender of Child
1	44	Female	Caucasian	Mother	2	18 16	Male Male
2	41	Male	Caucasian	Father	1	15	Male
3	53	Male	Caucasian	Father	1	19	Male
4	52	Female	Caucasian	Mother	1	17	Male
5	45	Female	Caucasian	Mother	1	15	Male
6	38	Female	Caucasian	Mother	1	15	Male
7	41	Male	Caucasian	Father	1	15	Male

Data Collection

I created a demographic questionnaire, which represented the instrument used for this study. I used the demographic questionnaire to collect data from the seven participants, along with an interview guide to obtain the perceptions of parents of children with autism, who participated in the inclusion model within the last 5 years. The interview questions included their experiences (a) regarding the inclusion model, (b) the parental role working with the inclusion model, (c) with role conflict, (d) stressors from the inclusion model, and (e) influence of how stress affects parental participation. These experiences helped me to provide recommendations for other parents working with the inclusion model. I audio-recorded interviews, which took approximately 45 minutes to 1 hour.

Data Analysis

I analyzed the data multiple times. The lived experiences and perceptions of the parents of children with ASD represented the focus of the data analysis. Table 2 shows the major themes and important perceptions generated from each research questions.

Table 2

Major Themes and Important Perceptions

Research Questions	Major Themes	Important Perceptions
RQ1. What are the lived experiences and perceptions of parents of children with ASD regarding the efficacy of the inclusion model of education on their children's academic success?	1) The inclusion model of education can either have positive or negative effects on different children diagnosed with ASD	It is not always true that the inclusion model will always have a positive effect on the students. The school and the inclusion model of education can have an impact to the development of the students, in both academic and non-academic developments
RQ2. What are the parents of children with ASD's lived experiences and perceptions regarding their role in the inclusion model of education?	(2) The development of emotional skills of autistic children can be improved to enrich their participation and social relationships with other people	Human interactions should be encouraged so that the children are able to have fruitful relationships with their peers. To ensure the healthy interaction of the child through the inclusion model, the normal children must be aware that there is going to be an inclusion
RQ3. What are the parents of children with ASD's lived experiences and perceptions regarding the stresses that may result from their perceived roles in the inclusion model of education?	(3) A strengthened support system for children with autism must be advocated through accessible information and services.	People always side with the school and that the mainstream teachers are not as great because they were not educated about special education. The accessibility of information and services would also create an impact to the development of the children with ASD

I identified provisional deductive codes from the lived experiences of the parents who participated in the study. The deductive codes from the lived experiences of the parents guided my identification of relevant inductive information concerning the program. The following represented the deductive codes derived from this research: (a) academic performance, (b) social skills, (c) role of parents, (d) support, and (e) role of teachers. Out from these codes, I identified 17 codes covering interview questions responded to by seven participants. I read, reviewed, and sorted transcripts for the codes, as presented in Table 3.

Table 3

Emerging Codes

Emerging Codes	Meaning	Sample Verbatim Responses
Academic performance	The academic performance of persons associated with autism is hampered.	I felt my son did well academically. (# 5)
Social skills	There are various social quirks experienced and exhibited by the children.	He demonstrated focus problems and social quirks. (# 5)
Role of parents	The parents should have an active role in supporting their children.	I believe my role as a parent is twofold. (#1)
Support	Support from other people and institution is important to ensure the development of the children.	The teachers were also very supportive. (# 6)
Role of teachers	The teachers should always support the performance and learning of the students.	The teachers did not seem to like this and appeared to feel that I was being intrusive. (# 1)
Stress	There are various stressors because of the disability of people with autism and Asperger.	Stressors due to lack of support and knowledge about my child's condition. (# 1)
Diagnosis	Diagnosis should be in the early stage to promote the development of students.	My child received a late diagnosis. (# 2)
Advocate	The support system of the children with autism should advocate their development.	You have to be an advocate. (# 1)
Services	The government and schools must provide services to address the special needs.	The private school had no support for kids with autism. (# 3)
Participation	Participation is expected from the parents to ensure holistic growth.	Participation for me was pretty much mandatory because I had to come in to help calm him down. (# 6)
Information	Information of what can be of help to the families with autistic children should be readily available.	We had no information on the services provided by the school. (# 2)
Calm	The problems of children with autism can be addressed in a calm manner.	I was very involved making sure he was calm. (# 6)
Love	Children with autism should be loved by their children.	Love is parent advocating or teaching the child to advocate for themselves. (# 4)
Education	The educational system for children with autism must be adjusted to focus on their special needs.	I would encourage people to try to spend as much time as they can in the school and in the classroom. (# 3)
Lack of understanding	Lack of understanding is prevalent because of the difference in the mental capacity of children with autism.	Lack of understanding That was the biggest stress that lack of understanding of the work. (# 3)
Emotional skills	The emotional skills of autistic children should also be developed.	He is very good in compensating for the things but he doesn't do so well. (# 3)
Inclusion model of education	The education model must be inclusive and should take into consideration the different needs of autistic children.	Inclusion should be a parent/student choice. (#3)

Table 4 contains a summary of the number of participants and the percentage of occurrence, in relation to the emerging codes. These participants showed that they had common lived experiences and perceptions regarding their lives as parents of children with ASD.

Table 4

Codes and Percentage of Occurrence

Codes	No. of Participants	Percentage of Participants
Academic performance	7	100%
Social skills	6	86%
Role of parents	7	100%
Support	7	100%
Role of teachers	6	86%
Stress	6	86%
Diagnosis	3	43%
Advocate	3	43%
Services	3	43%
Participation	3	43%
Information	2	29%
Calm	2	29%
Love	2	29%
Education	6	86%
Lack of understanding	4	57%
Emotional skills	5	71%
Inclusion model of education	7	100%

As codes emerged in the transcripts, I reviewed and categorized these codes for further analysis. Out of the 17 codes, I identified three categories. These included academic skills, social relationships, and support. Table 5 shows the meaning of the categories.

Table 5

Emerging Categories

Categories	Associated Codes	Meaning
Academic Skills	Academic performance Education Lack of understanding Inclusive model of education	The inclusion model of education can either have positive or negative effects on different children diagnosed with ASD.
Social relationships	Social skills Stress Diagnosis Participation Calm Love Emotional skills Role of parents	The development of emotional skills of autistic children can be improved to enrich their participation and social relationships with other people.
Support	Role of teachers Advocate Services Information	A strengthened support system for children with autism must be advocated through accessible information and services.

Based on the analysis of the codes and the categories, the following themes emerged: (a) The inclusion model of education can either have positive or negative effects on different children diagnosed with ASD. (b) The development of emotional skills of autistic children can be improved to enrich their participation and social relationships with other people. (c) A strengthened support system for children with autism must be advocated through accessible information and services.

Theme 1

The first theme was the inclusion model of education could either have positive or negative effects on different children diagnosed with ASD. This subsection contains the findings for this theme. Participant 3 mentioned that the inclusion model of education was a great thing because it represented a tool that made the children who did not need inclusion aware that there were a lot of different people in the world with different needs. He continued:

> If you are told that somebody has a challenge, it is a lot better than you just perceiving that that kid is different. I found that there was a pretty good degree of acceptance and tolerance. But I would have to say that the children who were more disruptive in the inclusion model which wouldn't have been my son, even he was disturbed by that which is interesting because he knew that he was being accommodated.

It was not always true that the inclusion model would always have a positive effect on the students. There were times when the inclusion model could prove more detrimental than helpful in the development of the child. The school and the inclusion model of education could influence both academic and non-academic developments of the students. According to Participant 7:

> My child started in Catholic school but we were advised that he would need to either go the public school or be homeschooled due to his behaviors. The private school had not support for kids with autism. Since taking him out of private school, he has always been in an inclusion learning setting. In the public setting here, there was no alternative to inclusion. I was initially told that my child was shy and that sometimes he doesn't like the assignment so he would not participate and throw angry fits. In second grade, the fits increased and the school did not know how to deal with it. We were constantly asked to pick him up from school. When we moved him to the public school, the experience was much better.

Theme 2

The second them was that the development of emotional skills of autistic children could be improved to enrich their participation and social relationships with other people. This subsection contains the findings for this theme. In addition to the comprehension skills of children with autism, their emotional skills also needed improvement to enrich their participation and social relationships with other people. Human interactions should be encouraged so that the children could have fruitful relationships with their peers. Participant 3 noted that many non-verbal skills must be learned by the children with autism to interact with other people. If the child had not yet acquired these non-verbal skills, it was best to continue educating the child in a non-inclusion class. According to him:

> I noticed that a lot of the kids had severe issues, behavioral issues, and tics. There was one boy who constantly blows his nose into a tissue and then eats it in front of the class. That took away from the class because the teacher had to say stop, stop. We would always hear him down the hall yelling and screaming if he was having a fit. But again, he was a verbal kid and was a t kid and he deserved to be there. But, it was just really hard for the kids.

Participant 3 mentioned that the parents should allow the interaction of the child with ASD with other children. However, there was a need to make sure that the child was not picked out and did not become a subject of bullying. To ensure the healthy interaction of the child through the inclusion model, the normal children must be aware that there was going to be an inclusion. It was also important for the parents to monitor the happiness level of the children.

Theme 3

The third theme was that a strengthened support system for children with autism must be advocated through accessible information and services. This subsection contains findings for this theme. A support system from parents and other parties must be developed to advocate the development of the children. The support felt by a child with ASD was also important in making sure that there was someone who looked after the child with autism. According to Participant 5, she was supportive of her son. She would volunteer in different activities for the welfare of her son:

> The teachers did not seem to like this and appeared to feel I was being intrusive. While in kindergarten, I attempted to have him tested but I was told that my child did not have Asperger's. Because of problems in the first grade, my child's 504 did not transfer. It was noticed by this teacher that there was a problem. I am an advocate for my child's services and hiss IEP and the teachers now seem to be very supportive.

There was a need for the teachers to support the students. Participant 5 also felt that the people always sided with the school and that the mainstream teachers were not as dependable because they were not educated about special education. She mentioned that a parent had to be an advocate for the betterment of the child’s condition. Quoting her:

> I feel that my parenting style and advocating for my child made a huge difference. He still needs assistance with his social interaction but he does well academically.

> I believe that stress made me participate more due to fears of my son not getting the services he needed.

The accessibility of information and services would also create an impact to the development of the children with ASD. According to Participant 5:

> I would like for other parents to know that many public schools will not volunteer to test. I have found that it's normal for the school system to say the child has ADD or ADHD. It is important not to let the school push you around. When the school pushes, the parent should push to get what's best for their child.

There were times when the schools and even the educators would not provide reliable services and information for the children with ASD. Likewise, Participant 6 noted that there was not sufficient presence of services available for the learning of the children with ASD. According to her:

> Since autism was fairly new to the school districts or parents, they did not recognize there was a need to have an IEP. We were just told that he was shy or off but not told what the issue was. There were not many available resources. There is also the stress of the school district not wanting to provide services.

There was also the lack of information that made it more difficult for the parents to assist their children. According to her:

> When my child was diagnosed, there was less information available. We had to dig and find information on our own. There is much more information available about autism. Look for the signs and find help or support early to assist your child.

Based on these interviews, the parents must continuously advocate for the provision of more services.

Evidence of Trustworthiness

To display evidence of trustworthiness, in the phenomenological study, I used credibility, transferability, dependability, and confirmability. I established credibility by presenting the topic of discussion and relaying the research questions in a clear and concise manner, throughout the study. I provided each participant with the same opportunity to answer the same interview questions, without unintended interruptions or the need to prematurely end before necessary. I further established credibility with the use of the demographic questionnaire, which offered an additional data sources. I transcribed the data and reviewed the transcripts multiple times, obtaining multiple data sources. I also maintained a journal throughout the research project. In this study, 17 codes emerged out of the lived experiences of the parents who have students with ASD. Furthermore, I established transferability by providing a thick description of the data (Lincoln & Guba, 2005). With the thick description, others could apply the data to their situations.

I established dependability of the results using an audit trail through proper handling of data collected from the participants. The audit trail consisted of chronological narrative entries of research activities, interviews, transcriptions, and initial coding efforts (Creswell, 2013). I kept audio files of the interviews and had the transcript of the responses readily available for consultation. I stored both the audio files and the transcripts under lock and key. These will stay stored for 5 years, as required by Walden

University. After analysis of the data, I conferred with a committee member/dissertation chair to assist in establishing dependability. To establish confirmability, I also used reflexivity. Meaning, I remained honest with the interviewees regarding my previous background as a special education teacher. I also allowed the participants and their responses to shape the study by allowing them to provide as little or as much feedback needed to present their experience(s). I coded data until major themes and perceptions emerged and I reached saturation.

Results

The following themes emerged from the analysis of the responses of the participants based on their perceptions and lived experiences. (a) The inclusion model of education can either have positive or negative effects on different children diagnosed with ASD. (b) The development of emotional skills of autistic children can be improved to enrich their participation and social relationships with other people. (c) A strengthened support system for children with autism must be advocated through accessible information and services. This part of the chapter will reflect the answers to the research questions of the study.

Research Question 1

Research Question 1 stated, what are the lived experiences and perceptions of parents of students with ASD regarding the efficacy of the inclusion model of education on their children’s academic success? The efficacy of the inclusion model was evaluated by the lived experiences and the perceptions of the parents on how the inclusion model applied to their personal lives and to the lives of their children. In the inclusion model, Participant 5 felt that her son did well, particularly in inclusion. Her son, however, demonstrated focus problems shown by his social quirks. According to her:

> Students seem to be very accepting of him. If they didn't like the quirks, they would ignore him and this would be tough at times. We had great special education teachers but the general education teacher seemed to make things difficult. Things seemed to get tougher as he aged. He started exhibiting arrogance and conceitedness. This caused me to be concerned about his developmental stage. When he met for his IEP meeting, we discussed with the team. He was able to begin lunch bunch. He would meet other students and participate in social skills classes.

I concluded, based on the lived experiences of Participant 5, the inclusion model indeed allowed her son to be more participative in activities.

It was not always true that the inclusion model would always have a positive effect on the students. There were times when the inclusion model could prove detrimental than helpful to the development of the child. The school and the inclusion model of education could influence the academic and non-academic developments of the students. According to Participant 7:

> My child started in Catholic school but we were advised that he would need to either go the public school or be homeschooled due to his behaviors. The private school had not support for kids with autism. Since taking him out of private school, he has always been in an inclusion learning setting. In the public setting here, there was no alternative to inclusion. I was initially told that my child was

> shy and that sometimes he doesn't like the assignment so he would not participate and throw angry fits. In second grade, the fits increased and the school did not know how to deal with it. We were constantly asked to pick him up from school. When we moved him to the public school, the experience was much better.

Research Question 2

Research Question 2 stated, what are the parents of students with ASD's lived experiences and perceptions regarding their role in the inclusion model of education? The parents played an important role in the success of the inclusion model. Based on the lived experiences, I discuss the perceptions of the participants on the role of the parents in this part of the chapter. Participant 1 believed that the success of the inclusion model depended on the willingness of the parents to try something new that might be helpful for the child with ASD. Quoting Participant 1:

> Try everything. Try it all. Respond. Constantly ask questions. Constantly keep on your child. Make sure your child is doing their part. They have to be accountable for what they are doing. You cannot do everything for them. They have to do the work.

Thus, while I inferred that the parents must learn how to be proactive in advocating for their children, it was also the role of the parents to teach the children how to advocate for themselves. Parents should also know how to take advice from other people and to discern which advice worked on specific instances.

The role of the parents could also be that of a mediator between the teachers and the child. According to Participant 2, "He had a 504 plan and my experience was I had to be sort of constantly involved, contacting teachers, talking to teachers, making suggestions kind of a daily thing." The parents should also have an answer to the questions posed by the teachers on how to handle the children with ASD. Participant 2 encouraged the parents to be more active in participating in the inclusion model:

> I would encourage people to try to spend as much time as they can in the school and in the classroom and make sure that the children are given the interventions and the attention that they say they are being given. Bring advocates with you if you have worked with other providers set them in to observe because it is very difficult as parents. What happened to me is that I would hear one story from my son and I would hear another story from the teacher and oftentimes the truth was somewhere in between.

According to Participant 4, she served the role of advocating for her son's needs; in trying to do so, she ensured that an educational team promoted her son's welfare. The parents should cooperate with the teachers and educators to ensure holistic development of the students. According to her:

> While I will stand firm as advocate for my son vigorously, I also totally recognize that whatever I ask of the team, there are only so many hours in a day and so many resources in a public school. So whatever I ask of them that takes extra time, it is time that is not being spent on another student and so I do see my role as being one of trying to help the educators to see my son's needs clearly. I see my role as being the one with the most intricate invested interest in the success of my son in that educational setting.

Participant 5 noted that the parents should be advocates in getting the best for their child because the schools would not always be supportive of the child’s welfare: “It is important not to let the school push you around. When the school pushes, the parent should push to get what's best for their child.” The parents should always be the ones to assess and evaluate if the inclusion model was working for the benefit of their children. If the inclusion model did not promote the welfare of the child, it was also the duty of the parents to find a place more conducive for the education of the child with ASD.

According to Participant 7, participating in the inclusion model should be the choice of both the parents and the child: “We are okay with inclusion because we wanted him to have the most normal life possible. If the child is not ready for inclusion, it could be unfair to the regular education students.” Participant 7 further mentioned, “For some autistic children, it may not be the proper setting. If we did not advocate for him, it seems like he would be a bit more restrictive.” Thus, Participant 7 believed that the role of the parents also involved encouraging the child with ASD to absorb and live the life of a normal student. The parents should also make sure that the inclusion was the proper setting for the child to ensure that the child and the regular students both benefited from the interaction.

Research Question 3

Research Question 3 stated, what are the parents of students with ASD’s lived experiences and perceptions regarding the stresses that may result from their perceived roles in the inclusion model of education? Participant 1 had two children diagnosed with

ASD. I inferred that the lived experiences of this parent would pose more stressors compared to those who only had one child with ASD. According to Participant 1:

> It is like going to work, you like some people, and you don't like others. But that is also a great stressor because you know how much you lost in a short amount of time with these kids than with a typical developed kid and that is a stressor. When my younger son was in the two months of inclusion, it was horrible, it was devastating. He had not a clue how to do the work they gave him, very depressing, very sad.

Participant 1 mentioned that parents needed more patience to understand the inclusion model and not have this educational system model a source of stress. With her older son, she mentioned that her son could not go to college because his writing was horrible. She had a problem with helping her son obtain an acceptable score on the SAT to make him desirable to colleges. She even focused on watching the GPA of her son, not knowing all of these focuses created stressors. Quoting Participant 1, she mentioned, “There is always that stress. What don't I know? You always know there is something that you don't know.” Thus, the idea of uncertainty remained present among parents of children with ASD.

According to Participant 2, his biggest stress was when no one seemed to understand. There was no sense of understanding with the teachers and school of how much he really struggled and the kind of help that he needed. He said, “I regularly ran into people who believed it was just a behavior issue and that we weren't good parents or he wasn't raised well or we weren't tough enough on him and he was lazy.” Handling stress could also affect the life of the child with ASD. According to Participant 2, “It led to us taking him out of the school because it was so stressful and I was trying to be in graduate school myself and there just wasn't enough time to do both. He was miserable.” The lack of support from the school was also evident and caused stress. The teachers and school administrators were less interested in helping the child as the child aged. Likewise, there was no sufficient time or resources where the child with ASD could succeed.

For Participant 3, the 504 program was also a stressor:

> The first one is that they wanted to give him a 504. I understand that you need to go slow; you don't just jump into an IEP (Individualized Education Program). But they left that too long, from kindergarten and first and second grade he had a 504. By second grade, I said this kid needs an IEP for goodness sake. I designed it with my cousin who is a special Ed teacher.

Based on these interviews, the stress level that these parents experienced increased due to having an educational system that was not supportive to the students.

Parents have experience with various stressors in dealing with other parties to promote the welfare of their children with ASD. According to Participant 4, the answer to the questions would vary on how the parents handled different situations, even on the level of educational attainment of the parents. As a person who already attained a degree in PhD and as a teacher in a private institution who came from a family of educators, Participant 4 understood the plight of the educators. According to Participant 4:

> There are two sides of it. We walk into a room on one hand fearing what they are going to say potentially get hurt and feel bad for what they are going to tell you. On the other hand, you don't know what they are not saying. They have learned that people are going to react badly when they hear that Johnny is not perfect. And yet, I want to know because I can't advocate for my son what he needs unless I know what is happening.

Participant 4 experienced dealing with teachers of her son; these teachers seemed to struggle in telling him about his son's actions. The teachers would not be upfront because the parents of children with ASD might take offense. It was a stressor for Participant 4 and her husband because they lacked the complete picture on how their son was performing in school. The stress level of having a child with ASD even affected the most personal aspect of the life of Participant 4; however, as she said it, any amount of sacrifice or stress would be worth it as long as it was for the welfare of her child: "The amount of stress contributed to the end of my marriage, the amount of stress contributed to the change of my job, the amount of stress contributed to whether I get my exercise done."

Participant 5 said that the stressors often derived from a lack of support and knowledge about the child's condition. According to her, she still managed to move forward despite the stress. She mentioned, "I believe that the stress made me participate more due to fears of my son not getting services he needed." Based on these interviews, being involved in the development of the child with ASD was important. According to Participant 6, she was involved. She would make sure to calm her son down. She gave information about how her son functioned and advised her son on how to decrease the stressors.

According to Participant 7, various stressors could cause stress to the parents. For example, his son could not do math and he even went to ask, “How he is supposed to be if he has Asperger’s?” The teacher just wrote back, “Yes,” to his question. Hence, this issue represented another stressor since teachers did not seem to understand why the children were different from other children who did not have ASD.

Summary

The chapter presented the data analysis and results of the study. The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design. The analysis employed the qualitative phenomenological approach to have an in-depth analysis of the study. I analyzed the responses from seven participants. The following themes emerged. (a) The inclusion model of education can either have positive or negative effects on different children diagnosed with ASD. (b) The development of emotional skills of autistic children can be improved to enrich their participation and social relationships with other people. (c) A strengthened support system for children with autism must be advocated through accessible information and services.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Researchers characterized ASD as a neurodevelopment disorder that affected a person's social interaction with others (Blumberg et al., 2013). Education researchers have brought this psychological disorder to the attention of the public. To address the concern of this psychological disorder, policymakers mandated the IDEA Act (2004) and the NCLB Act (2002) to provide equal opportunities to students with disabilities. Despite the wide adaptation of the inclusion model in the school system, scholars have highlighted the reservations of schools toward the inclusion model (Allison, 2012; Pasha, 2012; Rothstein, 2000; Watnick & Sacks, 2006). For instance, Allison (2012) pointed out that parents might think that cases existed in which the student's disabilities remained too severe to integrate in the classroom fully.

The purpose of this study was to develop a deep understanding of the perceptions and lived experiences of the parents of students with ASD regarding their education in an inclusion model, using the phenomenological design. In this study, I used a qualitative phenomenological research design to explore the themes and better describe the lived experiences of parents with an autistic child who participated in the inclusion model. The goal of this study was to address the following research questions:

RQ1. What are the lived experiences and perceptions of parents of students with ASD regarding the efficacy of the inclusion model of education on their children's academic success?

RQ2. What are the parents of students with ASD's lived experiences and perceptions regarding their role in the inclusion model of education?

RQ3. What are the parents of students with ASD's lived experiences and perceptions regarding the stressors that may result from their perceived roles in the inclusion model of education?

In this study, I conducted seven secure teleconferences interviews with parents of ASD students currently enrolled in a school with an inclusion program. The parents had to reside in Pennsylvania to match the criteria for participation selection. The participants could be either the mother or the father of the children, as long as they self-identified as the primary caregiver to their child with ASD. At one point, I successfully recruited 10 parents. However, two parents lived outside of the designated region; hence, I excluded their data from the study. One parent dropped out of the study, leaving seven parents. Data collection ended at this point because no further participants met the selection criteria and I reached saturation.

In this chapter, I discuss the interpretation of the findings. The chapter also contains an alignment of the results to the existing literature. I also present the limitations of the study, as well as my recommendations for further research and implications from the findings. This chapter concludes with the summary of the key points.

Interpretation of the Findings

The following themes emerged from the analysis of the participants' responses based on their perceptions and lived experiences. (a) The inclusion model of education can either have positive or negative effects on different children diagnosed with ASD. (b)

The development of emotional skills of autistic children can be improved to enrich their participation and social relationships with other people. (c) A strengthened support system for children with autism must be advocated through accessible information and services.

Research Question 1

The one major theme that emerged while studying this research question included whether the inclusion model of education either had positive or negative effects on different children diagnosed with ASD. Participants perceived that the inclusion model of education could have positive or negative effects on different children diagnosed with ASD. This finding showed that parents had different experiences in the inclusion model of education. This finding supported the various findings from Leyser and Kirk (2011), Kasrai et al. (1999), and Yell (2006), who found that some parents of children with disabilities retained concerns over inclusion, while others saw it as a positive development.

I found that some parents agreed with their child participating in the inclusion model, which reflected Davey’s (2004) findings. For example, Participant 3 mentioned that the inclusion model of education seemed a positive contribution. This participant felt this way because educators could use the inclusion model as a tool to aid children who did not need inclusion by raising awareness of the different types of people in the world. The participant posited that this could greatly aid in expanding a child’s mind.

This participant’s viewpoint supported several researchers’ findings. For example, Nutbrown and Clough (2009) suggested that including special needs students with their regular education cohorts heightened self-esteem and increased social skills. Other researchers have postulated that effective collaboration among teachers and parents may increase classroom expectations (Sayeski, 2009). When regular education students were taught alongside those with special needs, a greater level of tolerance and understanding was fostered (Staub & Peck, 1995; Mastropieri et al., 2007; Newburn & Shiner, 2006).

All students were taught about equality, although in different ways. For example, students with disabilities were taught equality by showing them that they were not so different from their nondisabled peers, while nondisabled students were taught equality by showing them that different people existed. These different people deserved the same kind of respect. The findings from this study and the literature (Staub & Peck, 1995; Mastropieri et al., 2007; Newburn & Shiner, 2006) showed support for inclusion because of the possible positive collaboration process that may occur.

However, despite the studies that found positive effects of inclusion (Staub & Peck, 1995; Mastropieri et al., 2007; Newburn & Shiner, 2006), one must note that this study included all special needs students and was not limited only to autistic students, which may color the results. Leyser and Kirk (2004) posited that parents of students with milder disabilities often perceived inclusion as a positive development, as compared to the parents of students with moderate to severe disabilities. These findings showed that the opposing views of parents toward the inclusion model might be due to the different types of autism. For instance, parents of students with less severe disabilities were more likely to push to have their children included in the classroom with regular students.

Parents of students with more severe disabilities tended to fear social isolation, which could lead these students to fall behind (Leyser & Kirk, 2004).

One of the participants in this study expressed this negative aspect of inclusion, acknowledging that times occurred when the inclusion model could have a detrimental effect, rather than a helpful one, on the child. Participant 7 mentioned,

> My child started in Catholic school, but we were advised that he would need to either go the public school or be homeschooled due to his behaviors. The private school had no support for kids with autism. Since taking him out of private school, he has always been in an inclusion learning setting. In the public setting here, there was no alternative to inclusion. I was initially told that my child was shy and that sometimes he doesn't like the assignment, so he would not participate and throw angry fits. In second grade, the fits increased and the school did not know how to deal with it. We were constantly asked to pick him up from school. When we moved him to the public school, the experience was much better.

From this perspective, the varied types of schools available to these special needs children actually played a role in the outcome of the inclusion setting. Therefore, while I surmised that placing special education students in the same classroom as their nondisabled peers and holding them to the same standards increased self-esteem, such possible gains might be mitigated by the resulting difficulties they faced. These difficulties could stem from special education students being held up to standards that might, in reality, differ from their existing abilities.

Each school’s leadership had different standards that they expected the child to uphold. As McLeskey and Waldron (2011b) mentioned, educators cannot solely rely on inclusion for the education of students with disabilities, especially if the emphasis on inclusion allows the efficacy of the programs or the achievement levels of the special students to relegate to the background.

Society’s perception may change if educators focus on inclusion. People may perceive inclusion as a benefit to society because it has become a societal norm, without reference to the fact of whether it works best and most realistically for students with disabilities (McLeskey & Waldron, 2011b). Additionally, researchers discovered that leadership struggled to enact full inclusion beyond simply enacting the policy. For example, McCarthy et al. (2010) found that school administrators’ experiences under the segregation system continued to permeate into their current policies. Some of these experiences with segregation consciously and unconsciously informed the school administrators’ decisions regarding the inclusion model in their schools, and undermined the goals of full inclusion. Therefore, McCarthy et al. (2010) proposed that policies of inclusion in schools could not rely solely on legislation, as the personal and institutional factors that have been in place for long periods continue to exert influence on the school administrators.

This has resulted in a paradox, where leadership espouses an overt goal of inclusion, but may subscribe unconsciously to beliefs that reinforce a philosophy of difference (McCarthy et al., 2010). Leyser and Kirk (2011) conducted a study of parents of children with disabilities. The authors found that parents felt concerned about inclusion. This concern developed because of a lack of knowledge and training for general education teachers to educate their child properly, a lack of resources on the part of the school to accommodate the special needs of their child, and a fear their peers might socially reject and tease their child by in a general education classroom. This finding parallels with Participant 7’s experience. For example, Participant 7 clearly stated that the Catholic school lacked knowledge and resources to work properly with the child.

Research Question 2

The second research question has generated one major theme: The development of emotional skills of autistic children can be improved to enrich their participation and social relationships with other people. In addition to the comprehension skills of children with autism, their emotional skills should also be improved to enrich their participation and social relationships with other people. Educators should encourage human interaction so that children develop positive relationships with their peers. Participant 3 noted that children with autism must learn many nonverbal skills to interact with other people. If the child had yet to acquire these nonverbal skills, educators should continue educating the child in a non-inclusion class. According to Participant 3:

> I noticed that a lot of the kids had severe issues: behavioral issues and tics. There was one boy who constantly blows his nose into a tissue and then eats it in front of the class. That took away from the class because the teacher had to say, “Stop, stop.” We would always hear him down the hall yelling and screaming if he was having a fit. But again, he was a verbal kid and was a kid and he deserved to be there. But, it was just really hard for the kids.

This comment showed support for findings from other researchers. For instance, Avramidis (2005) found that leadership created contrasting concepts of inclusion when they created a standard for education based on narrow definitions of academic success. Standardizing a person poses a problem in education as each person has different disabilities, different communication levels, and different learning capabilities.

Other researchers supported this study's finding (DeSimone & Palmer, 2006). Their findings derived from teachers' perceptions of inclusion; however, these teachers' comments mirrored Participant 3's statement as well. DeSimone and Parmer (2006) found that a majority of their participants, who taught general education classes participating in inclusion, supported the idea of inclusion. However, these teachers felt that a general education classroom might not be the ideal place for students with disabilities, since they found it difficult to give these disabled students the attention and special services they required while covering the mandated curriculum (DeSimone & Palmer, 2006). This finding directly related to the comment above, which included an example of a disabled student interrupting the normal class and the teacher's inability to continue the natural flow of education due to this situation.

Generally, other researchers have found that this state of affairs holds true: teachers have indicated that although they believed in the inclusion model, they continued to have some reservations to teaching a fully included classroom (Damore & Murray, 2009). This reluctance might stem from a limited knowledge about the disabled population being served, inadequate training to service the population, limited support staff for problems that might arise, and the idea that the students with disabilities would require more assistance and take time away from regular education students (Daane et al., 2000; Gartin & Murdick, 2005; Goodman & Williams, 2007). Participant 3 seemed to agree with these teachers and researchers' assessments of the situation.

Participant 3 further mentioned that the parents should allow the interaction of the child with ASD with other children. However, there was a need to make sure that the child was not picked out to become a subject of bullying. To ensure the healthy interaction of the child through the inclusion model, the other children must remain aware that inclusion is going to occur. In addition, the parents must monitor the happiness level of the children.

Participant 3's comment showed support for the necessity of educators, students, and parents to collaborate about the inclusion setting. However, some conflict may arise from collaboration if people do not remain sensitive to others' emotions. For example, McCabe (2007) conducted a study on limiting role conflict between parents and teachers of disabled children in inclusion programs, finding that parents and teachers needed to communicate more for services to be effective. He further reported that respect was an issue behind much of the conflict experienced by participants.

Teachers should remain sensitive to the emotional issues that might arise in the family. A stronger relationship might occur if educators were aware of the children's emotions. This concept of respect between teacher and parent could also apply to Participant 3's belief that the other students must understand the situation before entering the inclusion setting. All children must have a modicum of respect to treat one another ethically in the classroom. However, teachers and parents must first work together to demonstrate the appropriate behavioral conduct by example (Howland et al., 2006). If they do not collaborate, then much of the hard work from the parents and educators may have contradicting outcomes for the child with disabilities.

Therefore, to work together effectively, Hall et al. (2004) advised that teachers must blend ideas. Key players in the inclusion model should conduct the following steps to foster success; (a) define what support students' needs, such as who will provide them, and how they will be provided; (b) adapt general education curriculum or settings to suit student needs and abilities; (c) accommodate students physically; (d) evaluate student outcomes; and (e) enhance understanding among all who interact with students with disabilities (Hall et al., 2004, pp. 10-11).

In summary, participants perceived that the development of emotional skills of autistic children could be improved to enrich their participation and social relationships with other people. Furthermore, parents played an important role in the success of the inclusion model. In relation to this finding, the existing literature showed that role conflicts between parents and teachers did occur. To assist with limiting role conflict, McCabe (2007) found that parents and teachers needed to communicate more for services to be effective. Findings also revealed that teachers and parents must demonstrate respect to resolve these conflicts effectively. Parents and teachers must work hand-in-hand to ensure that the needs of the students experienced an effective inclusion program (Howland et al., 2006).

Research Question 3

I designed the third research question to enhance findings about parents' perceived stress regarding their roles in the inclusion education model. The participants stated that they felt heightened stress from an inability to access information about their disabled child easily. Participants perceived that educators must advocate a strengthened support system for children with autism through accessible information and services, which supported the literature review's findings. For example, Martinez et al. (2012) posited that parents need access to knowledge about current research on specific disabilities; this access might help parents understand more about their child's disability. Therefore, establishing how parents access information about the inclusion model is essential for students with disabilities to succeed in their education.

Heightened stress levels for parents may derive from the negative effects of inadequate access to information, especially when parents perceive the school's leadership and educators as unhelpful. Participant 6 cited times when the schools and educators would not even provide reliable services and information for the children with ASD. Participant 6 noted that an insufficient presence of services existed for the learning of the children with ASD. According to her:

> Since autism was fairly new to the school districts or parents, they did not recognize there was a need to have an IEP. We were just told that he was shy or off but not told what the issue was. There were not many available resources. There is also the stress of the school district not wanting to provide services.

The lack of information also made it more difficult for the parents to assist their children. According to Participant 6:

> When my child was diagnosed, there was less information available. We had to dig and find information on our own. There is much more information available about autism. Look for the signs and find help or support early to assist your child.

This statement showed that the parents must continuously advocate for the provision of more services, causing more undue stress.

In this regard, Epstein and Jansorn (2004) investigated how to involve parents in the education of their student effectively. Again, it was not enough to involve parents; their involvement must be productive and informed by current research on the issues facing students with disabilities. Epstein and Jansorn (2004) found that schools' leadership needed effective, purposeful, and planned partnership programs to involve parents in the education process. Parents felt grateful when teachers who took the time to show how they were involved and provided examples of how they could be of assistance in the learning process.

Therefore, a support system from parents and other parties must be developed to advocate the development of the children and lower stress levels. Participant No 5's showed an example of parental support. For example, she would volunteer in different activities for the welfare of her son:

> The teachers did not seem to like this and appeared to feel I was being intrusive. While in kindergarten, I attempted to have him tested, but I was told that my child

> did not have Asperger's. Because of problems in the first grade, my child's 504 did not transfer. It was noticed by this teacher that there was a problem. I am an advocate for my child's services and his IEP and the teachers now seem to be very supportive.

Despite the positive aspect of support demonstrated in the comment above, the participant also cited misunderstandings that developed because of this support. Based on this participant’s comment, a need also existed for teachers to support and understand the needs of students and parents. In addition, this participant’s comments supported the literature’s findings regarding role confusion (Stoner et al., 2005). In relation to special education and the specific roles that both parents and teachers played in the education of a student with disabilities, role stress might arise if either party was unclear on what their role is in the system (Stoner et al., 2005).

Parents may experience stressors through “role conflict” within the inclusion model when an expectation of their role or participation is inadequately defined or contradictory to their expectation (Pearlin, 1989). If the parent does not have adequate skills to resolve the conflict or participate as needed, due to other work or family obligations, the parent may experience an imbalance, frustration, and stress because of this uncertainty (Stoner et al., 2005). Being unable to resolve this conflict may also lead to chronic role strain (Pearlin, 1989). When roles are continually undefined, for the parents, this may cause added problems and threats in their daily lives (Pearlin, 1989). Similarly, if a teacher feels that their role is being undermined or contradicted by the parent, they may feel stress and demoralization. Both of these instances may derive from individuals not doing what they perceive as their job.

Role conflict may also lead to greater dissatisfaction. Stoner et al. (2005) examined the lack of parental trust of the current services being provided to their student. The study's findings showed a correlation between distrust and dissatisfaction. If the parents had a lack of trust and were dissatisfied, they were less likely to participate in their required IEP meetings or participate in their expected role. For instance, Participant 5 demonstrated a lack of trust, stating that she felt that people always sided with the school. Furthermore, she felt that mainstream teachers did not receive proper education about special education. This belief seemed to foster a lack of trust in the system. She mentioned that a parent had to be an advocate for the betterment of the child's condition. She stated,

> I feel that my parenting style and advocating for my child made a huge difference. He still needs assistance with his social interaction but he does well academically. I believe that stress made me participate more due to fears of my son not getting the services he needed.

The accessibility of information and services would also have an impact on the development of children with ASD. According to Participant 5:

> I would like for other parents to know that many public schools will not volunteer to test. I have found that it's normal for the school system to say the child has ADD or ADHD. It is important not to let the school push you around. When the school pushes, the parent should push to get what's best for their child.

Titone (2005) also supported the notions that working together was important and that parents needed better access to information about their child's education to lower stress levels. In his study, parents of the focus group showed concern that not all participants in their child's education worked together. In addition, within the focus groups, parents suggested that special education and regular education teachers should understand the scope of each person's participation. The parents emphasized the need for teachers to have a great understanding of the overall curriculum to "take it, diversify it, differentiate it, and make it more accessible to the student with special needs" (Titone, 2005, p. 21). In other words, these teachers must not just learn how to interact with and teach their students using information gleaned from a book, but through experience and adapting to that experience as well. This concept supported findings from Research Question 3 that educators must advocate a strengthened support system for children with autism through accessible information and services.

Parents of students with ASD experience stressors related from several factors, such as stress due to limited support from the school system, limited resources available, varied issues with role conflict (Pearlin et al., 1989). These stressors presented from the parents surrounding social structures and their location within the structure (Pearlin et al., 1989) being that the parent in the main advocate, for the student. When dealing with the stressors, they activated what Pearlin (1989) identified as mediators. For the parents of students with ASD, these mediators were influenced by the effects of the stressful experiences and their manifestations. One parent stated that she would become "mama bear," which caused her to push harder for the things needed for her student with ASD.

With the added stress, Pearlin (1989) believed that stress could manifest in many different ways, to include both physical and emotional ailments. The stress may result in problems of the cardiovascular, endocrine, or immune system and may cause anxiety or depression (Pearlin, 1989). Although none of the parents provided the actual terms on how the stress may have affected them physically or emotionally, a few of parents reported that the stress affected their family life. For one parent, this caused stress between the parents, which resulted in divorce, while another parent advised that she felt bad for having to work so much more with her student with ASD compared to her other none ASD student.

Learning is a continual process, which has no limits as to where it may take place; in addition, the school, community, and home play a huge role in what and how students learn (Epstein, 2001). Further, Epstein (2001) found that parents felt that they lacked sufficient information from the school or community to be productively involved. With this lack of clarity, schools, communities, and or families have a possibility of positively or negatively influencing the child’s learning environment. For instance, if a parent of a disabled child has specific ideas about how to educate and socialize their child, these ideas must be close to what is being taught in school, since a contradiction may confuse the child and cause them not to learn effectively. Similarly, the school must tailor its program to fit the needs of the parents, given that parents also play a large role in the support of a child with disability and may be more aware of certain personal factors that, if accounted for, can help a child overcome their disability and achieve academic success. Parents may have reduced stress levels if more clarification occurs throughout the entire inclusion process. This clarification includes understanding their parental role in the education process, understanding the curriculum their disabled child will follow, having easy access to knowledge about their child's development, and being provided with information and knowledge regarding their child's disability. This clarification may lead to positive outcomes for students with disabilities.

Limitations of the Study

The study has two important limitations. First, the sample size of seven parents was not the number intended for this study, although the final sample size was acceptable for phenomenological research (Creswell, 2013; Marshall, 1996). I intended the original sample size for this study to equate to 12 parents, even though the acceptable range equated to five to 25 or even one to 100 participants, according to Creswell (2013). Based on best practices of this form of qualitative research, seven interviews provided sufficient data to reach saturation of the interview topic.

Best practices also dictate that the researcher test the interview questions with subjects whom have similar attributes to the people intended for the study (Creswell, 2013; Marshall, 1996). Therefore, two interviews took place with parents who lived in Virginia. The interview questions were tested for clarity and logic. However, I could not use those two interviews as data in this study because the parents lived in Virginia; the criteria required that parents live in Pennsylvania. Therefore, I used a number of recruitment activities, as described in Chapter 3, to find 12 parents, as referred by my contact. Once I interviewed these parents, I engaged the snowball technique to identify other parents of children with autism.

Altogether, I recruited 10 parents; one potential participant did not respond to follow-up phone calls to set up the interview. Therefore, I lost data from one parent due to dropping out, and I excluded two parents' data from analysis because they lived outside the region. Seven participants ultimately participated in the study, and interview analyses showed similar themes across all research questions.

The participants knew that they could drop out at any time, per ethical regulations. Therefore, I could not stop any participants from leaving the study. With a larger selected area, another researcher could gather a larger sample size that might account for participants who later remove themselves from the study.

Recommendations

I recommend that future researchers consider modifying the research methodology and use a quantitative methodology to explore whether the perceptions of these parents apply to a representative sample of the population. Researchers could use the quantitative methodology to study the relationship between certain variables, such as parents versus educators' understanding of inclusion practices. I also recommend that future researchers use a mixed method research design. The mixed methods design also contains a blend of interviews and numerical data, which may allow for a richer understanding on inclusion practices for disabled children. For example, a researcher may study teachers' perceptions of disabled students' success levels in inclusive classrooms and compare these to actual test scores from these students.

With the discussions of the limitations in the previous section, I recommend that future researchers seek to consider different segments of the population to see if the perceptions are similar across different samples of parents of ASD. Additionally, researchers can seek to investigate these kinds of questions in person, using the results of this study to inform their work. I also recommend that researchers focus on other variables that may have affected the findings of the current study.

The existing literature recommended that future studies should focus on special education and social validity (Ryndak et al., 2012). Ryndak et al. (2012) also suggested that students with disabilities should receive equal opportunity to speak for themselves. Lastly, the existing literature recommended that helping students with disabilities should not be limited to the implemented policies, such as the NCLB Act (2002; Ryndak et al., 2012). Furthermore, students with disabilities must be involved in community-based contexts, such as employment sites for them to acclimate themselves to their future endeavors (Ryndak et al., 2012).

Based on the findings, I recommend that parents and practitioners must remain aware of their important roles in helping students with disabilities cope in the challenges faced in school. I also recommend that parents and practitioners work hand-in-hand, for the findings showed support for needing a supportive collaboration system in the inclusion model for education (McCabe, 2007). This support may occur through fostering empathy and respect about the inclusion situation, as cited by McCabe (2007).

Implications

There has yet to be a consensus among medical professionals regarding the cause or cure for ASD, which has led to the continued gaps in understanding its full nature (Shattuck & Parish, 2008). Mazurik-Charles and Stefanou (2010) noted that the most important aspect noted in children with ASD involved their social interactions. This aspect would necessitate that students with ASD in inclusive classrooms receive special services that would help them forge meaningful relationships with their classmates and learn along with their peers. Therefore, because of this study highlighting this perception from parents, I raised awareness of the need for collaboration.

The primary implication of the current research included the positive social change generated from this study. The parents, caregivers, teachers, and other people involved in helping students with disabilities could initially reflect positive social change. From this research study, one can see how parents perceive the inclusion model. This perception contributes to the available research on the topic of inclusion by providing real perceptions of parents as opposed to perceptions of other stakeholders, as examined by previous researchers (Shattuck & Parish, 2008). Understanding parental viewpoints should aid in schools' leadership making valid decisions on curriculum with more understanding about the effects inclusion programs have on the parents. Moreover, these educators and school leadership now may have more information because of this study, which can help them in how they design or approach inclusion settings.

Another implication of the study includes that parents may have a guide for their decisions in including their children with disabilities to regular classrooms as part of the inclusion model. This study showed that parents might become confused about the roles they should take in their child's education. The literature showed that this role confusion could easily impede the educational process (Stoner et al., 2005). Hence, raising awareness of the importance of defining roles may help parents understand better ways in which to help their children achieve success in school.

This study may also highlight aspects that could positively help and or influence the children with emotional disabilities. By providing more understanding of how their parents perceive their situation, the children may have an easier time being understood by schools and or researchers. If their community at school demonstrates more understanding toward the student, then they may feel more supported, especially if they see their parents being involved in their schooling in this manner. As seen from the literature review, collaboration may be key to helping these students feel more comfortable in an inclusion setting. Therefore, any research that encourages this type of collaboration, such as this study, may have positive effects on the inclusion setting by heightening the available knowledge on the subject.

The findings of the study can also help school administrators to consider adapting the inclusion model for students with disabilities in their respective schools. Specifically, school administrators may develop educational programs that cater to the emotional aspects students with disabilities experience. The literature showed that educators who respect children with disabilities’ emotions play a major role in helping students with disabilities in school succeed and feel comfortable (McCabe, 2007). Furthermore, school administrators may focus on effectively providing parents with information about the status of their children, since this study revealed that such a support system remains necessary.

Based on the individual, positive aspects of adapting the inclusion model, one can see how this will aid a larger unit, such as the entire family or the class of students who are involved with the emotionally disabled child. With more understanding, which this study provides, negative feelings of confusion or anger may be avoided. This may help students feel more adapted to the situation of inclusion. Because this study raises awareness of different perceptions, understanding of this subject should be raised as well. Therefore, enhanced understanding should aid in positive family reactions and positive outcomes amongst peers in the classroom.

This positive outcome for families and the classroom setting may represent larger positive outcomes to society as a whole. Society also suffers from this type of misunderstanding about emotional disabilities. Therefore, providing more understanding to society may aid the emotionally disabled child to feel more welcome in society as well, especially as society becomes more informed of these issues and perceptions. Another broader implication includes that if the children experience proper inclusion practices while at the school level, then the children may have an easier time outside of the school level interacting with society, as well. The children may understand how to function more appropriately in any given action, which will eventually further adapt society's perception of them.

Society may also benefit if this study helps administrators and educators adjust the inclusion curriculum to allow for a more conducive conversation with the parents about their roles. This type of inclusion setting would help demonstrate by example to the children in the classroom ways in which they should treat one another ethically.

Expanding a sense of kindness, beyond the concept of standardized inclusion, would help society broaden the view of disabilities. All people in society deserve equal treatment, regardless of their disabilities. If students see parents, educators, and administrators working together in a collaborative manner, then they may learn from this example and carry it with them into their future. This novel way of thinking and acting could positively affect the way these students react to society when they enter the workforce. Educators and teachers who provide examples of positive communication and demonstrate respect for one another may influence their students and children to broaden communication skills. These skills can help society by providing a more communicative and accepting generation.

This study also showed the need for broadening available understanding of disabilities in schools in general. This need represents a serious issue to society, as teachers educate children to prepare them to enter society, college, and or the workforce. If teachers and administrators do not have a proper understanding of disabilities, they may respond to parents in a non-sympathetic manner. Moreover, if parents require testing for their children, as mentioned by participants in this study, then the school leadership might feel more accommodating to this request, especially if more studies, similar to this one, show similar results. If these issues are addressed, society will greatly benefit from more well-informed, educated, and sympathetic teachers, administrators, and parents.

For future research, researchers may use the findings of the current study by focusing on examining the role of emotional aspects in helping students with disabilities. Furthermore, researchers may also focus on examining the importance of support system in terms of information dissemination. They may also use a larger sample that only includes autistic children, so that they can avoid any skew to the results. More research remains necessary to add further understanding to this issue so that the individual, their families, and society may broaden their viewpoints and find more acceptance amongst them.

Conclusion

This qualitative phenomenological study aimed to examine the lived experiences and perceptions of the parents of children with ASD regarding the inclusion model of education, in order to understand the phenomenon better. Findings from this study showed the following themes. (a) The inclusion model of education can either have positive or negative effects on different children diagnosed with ASD. (b) The development of emotional skills of autistic children can be improved to enrich their participation and social relationships with other people. (c) A strengthened support system for children with autism must be advocated through accessible information and services. Through the findings of the study and available literature, I concluded that there are opposing responses about the inclusion model. Moreover, I found that support systems for information dissemination should be strengthened. Furthermore, I found that educators should develop their emotional skills to help students with disabilities.

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Appendix A: Semistructured Guide for Phone Interviews

Demographics

1. How many children do you have?
2. How many are diagnosed with ASD?
3. How old is your child with ASD?
4. Is the child in question male or female?
5. What is your ethnicity?
   a. African American
   b. Asian
   c. Caucasian
   d. Hispanic
   e. Other
6. What is your age?

Interview Guide

1. What are your experiences regarding the inclusion model of education?
2. How would you describe your role in the inclusion model of education?
3. What are your experiences with regard to role conflict in the inclusion model?
4. What kinds of stressors do parents of children with ASD experience when working with the educational system?
5. How does stress affect the amount and type of your participation in the inclusion model?
6. Do you have anything you would like to share with other parents working with the inclusion model?