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Journey with Autism: Successful Educational and Social Interventions from a Single Case Study

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ABSTRACT

JOURNEY WITH AUTISM: SUCCESSFUL EDUCATIONAL AND SOCIAL INTERVENTIONS FROM A SINGLE CASE STUDY

by

Kwame M. De Jonge-Moore

Chair: Larry D. Burton

ABSTRACT OF GRADUATE STUDENT RESEARCH

Dissertation

Andrews University

School of Education

Title: JOURNEY WITH AUTISM: SUCCESSFUL EDUCATIONAL AND SOCIAL INTERVENTIONS FROM A SINGLE CASE STUDY

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Date completed: December 2019

Problem

Statistics indicate that Autism Spectrum Disorder (ASD) is on the increase in America and worldwide (Xu, Strathearn, Liu, & Bao, 2018; Baio *et al*., 2018). Autism spectrum disorder can impair an individual's ability to engage in neurotypical behavior, which has the potential to increase their vulnerability to being shunned and bullied. This makes autism a major societal concern with significant costs to the individual, their family, private/public health insurance, state financial aid programs, and to the nation. This present study was undertaken to determine, in the opinions of those connected to the case, whether the interventions engaged in this case were effective and to what extent the educational and social interventions practiced in this specific case were responsible for

enabling Carter to reach the place where the diagnosticians felt that he no longer met the criteria for receiving services for autism spectrum disorder.

Purpose

The purpose of this study was to identify social and educational interventions used in Carter's journey with Autism Spectrum Disorder and to document the social and educational interventions employed by several individuals who worked with him. Further, the study sought to describe the impact of these interventions on Carter, from the perspectives of the key individuals involved in the early education of the child. Additionally, the study set out to determine whether these interventions actually enabled Carter to no longer meet the criteria for receiving services for autism spectrum disorder.

Method

The study employed a qualitative case study approach which gathered data mainly through semi-structured interviews and focus groups. Other data sources included Carter's mother's (Meghan's) account of her experience, key documents, and examples of learning activities found to be of benefit to the child. The nine individuals who were interviewed were invited to participate because they had been directly involved with the case. The data was analyzed using NVivo data analysis.

Results

The results from the analysis of the data study indicate that there was a positive relationship between the interventions reported and Carter's no longer meeting the criteria for services for ASD. The activities reported proved to be too numerous to be mentioned individually and were therefore grouped thematically. The two large groups were the social interventions and the educational interventions. The social interventions group was comprised of activities, such as Gymfants (gymnastics for young children), Children’s Choir, Adventurers Club, and attending regular school which promoted social interactions. These groups facilitated Carter’s working with others, taking directions from others, imitating others, leading, following, and taking turns. Language was key to these interactions. Educational interventions included; reading, attending homeschool, regular school, strategic games such as Connect Four, Uno, and geographical puzzles, floor puzzles; foreign language videos and science videos among other activities. These interventions incorporated language and encouraged Carter in individual work, seated work, pattern identification, and viewing for a purpose among other things. These interventions were planned by Meghan outside of the Individualized Educational Plan (IEP) and in addition to Speech Therapy.

Conclusions

As a result of this study, the reader can see that the curriculum developed for Carter by Meghan was directly related to his progress. The study concluded that Carter’s family working together to provide the program of interventions contributed greatly to his no longer meeting the criteria to remain in the autism therapy program designed for him by the Individualized Educational Plan (IEP) team. It appeared that the intentionality of Carter’s support team had a significant relationship with his progress. It was also concluded that there was a strong relationship between Music as a theme and Carter’s progress. The study concluded that the combination of educational and social interventions employed with Carter helped to eliminate the need for him to receive services for autism spectrum disorder. The study showed that intervention in autism requires parental involvement as the delivery of a variety of social and educational interventions through the medium of the home allowed for a natural, meaningful and permanent transfer of knowledge and growth in a number of areas. It is therefore obligatory that the parent/therapist/school partnership be supported and empowered.

Andrews University

School of Education

JOURNEY WITH AUTISM: SUCCESSFUL EDUCATIONAL AND SOCIAL INTERVENTIONS FROM A SINGLE CASE STUDY

A Dissertation

Presented in Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

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APPROVAL BY THE COMMITTEE:

Chair: Larry D. Burton	Dean, College of Education, Alayne Thorpe
Member: Elvin Gabriel	
Member: Faith Ann MacGarrell	
External: Dan Applegate	Date approved

DEDICATION

This research is dedicated to my dear mother, Eldrena. You taught me by word and example to strive after knowledge and to never give up on my dreams. Wish that you could have been here. I also dedicate this study to my wonderful children Jeshua, Johann, and Jamison. You inspire me to be my best. You encouraged me by your thoughtful inquiries about my well-being and your keen interest in the progress of the dissertation. Your joy at my defense was truly palpable. It is my desire that this research becomes a source of inspiration and empowerment for us all.

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CHAPTER 1

INTRODUCTION AND BACKGROUND TO THE PROBLEM

This study addresses the question of whether it is ever possible for parents to provide intervention successfully to their children with autism. The background of the problem informs us that Meghan was an Elementary School Teacher. Jordan was an Engineer. Meghan worried that their son, Carter, age three, had been demonstrating some developmental delays and alarming behaviors. For example, his siblings spoke before their first birthdays, and were communicating in complete sentences before their second birthdays. Carter, however, could only say some words randomly. He did not use those words to make requests. Carter did not speak in sentences even though he was almost three years old. He also screamed often without reasonable cause. He drooled incessantly and was constantly preoccupied with his hands. Something seemed off.

Meghan and Jordan had thought that perhaps he simply had a speech delay. They discussed this situation frequently, hoping that if he could be helped to communicate then his other problems would be resolved. Meghan wondered whether finding someone to teach Carter sign language would be helpful. She called the Intermediate School District office to inquire about the possibility of teaching Carter sign language. She was told that an Individualized Education Plan (IEP) meeting was first needed to evaluate Carter and to create a plan for him. With no other options available, Meghan consented to the meeting, which immediately set in motion a number of actions.

First, there were several tests. The Speech Therapist tested Carter in her office. The team of Social Worker and School Psychologist visited Carter's home in order to evaluate him in his natural setting. The parents completed their tests at the Intermediate School District (ISD) office one night. Carter was diagnosed with autism.

This unexpected news, compounded by an additional diagnosis of retardation and ineducability as indicated by a meager score of thirty points on an I. Q. test, devastated his parents. Meghan, a successful teacher of other people's children for several years, was now facing the frustrating possibility that her own child might never be able to learn. She asked herself, "What does this mean?" "Will Carter ever be able to care for himself or will his father and I always have to take care of him?"

Meghan put the diagnosis of retardation out of her mind. She felt strongly that if her son could be helped to communicate, then he would be able to progress in other areas. She determined to find persons who could provide the help needed. Carter's arduous journey with autism began. Five years later, after much effort and agonizing prayer on the part of Carter and his family, the same IEP Team who diagnosed Carter initially, found that Carter no longer met the criteria as outlined in the DSM IV for receiving services for autism spectrum disorder. He was tested and was found to have adequate language. He also showed marked progress in his social relating, literal and figurative comprehension, and other skills.

This study presented analysis of the story of that journey and the social and educational interventions used. While Carter received a diagnosis of Autism Spectrum Disorder and retardation, I have elected to focus the study on the issue of ASD. Choosing to focus on one topic allowed the topic to be developed adequately and without constraint. Although the issue of retardation did not come up again, it became obvious from the data that Meghan and her family and the IEP team quickly discovered that Carter could learn and was not affected by retardation. Carter did not remain the same. Carter's experience is unique. Autism is a spectrum disorder affected by multiple variables: variables in environment, in prenatal factors, in genetics, and the child itself. The variables converge to impact both the manifestation of the disorder and the outcome of the interventions. Therefore, although similar interventions are implemented in other cases, results may differ.

Statement of the Problem

The effects of autism spectrum disorder (ASD) are far reaching. While many persons with ASD live productive and exceptional lives, and greatly benefit society with their differences and giftedness, having ASD can also negatively impact the individual's ability to become a productive member of society. ASD and its accompanying developmental delays can cause one to experience social rejection and loneliness. It can create poor academic achievement in an individual which can result in limited educational training. This produces the effect of lower levels of employment and even unemployment. Unemployment impacts one's ability to provide for oneself, creating a domino effect, contributing to homelessness, crime, hopelessness and despair. The increasing prevalence of autism constitutes a source of concern as it impacts individuals, families, health and education services, schools, and the work force of the society.

Research which investigated the effects of autism on parents concluded that ASD impacted parents' quality of life (QoL) heavily since caring for a child with ASD required much patience, time, and effort. Parents of a child with ASD experienced more frequent psychological distress, social rejection, shame, and stigma (Mak & Cheung, 2008; Dababnah & Parish, 2013; Kinnear *et al.*, 2015) and more reported poorer QoL compared to parents of typically developing children (Vasilopoulou & Nisbet, 2015). ASD also impacted parents by causing feelings of disappointment and parental loss of expectations for the child as well as for the parent (Picardi *et al*., 2018). Research showed that having a child with high functioning autism with no intellectual disability produces more stress in mothers. Stress was differentiated by parents into family stress which related to the behavioral factors of the child such as hyperactivity, and disturbed mood (Rao & Beidel, 2009), while parent stress was related to IQ level (Craig *et al*., 2012) and manipulative IQ (Pastor-Cerezuela *et al*., 2016). Raising a child with autism created stress, which negatively impacted the family dynamics, increasing the divorce rates among parents of children diagnosed with autism (Piper-Terry, 2012).

The total costs per year for children with ASD in the United States were estimated to be between $11.5 billion – $60.9 billion (2011 US dollars) accruing from various expenses; medical care, special education, and lost parental earnings (Lavelle *et al*., (2014). Having a child with ASD can bring financial hardship to the family because of the many services needed by the child (Montes & Halterman, 2008; Mugno *et al*., 2007; Xiong *et al*., 2011; Saunders *et al*., 2015). It was estimated in 2006 that caring for a person with autism across the lifespan cost $3.2 million (Piper-Terry, 2012). Autism causes loss of productivity and income for the family as one parent generally becomes the care-giver, with subsequent financial difficulties (Ou *et al*., 2015) resulting in poverty and loss of social support. Medical and healthcare costs for the family mount because of the care needed for the child with autism (Rogge & Janssen, 2019) as many of the helpful therapies are not covered by insurance. Studies show that autism also presents a financial burden to society (Horlin *et al*., 2014).

Research indicates that Autism Spectrum Disorder (ASD) presently affects 3% of the children in the United States (Christensen *et al*., 2019), and is on the rise (Learning Liftoff, 2018). Parents, teachers, and care-givers who are challenged with caring for children who are diagnosed with autism, are overwhelmed with the demands (Picardi *et al*., 2018). The scope of this problem calls for a thorough understanding of the possible roles that parents can play in interventions in order to formulate the most effective solutions to the increasing prevalence of ASD.

Preparing a child with autism to live independently as an adult is a formidable goal for any parent and one that requires commitment, effort, and support. Enhancing the opportunities for adults with ASD to join the workforce is beneficial from a societal perspective, not only from an inclusiveness viewpoint, but also from a strict economic standpoint (Hadjikani, et al., 2015). There is evidence that early intervention in the treatment of autism is significant and has far reaching consequences for the future of the individual, affecting their quality of life and that of their family. Parents may be aware that their child is achieving his milestones behind the other children in the medical office. As the parents in the case study, some parents may be concerned enough to point this out to their pediatrician. However, they may not be aware of the symptoms of autism, and thus, may not seek an early diagnosis. This may cause them to miss opportunities to start intervention early. The need for early diagnosis cannot be emphasized enough. Research shows that an early diagnosis is the key to intervention and growth.

Once a diagnosis has been established, the choice of treatments or activities is a factor that can be critical to the progress of the child. Several factors impact the choice of treatments. Research found that proximity to services, marketing, or word-of-mouth, maternal and paternal education, the family environment, severity of sensory processing symptoms, chronological age of the child, pre-treatment IQ and language abilities were some of the factors influencing the selection of early intervention programs by families (Patten *et al*., 2013; Eldevik *et al*., 2012; Ben-Itzchak *et al*., 2014; Vivanti *et al*., 2014). Another factor determining the selection of early intervention programs is the exposure of the parents and the community to autism, its symptoms, and its possible effects. Communities where autism is unknown display stigma, impatience, and fear toward the individual with autism. Traditional forms of punishment are administered to the individual who is perceived to be deliberately choosing to disobey or to be disrespectful, or unproductive. Significant individual differences are displayed in response to treatment outcomes in this population (Howlin *et al*., 2009). A knowledge of the issues connected with a child's response to early intervention affects the success of the intervention; and knowing which program benefits which child (Stahmer *et al*., 2011) could be a key to providing effective service and could influence best practice in intervention.

Purpose of the Study

The purpose of this study was to identify social and educational interventions used in Carter's home and to document the social and educational interventions employed by several individuals who worked with the child. Further, the purpose of this study was to analyze the data collected from the parents in the study, the child (Carter), siblings, teachers, and speech therapist and to determine the effects of the interventions used with

Carter. The purpose of the study was to describe the impact of these interventions on Carter, from the perspectives of the key individuals involved in his early education. Additionally, the study set out to determine whether these interventions actually enabled Carter to no longer meet the criteria for receiving services for autism spectrum disorder. It was also purposed to determine which interventions were held to be most effective for him. The intention was to provide knowledge and analysis of the interventions used with Carter, and to compare the results achieved using these educational and social interventions with the literature.

Research Questions

The research questions that guided this study asked whether in the opinions of those interviewed if the social and educational interventions used with Carter contributed to his no longer meeting the criteria as outlined in the DSM IV for receiving services for autism spectrum disorder. What educational interventions used with Carter contributed to his not needing further services for ASD? What social interventions contributed to his no longer meeting the criteria to receive services for ASD therapy?

Rationale for the Study

An educational tour to the Caribbean during 2007 afforded me, the author, opportunities to participate in discussions with teachers in Trinidad, Barbados, and St. Lucia. These teachers shared some of the frustrations they experienced working with children with disabilities without the support of a diagnosis. They felt keenly that the lack of expertise of School Psychologists, Speech Therapists, Behavioral Intervention Specialists, and Social Workers was negatively impacting their work. At that time, the term “autism” was not as widely understood in the Caribbean as it is now. The local teachers said that, traditionally, the way to deal with a child who behaved differently was to make the child behave by spanking the child. If that did not work, then the child needed more spanking since it was perceived that the child was being defiant, or lazy, or lacking motivation (from personal communications with K-12 teachers in St. Lucia and Trinidad). Being defiant, lazy, or unmotivated are some of the assumptions faced by the autism community. Those discussions motivated my interest in sharing Meghan's story, and the uncovering of the social and educational interventions that contributed to Carter's success as a learner.

Sharing these findings with the community is important because this study gives parents of children with disabilities a voice. While the literature contains accounts of children with autism, studies like this one, focusing on parents using interventions with autism are needed. Teachers, School Psychologists, and therapists, upon meeting Carter, have doubted that he could really have had such a diagnosis at any time. They have asked Meghan, "How can we encourage other parents to work with their child the way you have worked with yours?" Some friends of Carter's family who knew Carter as a young child have asked, "What did you do? He is so different now, so calm." This study provides an in-depth look at what was done with Carter. It enables teachers to have a better understanding of autism, its manifestation, causes, challenges, and equips them to facilitate students with autism (Saggers, 2016).

The incidence of autism is increasing (Zhang & Wheeler, 2011), yet many students with autism are undiagnosed and misdiagnosed (Mandell *et al*., 2005; Wiggins *et al*., 2006; Yeargin-Allsopp *et al.*, 2003). Obtaining a diagnosis is key as it makes parents aware of the nature of the disability and the services needed. Diagnosing Carter was the first step in the process that enabled him to receive interventions. Following the diagnosis, the IEP team recommended that Meghan enroll him in the school for the handicapped where, it was felt, he would receive more services than in the local school. The recommendation of that location for more services, highlights the issue that not all individuals with ASD receive the services that are needed (Lai & Weiss, 2017).

Accessing appropriate services is a concern for parents of children with ASD. Some school districts are better equipped than others to provide children diagnosed with autism the needed support and intervention. This research documents the interventions used with Carter and the results experienced. Carter's family began working with the symptoms of autism in their child when they felt that the options for his schooling while appropriate for some were probably not adequate for his needs. Because ASD is displayed differently in each person and modifies their response to therapy, the results achieved with Carter may or may not be achieved with another child even though the same educational and social interventions employed with Carter as outlined in this study are used.

Autism is a spectrum disorder and affects each child differently, therefore, while each outcome will not be identical to the one in this case study, the team members should all work together for the goal of the child's improvement. This research examines one case study highlighting educational and social interventions that worked effectively, sharing the lived experience of the parent (Eisner, 2002, Greene *et al.*, 1998). The interventions used were compared or contrasted with the literature and the practice in the field, in order to identify and document what worked or did not work for Meghan and her child. The educational and social interventions thus documented will be added to the body of literature on autism. Caregivers and parents of children with ASD face unique challenges similar to those of the parents in this case study when trying to secure interventions for their child. They are looking for what they believe is the best situation to help their child to function optimally, and seeking alternatives for the traditional educational option which may not be working well (Goodwin and Gustavson, 2012).

Evidence-based interventions for young children are of special interest because of the increasing numbers of young children being diagnosed with autism. This increase creates a greater need for early intervention and special education services, and demands that school districts, teachers, and families identify effective educational practices (Odom *et al.,* 2003; Stahmer *et al.,* 2005). Shavelson & Towne (2002) noted that education has a high demand for interventions that have science supporting their effectiveness (Odom *et al.*, 2009). This study employed a single-subject research method which identified effective educational and social intervention practices used with Carter, and which are supported by research. Although there are treatment methods proven to be effective with some children with autism in controlled settings, research shows that efficacious interventions are not frequently implemented in education and public mental health systems (Dingfelder & Mandell, 2011).

Students with autism regularly present singular challenges to schools. It is often difficult for teachers to meet their needs effectively (Saggers, 2016). In general, teachers support inclusion, but they have concerns about their ability to meet the needs of students with disabilities (Dybdahl & Ryan, 2009; Horne & Timmons, 2009) and do not feel very confident in their ability to support students with autism. Parents, doubtful of the teacher’s ability to teach their child (Saggers, 2016) look for resources to assist them in coping with the child’s needs.

The literature on autism indicates that there is a need for case studies researching interventions emerging from the experiences of parents working with their autistic child. This study presents the parents’ experience, and will therefore benefit persons with an interest in facilitating a child diagnosed with autism. It explored the educational option of homeschooling as a case study and identified the educational and social interventions used. The successful interventions that emerged were then compared with those found in the literature on autism. The findings will contribute to improved knowledge in the area of educating children with autism, which will influence the lives of families working with autistic children. We now look at the reasons contributing to the significance of the study.

Significance of Study

Study in this area is significant because the information it delivers to parents, care-givers, therapists, educators, and administrators, who are all shareholders in the success of their students, is essential and relevant in addressing the growing incidence of autism worldwide. The findings from this present study will benefit society by contributing to its understanding of autism the evidence of the impact these successful educational and social interventions had on an individual diagnosed with autism. This study is also of significance to the worldwide community of autism as it highlights the need for diagnosis (Mandell *et al.*, 2005; Wiggins *et al.*, 2006; Yeargin-Allsopp *et al.*, 2003). This study supports the use of the diagnosis as the first step toward autism intervention. Educational and social interventions emerged from the case study. These were determined to be instrumental in Carter’s no longer meeting the criteria for receiving services for ASD. Knowledge of these interventions will benefit parents, caregivers, and educators of children with autism as they facilitate all-around development and enhance the cooperation between the home and school. The findings of the study regarding the effectiveness of Carter's family's contribution to his reaching the place where the diagnosticians felt that he no longer met the criteria for receiving services for ASD, will be of interest to those researching effective strategies involving families in the treatment of ASD. The findings derived from this study will be added to the literature to address the problem of the growing prevalence of autism and will contribute to an improved quality of life for families affected by ASD.

Definitions of Terms

Autism Spectrum Disorder - (ASD) is a developmental disability with a broad range of conditions affecting communication and behavior resulting in difficulty with communicating and interacting with others. Autism is a spectrum disorder which means that individuals with autism may present a wide range of symptoms; mild, moderate, or severe. It is also marked by restricted interests and repetitive behaviors; symptoms that hurt the person's ability to function properly in school, work, and other areas of ... (DSM-V, 2018).

Intermediate School District - in the state of Michigan is a government agency usually organized at the county or multi-county level that assists a local school district in providing programs and services.

Intervention - the act of interfering with the outcome or course especially of a condition or process (as to prevent harm or improve functioning) by using a strategy or combination of strategies (Intervention, n.d.).

Evidence-based Intervention – Interventions that researchers have found to be effective. (National Professional Development Center on Autism Spectrum Disorder, n.d.).

Quality of Life – Standard of health comfort, and happiness experienced by an individual or group (https://www.lexico.com/en/definition/quality_of_life).

Focus Group Interviews - Focus Group Interviews are interviews on a topic with a group of people who have shared knowledge of the topic (Merriam, 2009). In a focus group, each participant gets to hear each other's responses and can inform their own memories/opinions or responses.

Organization of the Rest of the Study

Autism is a spectrum disorder therefore each case can be different. Many persons with ASD contribute in countless ways to the progress of society. For many, the symptoms of autism are their strengths, however, some symptoms of autism (ASD) can negatively impact the ability of some to become productive members of society. The adequate preparation of all individuals with autism for independence and lives of productivity is the primary goal of each parent, caregiver, therapist and educator. Understanding the importance of all shareholders in the creation of secure futures of these individuals highlights their roles and underscores the relationship between school and home in supporting and creating growth.

Chapter 2 presents research done previously in the field of the present study. It provides a base for the study by providing definitions of autism. It then reviews the history of autism, its causes, and effects. Chapter 2 also provides the foundation and the scope of the Individuals with Disabilities Education Act (1990), and gives summaries of previous research findings. Chapter 3 presents the general overview of the methodology of the research including the description of the research design, detailed study procedures, data collection procedures, participants, instrumentation, internal validity, and data analysis. Chapter 4 provides Meghan’s narrative and its key themes. Chapter 5 presents the findings from Meghan’s narrative, and interviews. It provides the findings and summaries from the analysis of the data. Chapter 6 presents the discussion, the conclusions, and recommendations for future research.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

Increasing rates of autism (ASD) are being documented around the globe. This review of the available literature provides a background in prior research which investigated ASD’s effects on the lives of children, their parents, and the society. It also presents definitions of autism, a review of the history of the disability, recent research on possible causes of autism, diagnostic criteria for autism, description of symptoms, sex/gender differences, increasing incidence of autism, interventions, and the challenges of autism. This review of the literature also discusses existing research on intervention.

The identification of the what of autism, the role of the therapist, the history and evolution of the Individuals with Disabilities Education Act (IDEA), and its impact on autism engenders preparedness among educators, elicits cooperation among the responsible parties, fosters literacy which can impact societies’ response to autism, and eradicates stigma which still surrounds autism.

The search was conducted using databases including ERIC and Google using key words and their synonyms to uncover relevant material. The criteria for inclusion were studies done on ASD, causes of ASD, children diagnosed with ASD. Both qualitative and quantitative research were included in the study. The literature review used research from

1935 to 2018. The search turned up 4,371 results for the term autism, which included numerous biographies and research articles.

The purpose of the literature review was to obtain information from a number of existing studies, which examined the effects of autism, autism intervention, and parental involvement. The literature review created a base for this study by providing definitions of autism, a historical background on autism, its diagnosis, and interventions. The topic of autism (Maurice, 1993; Lawson, 1998; Moore, 2004), its causes, symptoms (McDevitt & Ormrod, 2004; American Psychiatric Association, 2000; Creak, 1961, Connor, 1999), prevalence (Chakrabarti & Fombonne, 2001; Fombonne, 2003; Yeargin-Allsopp *et al.*, 2003), therapy (Gerlach, 1996; Shore *et al*., 2006; Sears, 2010), effects on the individual, and parental involvement (McCabe, 2007; Grinker, 2007; Rappoport, 2007) have been studied for several decades.

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a group of neurodevelopmental disorders demonstrated by a deficit in social behaviors and difficulty communicating with others, verbal as well as nonverbal interactions in early childhood (Park *et al.*, 2016; Charman *et al.*, 1997). Part A of the DSM-5 definition says: ASD is defined by persistent deficits in social communication and social interaction across multiple contexts, as manifested by

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to

abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a lack of facial expressions and nonverbal communication.

3, Deficits in developing, maintaining, and understanding relationships, ranging for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers (American Psychiatric Association, 2013.).

Impairment in social functioning is a recognized feature of ASD and has been well documented in the literature (Attwood, 1998; Myles *et al*., 2005; Rogers, 2000). Specific social skills deficits include difficulties with initiating interactions, maintaining reciprocity, sharing enjoyment, taking another person's perspective, and inferring the interests of others (Baron-Cohen & Wheelwright, 2004; Koegel *et al*., 2016).

Social skills have the power to promote emotional, cognitive, and social development and are pivotal in building meaningful relationships. A lack of social skills can hamper one's ability to form meaningful social relationships, resulting in withdrawal from social relations and retreating into a hermit-like existence. Social impairments can herald the onset of more severe outcomes, such as poor academic achievement, social failure, peer rejection, anxiety, depression, substance abuse, and other forms of psychopathology (Bellini, 2006; La Greca & Lopez, 1998; Tantam, 2000; Welsh *et al*., 2001). Without intervention, challenges with social skills can persist throughout the lifetime and even worsen, impacting an individual's ability to function (Koegel *et al*., 2016). Social skills interventions for children with autism is inadequate (Hume *et al*., 2005), even though it is known that social skills deficits play a major role in ASD. To provide effective behaviorally-based social skills interventions for children with ASD, implementing and assessing these interventions should be carried out in the natural context in which they are to be used (Bellini *et al*., 2007)

A Historical Perspective

The word ‘autism’ is derived from the word ‘auto’ which means self and was used as early as 1912. A professor at the University of Zurich, Eugen Bleuler, director of the Burgholzli Asylum in Zurich, Switzerland, introduced the term, autism, to describe a symptom of schizophrenia (Bleuler, 1912). Jean Piaget, the Swiss Developmental psychologist, described autism in his work in the 1920’s, defining it as a first form of thought during infancy; a kind of ‘symbolic thinking’ dominated by visual imagery and hallucinations which affected logical thought and social relations.

Dr. Leo Kanner was the first to describe autism as a distinct and unique disease separate from schizophrenia. In 1938, Kanner, psychiatrist, of the Johns Hopkins Hospital, Baltimore, Maryland, began studying eleven children who displayed monotonous repetitions, deficiencies of language, insistence on consistency, and preoccupation with objects among other symptoms. These were the first to be diagnosed with infantile autism (Cohmer, 2014). In 1943, autism was classified as a syndrome and its symptoms were outlined in an article by Kanner, Autistic Disturbance of Affective Contact in the journal *Nervous Child* (Cohmer, 2014). In it, the eleven patients were described as possessing high intelligence, a profound preference for being alone, and insistence on preserving sameness. In Kanner’s 1943 article, he described each child’s homelife, socioeconomic background, parents’ educational background, and the main issues the parents’ identified about their child’s behaviors. Kanner’s observations helped other psychologists to make diagnoses.

In 1944, Hans Asperger published an article in Germany, describing children with symptoms similar to those Kanner described but whose verbal and cognitive skills were higher (Johnson & Myers, 2007; Rutter *et al.*, 1999). This set of symptoms became known as Asperger's Syndrome. Research was critical to the development of autism as a disorder. Research substantiated Kanner's work, shedding light on autism's impact on the lives of children as they grew into adulthood. Research informed the field on the part IQ scores played in predicting clinical outcome. Research revealed the impact of neurological abnormalities. Research aided in the differentiation of autism from mental retardation, and research guided in the differentiation of autism from schizophrenia and psychosis (Rutter *et al.*, 1999). Partly due to Kanner's influence, autism came to be categorized as an "unusually early manifestation of schizophrenia, with its aetiology including the environmentally mediated effects of rearing by refrigerator parents" (Rutter *et al.*, 1999). This understanding influenced the development of therapies intended to undo the damage done to these children by 'negative parenting' styles. While it was generally thought that autism was caused primarily by environment (Landrigan, 2010), Kanner's conviction that the deficiencies originated internally remained unchanged. He was greatly responsible for identifying autism as a separate and distinct disorder (Trevarthen *et al.*, 2010).

Criteria for autism were developed during the 1950s and 1960s. Studies increased society's understanding of autism (Rutter *et al.*, 1999; Wolff, 2004) by revealing autism's impact on the children's lives as they grew into adulthood: the part IQ scores played in predicting clinical outcome; the impact of neurological abnormalities; the meaning of the children's cognitive test scores patterns; differentiation from mental retardation; and, differentiation from schizophrenia and psychosis. Individuals with autism were said to be impaired in social interaction, imagination, and communication (Lorna Wing, 1960). Identification of these impairments used puzzles, games, testimonies of family members, and other means. Autism was now viewed as a neurodevelopmental disorder instead of a psychosis. Psychologists and neuroscientists used behavioral intervention while searching for autistic genes. Educational and behavioral treatments came into use during the 1960s (Rutter *et al.*, 1999). Special schools, classes, and parent groups emerged which were pivotal in the development of educational programs amid more research.

Autism was viewed in the 1970's, as a biological disorder of brain development instead of a kind of neurodevelopmental disorder (Courchesne *et al*., 2001; Hashimoto *et al*., 1995; Hazlett *et al*., 2005) spawning new therapies. The use of electric cattle prods as a shaping technique was frowned upon. Modifications to treatment techniques evolved which shaped the beginning of the current trends in treatment. Another debate emerged online questioning whether autism was an illness to be treated, an impairment, or a naturally occurring difference that calls for acknowledgement (Elliman, 2007). It was claimed that autism did not make people sick or abnormal, but rather individuals with autism display many strengths (Baron-Cohen, 2004). For example, persons with Asperger's Syndrome have closer attention to detail and perform better than their typically developing peers on certain parts of intelligence tests (Mayes & Calhoun, 2002; Shah & Frith, 1993). Some neuroscientists believe that some well-known geniuses; Wittgenstein, Mozart, Isaac Newton, Albert Einstein, and Charles Darwin had a form of autism (Wlassoff, 2018; Fitzgerald, 2004; Ledgin, 2002).

Autism self-rights groups have sprung up advocating for autistic rights. They have sought to showcase their talents in order to downplay the negative concepts of autism (Baker *et al*., 2002). Increasingly autism is viewed in terms of strengths and weaknesses. It is seen by autistic scholars and self -advocates as a form of neurodiversity rather than pathology (Pellicano & Stears, 2011). Society benefits from having people with autism. For example, it is suggested that individuals with autism display systemizing abilities which might have been very useful for early humans (Armstrong, 2015). Employing adults with autism is beneficial both to the autistic adults and to society (Hadjikhani, 2015). Neurodiversity's importance to humans is compared to biodiversity's importance for life (Armstrong, 2015), hence inclusion is advocated for people with autism. We now turn our attention to the diagnostic measures developed to determine a diagnosis of autism.

Diagnostic Criteria for Autism

This section of the study discusses some of the diagnostic criteria which were developed. In 1938 Hans Asperger adopted the term "autistic" from Bleuler who first used the term (Park *et al.*, 2016). Asperger observed four boys who did not mix with their peer group, did not understand the meaning of the words, "respect" and "polite", and had no regard for the authority of an adult. Their habits and movements were unnatural and stereotypic. Rutter *et al.* (1999) studied the effect that research and clinical practice have on each other, and cited the Maudsley Hospital Study as the first attempt to use empirical research findings to determine diagnostic criteria. The criteria developed from this study have been established as a hallmark and includes an onset before 30 months.

The Maudsley Study was significant because it marked the beginning of a greater understanding of autism and improved the ability of professionals to diagnose autism. Diagnostic measures were developed that included “General developmental screening; Screening for autistic symptoms; and Rating scales for autistic behavior” (Rutter *et al.*, 1999). Much progress was made in setting the guidelines to facilitate diagnosis during the period of the 1970s through to the 1980s (Rutter *et al.*, 1999), using methods such as: questionnaires, interviews, and observations. Constant research and review provided clarification and effective tools. Several studies have resulted in autism being detected as early as 18 months (Landa & Garrett-Mayer, 2006).

In 1980 the DSM-III differentiated between autism and childhood schizophrenia. The DSM IIIR provided a checklist of criteria for diagnosing autism by 1987. In 1994-2000 DSM-IV expanded the definition of autism and added Asperger syndrome. The 2013 edition of the DSM-5 included all subcategories in the main diagnosis of autism spectrum disorder (ASD), but at the same time provided two categories – impaired social communication and/or interaction and restricted and/or repetitive behaviors (National Autism Center (2009).

Initially, there was no method found that identified biological markers for ASD, and therefore screening was based solely on the behavior of the child. However, the Weizmann Institute of Science researchers working together with Carnegie Mellon University and the University of California, San Diego have been able to identify biological signs of autism in toddlers (Siegel-Itzkovich, 2011). This involved scanning the brain activity of sleeping children. Scientists found weaker synchronization between areas relating to language and communication in the autistic brain than in the non-autistic brain. This synchronization was strongly associated with the autistic child's ability to communicate. The autistic symptoms increased as the synchronization decreased. Using the scans alone allowed scientists to identify 70 percent of autistic children between the ages of one and three. 'This breakthrough may allow early diagnosis.

Studies comparing 109 autistic and 33 typically developing children demonstrated that problems with eye contact, orienting to one's name, joint attention, pretend play, imitation, nonverbal communication, and language development are measurable by 18 months of age (Lord, 1995; Charman *et al.*, 1997).

ASD's broad array of symptoms, the lack of symptoms, the similarities between autism behaviors and age-appropriate behaviors, similar symptoms of other disorders, age of the child, as well as cognitive functioning all combine to make it difficult to diagnose ASD (Richler *et al*., 2007; Sigman & McGovern, 2005). Within ASD one child can be verbal and echolalic, while another child is nonverbal but screams.

The symptoms are so diverse that diagnosis is not done by a single individual but by a multi-functional team which could be a team consisting of several members or a panel of professionals assessing multiple areas of functioning. This starts in the pediatrician's office where the doctor calls for screening if the child displays any behaviors that cause concern, or if the caregiver reports any behaviors observed at home which cause concern. Should the screening confirm that there is need for follow-up screening, then a formal diagnostic evaluation is required (Johnson & Myers, 2007).

The American Psychological Association recommends surveillance that begins in the Pediatrician's office with well-baby visits. The American Academy of Pediatrics and the American Psychological Association have proposed that identifying ASD be done in steps as stated above, and if necessary, steps can be revisited (Johnson & Myers, 2007; Huerta & Lord, 2012). This sequential and recursive method of evaluating autism has aided in the identification of ASD (Jarquin *et al*., 2011). In spite of the steps taken to diagnose ASD, there are many who slip through this first level of screening and go on to be identified in the classroom. Still, some do not get diagnosed at all. The National Research Council Committee on Educational Interventions for Children with Autism has recommended that evaluations for ASD include these three guidelines: the assessment of multiple areas of functioning including adaptive skills, an appreciation that variability in performance and ability is common in autism, and the use of a developmental perspective when assessing behavior and synthesizing results (Huerta & Lord, 2012).

The Diagnostic and Statistical Manual (5th ed., DSM-5), which is recognized by the American Psychiatric Association as the authority on criteria for diagnosis of autism, recommends the following nine diagnostic points

Sustained impairment of interpersonal relational relationships

- Unawareness of personal identity
- Pre-occupation with particular objects
- Striving to maintain sameness
- Acute anxiety produced by change
- Abnormal perceptual experience (hearing and vision)
- Failure to develop speech beyond a very limited level
- Distortion of movement
- Some learning difficulty, but some islets of particular skills or abilities or knowledge."

Faulty executive management, though not mentioned in this list, is also a critical factor. It is not necessary for all the points to be present in order for a diagnosis of autism to be made. Behaviors in a child can be varied, which complicates the process of diagnosing, especially when considering the developmental age and language level of the child. Some symptoms can be misleading as they may occur in other disorders. The National Research Council Committee on Educational Interventions for Children with Autism (2001) has recommended that evaluations which include the assessment of multiple areas of functioning include an appreciation that variability in performance and ability in different settings is common in autism, and that the use of a developmental perspective when assessing behavior and synthesizing results be used with children suspected of having autism. Best practice diagnostic tools should assess social behavior in a developmental setting.

Many tools exist to facilitate screening for autistic symptoms. Current literature on ASD contains a valuable resource of diagnostic instruments. The Autism Diagnostic Observational Schedule (ADOS) is highly recommended (Lord *et al*., 1999), as is the toddler version of the Autism Diagnostic Observational Schedule; the Screening Tool for Autism in Toddlers and Young (STAT); and the Communication and Symbolic Behavior Scales (CSBS), also for use in young children. These provide careful assessment of social behavior because of their standardized administration and coding (Heurta & Lord, 2013).

Diagnostic evaluations are immensely beneficial to the families as they provide parents with answers; confirmation of what was suspected or feared as well as relief (Midence & O’Neill, 1999). Further testing is helpful to the parents and caregivers as it enables more support to be provided based on the additional information to be received regarding the child’s strengths and challenges (Braiden *et al*., 2010). Parents are an important part of the process and should be included in the discussions about what to expect and how to benefit from the evaluation. Another integral part of the process are Pediatricians. These physicians are chiefly involved in monitoring needs of children with ASD, but are mentioned here to underscore the key role physicians play as part of the initial identification of ASD (Huerta & Lord, 2012).

Studies demonstrate that behavioral signs of developmental delay can be detected as early as between six to twelve months, but in order for a stable diagnosis to be made, where symptoms are steady and not emerging or fading away, most professionals wait until the child is at least 18 months old (https://www.autismspeaks.org/expert-opinion/how-early-can-autism-be-diagnosed). Autism is more accurately diagnosed at present (Wolff, 2004) enabling individuals to receive the special education and services they need. The number of epidemiological studies of autism has increased in recent years (Fombonne, 2003), including in the United States.

Symptoms of Autism

Autism includes a disturbance of verbal and nonverbal communication, a disturbance of attention and perception, a disturbance in motor functions, compulsive behavior, and restricted interests (Vernazza-Martin *et al*., 2003; Folstein & Rosen-Sheidley, 2001). Autism’s manifestation ranges from highly noticeable to subtle, making it difficult to have a typically autistic person. ASD can present in a range of expressions, such as; from nonverbal to fluent; very intelligent and answering to one’s name to uttering previously memorized scripts, from unawareness of the presence of others to the individual touching things of interest. Autism is known as a spectrum disorder because its range of effect is so wide. Profound autism can occur in combination with pronounced symptoms and additional disabilities, or retardation. Normal or high intelligence and language development with autistic-like behaviors and deficits in social and communication skills are known as Asperger's syndrome.

Some of these behaviors and nonverbal interactions are; aversion to physical contact, reduced eye contact, lack of speech, facial expressions early in childhood. Autism's impact on social skills and language abilities is discussed below. A well-documented symptom of autism is the inability to understand social situations and facial expressions which may be included in the act of communicating (National Health Services-Scotland, n.d.). An example of this is the way some individuals with autism openly observe other people with avid interest, unconscious that their staring produces discomfort (Schoen, 2003). It is also common for someone with autism to avoid making eye contact with the person addressing them. The autistic child will sometimes look off to and address the side of the individual.

Sensory overload can happen readily in a person with autism. Sunlight streaming into a room, photographs, lights, the eyes of people in a portrait – all visual stimuli - can easily trigger a meltdown. Other children may experience satisfaction with spending longer periods of time observing a visual stimulus; light streaming through a prism, a mobile toy, pictures, or lines in a stained-glass window. Acute hearing allows them to hear sounds that are barely audible and some can even attend to conversations in the distance (Wallis & Cray, 2006).

Everyday sounds of tools such as the blender and electric shaver can also send the autistic child into overload. While noises in the average classroom can be distracting, a number of studies have found that people with autism are more likely to have absolute pitch than the general population (https://iancommunity.org/ssc/perfect-pitch-autism-rare-gift).

Absolute pitch combined with an outstanding memory allows some children to play some music without reading the score. In a study of musical abilities, Dr. Stanutz found that children with autism performed better than typically developing children in musical games that tested their pitch discrimination and music memory (Sarris, 2015). The children, ages 7-13, were asked to tell if two tones were the same or slightly different, when they were alone or part of a melody. The children also had to remember melodies over a week's time. The children with autism displayed a "striking" ability to recall the melodies, including one boy who didn't look like he was paying attention (Stanutz *et al*., (2014).

Autism can cause sensitivity to smells, creating waves of nausea or disgust, influencing them to insist on their personal space, rejecting physical closeness while some sniff everything. Temperatures that are comfortable for some may be extreme to the person with autism. The touch of fabrics can produce either pain or pleasure. Sitting still for long periods of time can be torture. Repetitive behaviors may take the form of head-banging, rocking, running in circles, repetition of phrases, spinning or flicking of the fingers, and eating the same foods. While it is true that the smells, tastes and textures of foods may be challenging, resistance to change may be another form of insisting upon sameness and repetition or replacement (Szatmari, 2004). Greenspan and Wieder (1999) estimated that 39% of children with ASD are under-reactive to sensation, 20% are hypersensitive, and 36% show a mixed pattern of hypersensitivity and hyposensitivity.

Communication can be challenging for individuals with autism. Babbling is an activity that most infants engage in before talking, but some children with autism do not babble. Use of idioms, figurative language and metaphors can create confusion in the mind of someone with autism and can lead to unexpected outcomes, as someone with autism may be very literally minded, or unresponsive. For example, telling someone with autism to, "Go fly a kite" may result in the individual actually seeking to fly a kite outside instead of going away. Some may be geniuses or savants who are able to compute large mathematical equations unaided or accurately play a piece of music heard only once (American Psychiatric Association, 2013).

Self-management which involves the ability to identify a goal, plan, organize, execute the plan, ignore distractions, respond to change, solve problems, develop effective strategies, manage one's time and oneself doing what is necessary to achieve the goal is an accepted part of life. These steps are categorized as executive function (EF). EF is a crucial ability for an individual when performing new tasks or adapting to a change in program (Frith, 2003). ASD can impact functioning in one or more of these steps. Two symptoms of impaired executive function are inability to focus on a task, or to successfully perform a multi-step task. The fluency performance of subjects with autism and clinical control subjects were compared at two different levels of ability. The results of the design fluency tasks show a deficiency in self-management, implicating impaired intentional thought and action (Turner, 1999). Next, we discuss causes of autism.

Causes of ASD

Despite the fact that the causes of Autism have been the subject of research for several decades, its cause continues to remain a mystery. Autism Spectrum Disorders are a diverse group of neurodevelopmental disorders with a wide number of causes. Abnormalities in the structure of the brain (Ha *et al*, 2015; Rutter, 1967; Bauman & Kemper, 1985), common gene variants (Gaughler *et al*. 2014), prenatal complications (Lobascher *et al*., 1970), raised serotonin levels in the blood (research has not yet proven whether reduced serotonin levels were beneficial), as well as being raised by cold, unaffectionate parents are factors which have all been thought at one time or the other to be possible causes of autism (Eisenberg & Kanner, 1956).

Research points to many factors such as genetic, environmental, toxic, metabolic, and the combination of these factors as contributing to the disorder (Abruzzo *et al.* 2015; Karimi *et al*., 2017). Subsequent studies of the nature of autism suggested that the social deficits in autism were caused by a lack of awareness that their associates do have thoughts and emotions, or a lack of ‘theory of mind’ (http://www.autismusa.net/papers-theory-of-mind.html). “Theory of mind” is the ability to interpret mental states of other individuals, as well as their beliefs and intentions. Gene scientists are suspicious about spots on chromosomes 2, 5, 7, 11, and 17 (Folstein & Rosen-Sheidley, 2001). It is also believed that environment, as well as a combination of genetics and environment could trigger autism.

Research at the University of Arizona found that children with autism had different types of gut bacteria and had less diversity in the numbers of different species of these bacteria, than kids without autism. When researchers looked at the metabolites, seven out of 50 were different in the children with autism. Some are known to play a role as message-carrying chemicals called neurotransmitters. It is suspected that gut microbes may alter levels of neurotransmitter-related metabolites affecting gut-to-brain communication and/or altering brain function”. Wallis & Cray, 2006). Metals, pesticides, and other toxicants have been investigated as possible causal factors in autism (Cone, 2009). When asked, parents reported that they considered genetic influence, diet, perinatal factors, postnatal factors, birth trauma and vaccines to be some pertinent factors in their child developing autism (Mercer *et al*., 2006).

In speaking of causes of autism, Nguye*t al*. (2010) state in their abstract on the research topic, Global methylation profiling of lymphoblastoid cell lines reveals epigenetic contributions to autism spectrum disorders and a novel autism candidate gene, *RORA*, whose protein product is reduced in autistic brain, that autism is currently considered a multigene disorder with epigenetic influences. Mutations of genes have been identified which impede normal neurodevelopment of childhood. Genetic influences play a definite role in the development of autism as demonstrated by extensive studies of genetic analysis (Folstein & Rosen-Sheidley, 2001; Karimi *et al*., 2017). Twin and family studies indicate that some people have a genetic predisposition to ASD indicated by a pattern of ASD or psychiatric disorders in many families. If one twin has autism, the other twin will be affected 36 to 95% of the time (https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Autism-Spectrum-Disorder-Fact-Sheet). Although ASD is largely considered genetic in origin because of its high heritability observed in twin and family studies (Bailey *et al.* 1995; Folstein & Rutter, 1977), recent evidence supports the involvement of epigenetic regulatory mechanisms in the pathogenesis of ASDs. At present, epigenetic modifications and its complex mechanisms are indicated as the most important moderator in the environment and genome interactions (Perera & Herbstman, 2011 from Karimi *et al*., 2017).

In a study to investigate the altered expression of microRNA's (miRNA) and that of their target genes, in the brains of mouse offspring, the researchers said that epigenetic modification is an important regulatory mechanism for controlling gene expression without the involvement of DNA mutations or polymorphisms (Sunwoo et al., 2018). This allows the gene expression to be transferred to the next cellular generation or even the next organism generation (Bollati & Baccarelli, 2010). Epigenetic regulation, including DNA methylation and histone modification, is essential for normal brain development, and dysregulation of the epigenetic machinery has been implicated in various neuro- developmental and neuropsychiatric disorders, including ASD (Jaenisch & Bird, 2003). Because no single genetic variation or mutation can account for a majority of ASD cases, the converging actions of ASD-related genes on common pathways, as well as interaction effects with non-genetic factors, are considered to be a likely explanation for ASD pathophysiology (Kim & Leventhal, 2015). The quality and quantity of gene expression can be affected by environmental factors without changing the DNA sequence through epigenetic mechanisms. Some of these mechanisms are DNA methylation, changes in histone proteins, and expression of noncoding RNAs (Karimi *et al*., 2017).

Another way in which environment can impact development of autism is through exposure during pregnancy to harmful environmental factors. Should this exposure occur during critical periods of embryo formation, these factors can change the expression of developmental important genes and increase the chances of genomic imprinting diseases, for example, autism (Foley *et al*., 2009). Neuroimaging studies have added key insights into the changes which take place in the brain of persons with autism spectrum disorder (ASD). The amygdala which is a key component of the limbic system and the affective loop of the cortico-striatothalamo-cortical circuit plays a role in autism as well as the nucleus accumbens which affects the social reward response in ASD (Park et al., 2016).

It has been suggested by researchers in recent years, that ASD is the result of complex interactions between genetic and environmental risk factors (Kim & Leventhal, 2015). It is therefore imperative that we understand the interaction between genetic and environmental factors in the pathogenesis of ASD in order to develop the optimal treatment strategy. Several environmental risk factors are known to affect autism pathogenesis. Some of these risk factors can be categorized as prenatal, perinatal, and postnatal. Each category corresponds to a period of neonatal development.

Prenatal – It is increasingly appreciated that altered neuroimmune mechanisms might play a role in the development of schizophrenia and related psychotic illnesses (Meyer, 2014). Meyer also reports that several translational models of rodents have been created to study the consequences of prenatal immune activation on brain and behavioral development based on maternal gestational exposure to human influenza virus, polyriboinosinic-polyriboctidilic acid, the bacterial endotoxin lipopolysaccharide, turpentine, or selected inflammatory cytokines. The findings from these experimental studies suggest that prenatal infection can act as a “neurodevelopmental disease primer” that may be relevant for a number of mental illnesses (Meyer, 2014). A study which utilized seven epidemiological studies found that prenatal characteristics linked with an increased risk of autism and ASD include advanced maternal age, advanced paternal age, and maternal place of birth outside Europe or North America.

A study investigating the pathogenesis of autism measured the concentration of lead and mercury in red blood cells, while glutathione-s-transferase (GST) and vitamin E, as enzymatic and non-enzymatic antioxidants, respectively, were measured in the plasma of subgroups of autistic patients with different Social Responsiveness Scale (SRS) and Childhood Autism Rating Scale (CARS) scores. The study confirmed previous studies that implicate the accumulation of toxic metal as a result of impaired detoxification in autism. It is believed that a combination of genetic susceptibility and environmental toxins at critical periods during brain development could result in autism (Garrecht & Austin, 2011).

Perinatal factors include birth weight and duration of gestation and intrapartum hypoxia – levels of oxygen in the tissues. Although these have not been proven to be independent risk factors for autism, it is recommended that they be examined in future research that uses large, population-based birth cohorts (Reichenberg *et al*., 2007). Studies to find whether obstetric complications played a role in the development of autism were inconclusive (Gardener *et al*., 2009). Instead these complications appeared in combination with other factors and were not the principal factors.

Caesarean Sections have been implicated as a possible cause of autism. Researchers gathered data from studies involving more than 20 million deliveries dating back to 1999, to assess risks associated with caesarean delivery. The combined results of 61 studies from 19 countries have suggested a possible link between C-section and autism. It is suggested that autism in a child is 33% more likely when a woman gives birth by caesarean section. Of the women who had vaginal deliveries, the autism rate was 0.8%. While it has not been proven that having babies delivered by C-sections directly cause autism, the study found that 17 of the 29 study populations examined, demonstrated an increased risk that was large enough to be statistically viable (Emery, 2019 from //www.reuters.com/article/us-health-csection-brain/possible-link-between-c-section-and-autism-adhd-idUSKCN1VI1VS). Caesarian section is believed to be overused in many countries with the rate of use across the world rising to 21% in 2015 from 6% in 1990. While evidence exists that children born through c-section have a higher risk of experiencing allergies, childhood diabetes, obesity, and acute lymphoblastic leukemia, delivering a baby through c-section can be lifesaving for mother as well as child.

Another study uncovered a higher occurrence of prenatal, perinatal, and postnatal factors in children with ASD when compared to typically developing siblings, and postnatal factors were represented mainly by respiratory infections (Hadjkacem *et al.*, 2016). This study showed a significant association between perinatal and postnatal factors and ASD (respectively $p = 0.03$ and $p = 0.042$), where perinatal factors identified were mainly as type of suffering acute fetal (26% of cases), and long duration of delivery and prematurity (18% of cases for each factor). Postnatal factors were represented mainly by respiratory infections (24%). As for parental factors, no correlation was found between advanced age of parents at the moment of the conception and ASD. Also, no correlation was observed between the severity of ASD and different factors. After logistic regression, the risk factors retained for autism in the final model were: male gender, prenatal urinary tract infection, acute fetal distress, difficult labor and respiratory infection. This study confirms the high prevalence of prenatal, perinatal and postnatal factors in children with ASD and suggests the intervention of some of these factors (acute fetal distress and difficult labor, among others), as determinant variables for the genesis of ASD.

The exact causes of autism are not known. Ha *et al*. (2015) in their review entitled Characteristics of Brains in Autism Spectrum Disorder introduced recent findings from brain imaging studies. According to this review dysfunctional activation in critical areas of social communication were shown. Neuroimaging studies have added key insights into the changes which take place in the brain of persons with ASD. This discussion is not exhaustive, but is an introduction to the search for the cause of autism. We turn our attention to sex/gender differences is autism.

Sex/Gender Differences in Autism

Male prevalence in ASD has been noticeably consistent from the beginnings of recorded descriptions of autism, occurring four to five times more frequently in boys than in girls (Baron-Cohen *et al.* 2011; Baio, 2018). Kanner described 11 cases, 8 of which were male (Kanner, 1943). Asperger documented 4 cases, of which all were male (Asperger, 1944). Surveys conducted since have shown male biases from 1.33:1 male: female (M: F) to 15.7:1 (Fombonne *et al*., 2009), with an averaged ratio of ~4:1(Werling & Geschwing, 2014). This sex ratio is affected by intelligence level. When accounting for cases that are high-functioning, the number of males dominate. However, when accounting for cases of severe intellectual disability, the number of males more closely equals the number of females (Banach *et al.* 2009; Yeargin-Allsopp *et al.* 2003).

That ratio has been questioned by recent epidemiological studies based on nationwide data which propose that the actual ratio for male: female is in the range of 2-5:1 (Lai *et al*., (2015); Kim *et al.*, 2011). Studies have demonstrated that contrary to previously thought the sex/gender ratio is not associated with intellectual disability (ID) (Idring *et al*., 2012; Mattila *et al.*, 2011). The lower sex/gender ratio may indicate that higher functioning females who may have been missed before, may now be identified. It could also be that the newly broader diagnostic range allows for more high-functioning females on the spectrum to be identified. Many boys with autism are also diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) (Dufault & Gilbert, 2017). Girls with this disorder are more likely to display more severe mental retardation (DSM-IV TR**).** Next, we look at the increasing incidence of autism.

Increasing Incidence of Autism

Statistics indicate that autism, a neurodevelopmental disorder which affects more boys than girls, has shown a steady increase in prevalence over the past four decades (http://www.time.com/time/magazine/article/0,9171,1191843,00.htm (Chakrabarti & Fombonne, 2001; Fombonne, 2003; Wing, 1996, Yeargin-Allsopp *et al*., 2003; Ozonoff *et al*., 2005; Baron-Cohen *et al.* 2009).

In the 1960s the occurrence of ASD was estimated to be 1 in 10,000 people (Russell, 2012). In the U.S. the prevalence of autism was 1 in 166 in 2005, but as of March 2020, has increased to 1 in 54 according to the biennial report released by the Centers for Disease Control and Prevention (CDC) (https://www.autismspeaks.org/press-release/cdc). This increase has affected nations globally (Bateman, 2013) with projections that the prevalence will mushroom to 1 in 22 in ten years (CDC, 2013)

Unstrange Minds: Remapping the World of Autism challenges the view that autism is on the rise. While the rate of diagnoses has risen from 3 out of 10,000 births when his daughter was diagnosed, to rates as high as 1 in 150 births, children with autism were not diagnosed as autistic – in the past they were diagnosed with mental retardation or schizophrenia, for example (Grinker, 2007). Many persons with autism and other disorders were institutionalized (Dawson & Osterling, 1997; Strain *et al*., 1998). Hertz-Piciotto, & Delwiche, 2009, argue that the seven to eight-fold increase in diagnoses of autism in California from 1990 to 2006 cannot be accounted for solely by methods of diagnosing or counting. The same study shows that the increase in cases cannot be attributed to migration or to diversity of population as the disorder strikes different ethnic groups at fairly similar rates.

The numbers of diagnosed cases of autism is increasing (Fombonne, 2005), but many are still undiagnosed and misdiagnosed (Mandell *et al.*, 2005; Wiggins *et al.*, 2006; Yeargin-Allsopp *et al*., 2003). This is so particularly among black children. A study involving 2568 children aged 8, which examined racial and ethnic disparities in the recognition of autism spectrum disorders, found that significant racial disparities exist in the recognition of ASD, and that

> children who were Black (odds ratio [OR] = 0.79; 95% confidence interval [CI] = 0.64, 0.96), Hispanic (OR = 0.76; CI = 0.56, 0.99), or of other race/ethnicity (OR = 0.65; CI = 0.43, 0.97) were less likely than were White children to have a documented ASD. This disparity persisted for Black children, regardless of IQ, and was concentrated for children of other ethnicities when IQ was lower than 70.

(Mandell *et al.*, 2009). Race and class affect schools' abilities to provide services and educational opportunities for students with autism as educational opportunities are dramatically different based on the students' social class. A paper addressing the inequality in teaching and schooling in the United States, states that analyses of data prepared for school finance cases in Alabama, New Jersey, New York, Louisiana, and Texas have found that on every tangible measure-from qualified teachers to curriculum offerings - schools serving greater numbers of students of color had significantly fewer resources than schools serving mostly white students making the educational system in America one of the most unequal among industrialized nations (Darling-Hammond, 2001).

Challenges of ASD

Many strides have been made in the treatment of autism however the following are some challenges which remain. Stigma is a challenge which still obtains in some communities because of the prevailing ignorance and mystery surrounding autism. Economic burden or the cost of raising a child with autism is another challenge. Managing the disorder through diet presents a challenge for parents and caregivers. Finding appropriate services such as transportation and therapy. Adequate placements that reflect the child’s level of functioning, and following due process when necessary are additional challenges of ASD. Creating social change through the legislative process, challenges other parents.

Autism is on the increase, yet it is still unknown to many. This leads to ignorance, mystery, and stigma. Many people have never heard of it or met a person with ASD, except through a movie like Rain Man or the Good Doctor. Consequently, some parents attempt to protect their child from stares, bullying, and from resulting painful comments and criticism. Fearing for the safety of their child, some parents may keep their child at home (Hunter, 1994; Rappaport, 2007).

Another challenge that autism brings is that of economic burden. Parents who choose to remain at home to care for a child with ASD face economic hardship wherever they live in the world. In a study comparing families of children with ASD, families of children with other limiting conditions, and families of children with no health limitation, it was found that mothers of children with ASD average 35% less income than mothers of children who have other health issues (Cidav *et al*., 2012; Knapp *et al*., 2009). Mothers of children with ASD were found to work 7 hours less per week and are 6% less likely to have a job than mothers whose children have no health concerns. Children with ASD are more likely to have a parent who remains at home, resulting in a 21% loss of income compared to those families whose children have another health limiting condition. Families whose children have no health limitation are able to earn substantially more than those who have children with limiting conditions. The fathers' working seemed to not have presented any statistically significant difference across the 3 groups.

A lower income impacts the social economic status of the family as well as the health care and therapy options available to the child with ASD. Society as well as the individual with ASD are impacted with lifelong economic burden (Knapp *et al*., 2009). The annual economic burden for autism alone in the U.S. for 2015 was estimated at $162 - $367 billion (Leigh & Du 2015). These figures include annual direct medical, direct non-medical, as well as productivity costs. Researchers predict that the costs will outstrip those of ADHD and diabetes by 2025 in the range of $276 – 1011 billion; (0.982-3.600 % of GDP) should the autism prevalence continue to rise.

Autism spectrum disorders have a dramatic effect on the learning process in the classroom, requiring classroom aides, and supplies. Proper management of the disorder is another challenge. It calls for an understanding of the causes and risk factors. Support is needed for families to prevent and manage the disorders. Exposure to heavy metals is associated with the disorder occurring through the ingestion of highly processed foods containing ingredients with permissible amounts of lead and inorganic mercury. Should these heavy metals not be excreted through the use of sufficient minerals, they become concentrated in the blood. Higher concentrations of lead and mercury in the blood are correlated with the increasing severity of social and cognitive impairment in children with ASD and ADHD, resulting in their behavior becoming increasingly difficult to manage (Alabdali *et al*., 2014). A healthy diet is one way to manage the risk factors of ASD.

A diagnosis of autism spectrum disorder (ASD), alerts parents and professionals of the reality that two types of services exist—services that are needed and services that are available (Murray *et al*., 2011). P.L 94-142 guarantees a free appropriate public education to each child with a disability. The law says that public schools have to provide students with disabilities the services that meet their individual needs. Transporting the student to the site for a particular service, is a needed service for many students. Speech, physical, and behavioral therapies are other examples of services needed by students. Obtaining the needed services may require that a parent file a due process complaint concerning services or disputing decisions on services for their child. Due process allows parents to try to access the special education services they believe that their children need. It also allows the school district to enforce special education assessments or placements which the district feels will be helpful to the child, but which have been refused by the parents or guardians. These due process cases are lengthy and settlements are costly, paying attorneys hundreds of thousands of dollars that could be used in providing services for students.

Due process is controversial among school districts and families, yet the number of cases is increasing. Between 2007-2008, 2,626 due process cases filed; ten years later, 4,854 cases were filed — an 85 percent increase, according to state data. Every year school districts across California settle thousands of these disputes by paying parents and lawyers millions of dollars in due process cases (Taketa, 2019). In many due process cases the school district pays the legal bill for parents. According to board-approved contracts, San Diego Unified pays two legal firms up to $610,000 a year to handle special education matters such as due process. Another district, Poway Unified, in 2018 paid a legal firm $489,000 to handle special education, in addition to the $487,000 spent for families' attorneys. Parents were reimbursed from the settlement money for special education services received in the past or expected in the future which should have been provided by the district. Some of the services which have been paid for through due process are; transportation for students with disabilities, tutoring, assessments, tuition payments for private school, and even attorneys for parents (Taketa, 2019).

One challenge in dealing with autism is that families of children with ASD often feel uninformed about educational assessment and the development of Individualized Education Programs, education, social services, leisure services, autism-specific services, and accessing those services (Fish, 2006; Renty & Roeyers, 2006). Finding adequate placements is another challenge facing parents of a child who has been diagnosed with ASD; placements that provide inclusion as well as appropriate instruction. Inclusion in a regular classroom can expose the child with ASD to typically developing peers who will serve as role models of social behavior. This full-time exposure to appropriate social behavior promotes the maintenance and generalization of social skills more effectively than when using adult role models (Carr & Darcy, 1990; Roeyers, 1996; Shearer *et al*., 1996).

Finding appropriate educational and social opportunities for children with disabilities, intellectual or developmental, is another challenge. Some parents of children with ASD are undecided about selecting special needs programs for their child. In addition to learning appropriate social behavior, parents want their child to be accepted by their peers, and to be able to form meaningful friendships with regular children. The board member of a Unified Robotics program which pairs typically developing youth with disabled peers observed that forming meaningful associations with typically developing young people enables students with intellectual disabilities to see their potential and to think of themselves as having more possibilities than previously anticipated (Bach, 2018**)**. Parents want programs that their child will experience success in, but are also desirous that their child experience challenges that will increase their potential. They would like the regular programs to include people with disabilities not exclude them (Bach, 2018).

Efforts are increasing to include children with ASD in general education classrooms as a way of improving their social involvement (Rotheram-Fuller *et al*., 2010; Burack *et al*., 1997). However, a study addressing the social involvement of children with ASD in elementary school classrooms concluded that inclusion is inadequate to fully integrate children with ASD into the social network of their peers. The inclusion may eventually have a negative effect on them socially (MacMillan *et al*., 1996; Ochs *et al*., 2001; Rotheram-Fuller *et al.*, 2010).

Another challenge in dealing with ASD is creating social change for children with disabilities through the legislative process, when necessary. Legislative advocacy takes place when the importance of a policy issue or law is communicated to persons who occupy positions with authority to make or create policy (National Consortium on Leadership and Disability for Youth, 2007). Parent interest groups have advocated successfully for legislative changes for individuals with disabilities in the United States since the 1970s. Two examples are; Rosa's Law, a federal law which replaced the term 'mental retardation' with "intellectual disability', initiated by the parents of a child with Down syndrome (Degeneffe & Terciano, 2011); and the passage of legislation providing preschool programming for three-and four-year-olds accompanied by an appropriation of one million dollars (Donovan, 1986). Much has been achieved through parent legislative advocacy, yet this is still an unknown force for reforming the system (Burke *et al.*, 2017). Some strategies used in methods of legislative advocacy include educating legislators, building relationships, having parents especially fathers meet with legislators, and collective advocacy (Burke *et al.*, 2017).

Persons with ASD are impacted by various challenges. The challenges mentioned represented a broad sampling; from the stigma that still persists due to ignorance of the disability to the challenge of effecting change through the legislative process. The economic burden brought on by autism due to costs of medical care, therapy, childcare, loss of income, and in some cases, lifelong care for the child cannot be overlooked. Managing the disorder through diet or supplementation is an additional challenge for parents and caregivers. Parents struggle with the challenge of educational jargon and intimidating processes when trying to access services and placements. This may lead to the challenge of following due process when necessary. Interventions are discussed next.

Interventions and Evidence-Based Interventions Used with Autism

Autism Spectrum Disorder is mainly known for the impairment in social functioning which affects many individuals with autism. The impairment in social functioning can become more pronounced in some individuals as they grow older and enter adolescence when the pubertal hormones become active together with neural reorganization (Picci & Scherf, 2015). At this very period of adolescent-specific neural development, society demands that these individuals transition into adult social roles. Their ability to adapt to different kinds of functioning needs support. Intervention is needed to develop social skills in this population as they can be prone to be socially isolated and victimized by their peers (Hobson, 2014; Mendelson *et al*., 2016).

Parents and caregivers of students diagnosed with autism are concerned that their children be well-prepared to adjust to life's experiences. The curriculum of experiences that educators promote should be so designed that the students are prepared to live independently and to create social consequence and to promote social transformation for everyone. Federally funded programs are available in every state to help parents with early detection and intervention. Early diagnosis and intervention can help most children with ASD to be included in regular classrooms and to even lose the diagnosis altogether (Cohen *et al*., 2006; Helt *et al*., 2008; Lovaas, 1987; Sallows & Graupner, 2005; Mukaddes *et al*., 2014). Early education is available through home as well as through school. Many forms of therapy are useful as intervention strategies for children with autism.

Individual interventions delivered in a one-to-one setting, as well as group interventions which are delivered uniformly to the group, have benefits. The one-to-one setting allows the interventions to be tailored to the individual and provides opportunity for feedback and questions. The group interventions enable; learning in a social setting, experiencing rules that guide group participation, engaging other children, and learning social skills. Parents are also able to meet other parents and network (Tachibana, *et al.*, 2018).

Medication is another form of intervention, focusing on the behavioral symptoms of autism. These are numerous; however, only two will be mentioned. Two medications approved by the FDA for use with symptoms of irritability seen with ASD are Risperidone and Aripiprazole. It is recommended that treatment of Children and adolescents with ASD be started with low doses measuring and adjusting the dosage very slowly according to the response since these individuals appear to be more susceptible to adverse effects from medications.

Peer-mediated interventions (PMI) trains peers or classmates in the intervention procedure to be used. Using this intervention in schools is practical as schools have an ample supply of peers to provide services to persons with ASD (Bass and Mulick, 2007; U.S Department of Education, 2006. The peers are trained to implement behavioral interventions, facilitate social interactions, and instructional activities (Laushey & Heflin, 2000). PMI is very versatile and effective with ASD as the peers can assume one or several roles, for example; modeling appropriate behaviors, implementing prompting, and reinforcing target behaviors (Chan, *et al.*, 2009). PMI can also foster inclusion in the school setting as it provides a legitimate way for students with ASD to enter into relationships with typical student in different environments (Chan *et al.*, 2009).

Applied Behavior Analysis (ABA) school-based intervention, has been the preferred intervention for individuals diagnosed with autism (DeMyer *et al.*n, 1981). ABA is an intervention which focuses on improving specific behaviors. The therapist works on social skills, hygiene, grooming, communication, academics, reading, as well as competence in job skills, punctuality, fine motor dexterity, domestic competence, and adaptive learning skills. The development of communicative, cognitive, and social skills is the focus of the behavioral intervention curriculum used most frequently. New research points to exercise, sports, and other physical activities as being equally useful in improving symptoms, behaviors, and the overall standard of living for people with autism (https://www.autismspeaks.org/science/science-news/sports-exercise-and-benefits-physical-activity-individuals-autism.)

Pivotal Response Treatment (PRT) is play-based using a more naturalized approach based on the principles of Applied Behavior Analysis. Initiated by the child, it focuses on the child learning certain skills as well as increasing motivations (https://www.autismspeaks.org/pivotal-response-treatment-prt-0).

Learning by observing others is an intervention with significant educational, economic, and social implications for children with ASD. Bandura’s Social Learning Theory teaches that generally, we humans learn how to behave by observing others. Observing new behavior in others provides instruction in the new behavior. Trying them out when the opportunity presents itself is a form of modeling that helps guide our actions (Bandura, 1997). Learning through observing the consequences delivered to another, can reduce instructional time and financial costs of intensive instruction, and lead to the acquisition of socially relevant behavior, thereby increasing social integration opportunities (Ledford *et al.*, 2008). This can take various forms, such as social stories, videos, and drama. Peers with typical behaviors were helpful to children with autism because they modeled cooperation and social interaction, while peers who demonstrated behavioral disorders were not helpful to them (Legoff, 2004).

It has also been reported that communicating and interacting within a given group which included children diagnosed with autism improved when siblings of those children were present as helpers and role models. Their familiarity with the behaviors of their siblings proved to be helpful (Case-Smith & Arbesman, 2008). Siblings provide learning opportunities as one aspect of the family interaction pattern is another educational intervention, in that the younger or less knowledgeable family members learn from those older or more knowledgeable (Cicirelli, 1975). Vygotsky taught that a student can with speech and supportive conditions from a knowledgeable person participate in and extend his/her present skills and knowledge to a high level of competence (Donato, 1994).

Another intervention by which children with autism can be enabled to increase their comprehension is by using visual strategy during the instruction (Bidin & Omar, 2015). Since it has been noted that people with autism process visual information easier than auditory information (Brown & Mirenda, 2006; Bryan & Gast, 2000), visual strategies including; using pictures, drawings, live roleplaying, and video modeling also known as visual supports have been used to teach individuals with autism and have produced positive results (Ganz *et al.*, 2008; Fogo, 2017).).

Many children with ASD are unable to communicate verbally. Some are severely speech disabled and unable to communicate their thoughts, wants, and preferences. Augmentative and alternative communication strategies (AAC) enable communication by giving these individuals a voice. Use of the internet has created new dynamics in the teacher-student relationship. Touch screen phones and tablets facilitate communication and deliver educational and behavioral services to persons with ASD as part of the evolution of technology (Lofland, 2016).). Sound therapies, such as Background Auditory integration therapy and Samonas Sound Therapy, and Auditory Training (Bettison, 1996) are said to improve abnormal sound sensitivity in individuals with behavioral disorders, such as ASD (Sinha et al, 2004; Zollweg *et al.*, 1997). On the other hand, behavioral benefits were not always observed from the auditory integration training for children with ASD (Mudford *et al*., 2000).

Parental Involvement in ASD Therapy

Family or parental involvement has been shown to have positive results in children without ASD. Family involvement produced less child problem behavior (Domina, 2005), increased social-emotional skills (Sheridan, Ryoo, Garbazc, Kunz, & Chumney (2013), and higher academic achievement (Fan & Chen, 2001; Jeynes, 2011; Manz *et al.*, 2004; Izzo et al., 1999). This indicates that family involvement is even more important for children with ASD as it increases the effectiveness of the interventions (Matson *et al*., 2009). Change of the ASD diagnosis was rapid in children whose parents displayed great effort and high motivation. This importance of family involvement is supported by ecological systems theory that highlights the role played by the home and other micro-systems on the child (Bronfenbrenner, 1977). Each microsystem impacts the child, as well as other microsystems in the child’s life. The child is also affected by the interaction between the microsystems (Bronfenbrenner, 1977).

Services from individual microsystems as well as from coordinated microsystems working together are needed to support children with ASD. They need home-based services as well as school-based services. This calls for communication between the various systems such as the home and the school. The parent-teacher relationship can be a source of strength or a source of stress. An amicable relationship between the parent and the teacher will be a source of strength and bode well for the success of the intervention. Parental involvement is critical to the education of the children and it varies according to parenting style and in response to their children’s academic achievement.

Effective early intervention includes a family and/or caregiver component (Johnson & Myers, 2007; Carter *et al.*, 2011). A parent or caregiver working with a child who has a disability can significantly lower costs, and can also provide parents and caregivers a sense of empowerment (Zwaigenbaum *et al*., 2015). Relationship-focused intervention is effective when working with a specific population (Greenspan and Wieder, 1999; Wieder & Greenspan, 2005), (Case-Smith & Arbesman, 2008). These methods improve outcome by improving instruction (Marzano *et al*., 2001; Barber & Mourshed, 2007).

The growth and development of the children is also influenced by the parents’ educational level. In families comprised of highly educated parents from the upper-middle class, the parents showed excellent collaboration with the entire team. These parents were able to provide a high-quality intervention program for their children which they monitored closely. Research examining parent-mediated intervention has indicated mixed results (DeFilippis & Wagner, 2016). A study which examined the factors associated with parent engagement in DIR/Floortime for treatment of children with Autism Spectrum Disorder, found that parents who applied the techniques for more than 1 hour/day, or had a high-quality parent engagement, significantly correlated with better improvement in child development. The study also found that factors associated with parents, children, and provider and service factors had a significant correlation with parent engagement in DIR/Floortime in which children whose parents had more engagement in DIR/Floortime techniques had better improvement in child development (Praphatthanakunwong *et al*., 2018).

The Role of the Individualized Educational Plan

The Individualized Educational Plan (IEP) is a legal document which is developed for each child in the U. S. public schools who has an identifiable disability and is attending elementary or secondary school. The IEP is created by a team comprised of the child's parents and district personnel who are knowledgeable about special education needs. The IEP ensures that each child with a disability receives specialized instruction and needed services (Blackwell, & Rossetti, 2014). As the student responds to intervention, he/she may no longer need the special education services. Some students are sensitive to the stigma that may come from being in special education classes. Some students with high-functioning autism can flourish in a regular education environment with minimal, but well-placed support. In these cases, a 504 Plan is a better option as it provides the student with accommodations to facilitate their success. The 504 Plan is less restrictive than the IEP and it is less stigmatizing.

The issue of ensuring that children with disabilities are prepared to the best of their abilities, hinges on many educational reforms over several decades. To understand the role of the Individualized Educational Plan (IEP), we will first look at the history of Public Education in America, then the function of the IEP. Public Education became an important concept in American Society during the Industrial Revolution when people began to be employed outside of the family (Hogan, 1974). Educating and training a child became a matter of interest not only to prospective employers but also to society. Educating an individual lessened the possibility of him or her becoming an economic burden. This is relevant to the discussion concerning educating individuals with autism because the more these persons are able to be employed outside of the home the less are the possibilities of their becoming an economic burden to society.

In 1954, it was determined that public education, when provided by the state, must be available to all persons (Brown v. Board of Education 1954). The United States Supreme Court in Brown v. the Board of Education, when assessing whether the state laws permitting or requiring the segregation of white and black children in public schools was constitutional, found that the "separate but equal" doctrine had no place in public education and that any state which has undertaken to provide education, must provide education to all on equal terms (347 U.S. at 493) to be in compliance with the fourteenth amendment (Brown v. Board of Education). The equal educational opportunity doctrine was not applied to the handicapped population until 1966 (Elementary and Secondary Education Act Amendments, 1966). The need of the states for procedural and financial assistance for the improvement of handicapped programs caused the handicapped provisions of the Handicapped Act of 1966 to be repealed and a separate Education of the

Handicapped Act was created in 1970. It authorized financial grants to assist in initiating and expanding programs for the education of handicapped children (Elementary and Secondary Education Act Amendments, 1970). In 1971, the Pennsylvania Association for Retarded Children (PARC) prevailed over the Commonwealth of Pennsylvania in a case over the right of handicapped children to an education (Coates, 1985).

The PARC case resulted in a consent decree recognizing the legal right of handicapped children to public education. Several right-to-education suits were filed on behalf of handicapped children in addition to PARC and Mills resulting in several actions (Coates, 1985). The court concluded that the Board of Education of the District of Columbia must, in addition to an equal education for handicapped children, provide a constitutionally adequate hearing and review of the status, progress, and the adequacy of any educational alternatives. The United States Congress, in 1975, guaranteed the availability of a public education to handicapped children by enacting the Education for All Handicapped Children Act (EHA) (Coates, 1985). The EHA provides a wide variety of provisions including funding, early identification of handicapping conditions, timely implementation of corrective services, reinforcement of procedural protections for parents and children, and the right of parents to participate in and challenge their child’s placement (U.S.C. 1415 (1982).

An Individualized Education Plan (IEP) is a road map created for a disabled child which forms the foundation of the child’s placement and provides guidance to those who will be working with him. The local education association initiates and convenes the meetings where the IEP is developed, and which the parents are within their rights to attend together with certain school and evaluation personnel (Coates, 1985). The IEP is customized to the student. The IEP team first considers a general education placement that is age-appropriate and has services and supports. Including children with autism in the general education program is referred to as inclusion. Inclusion facilitates interaction with peers who are developing typically in the daily program which has opportunities for interaction systematically incorporated into it. The program facilitates the student's success by coordinating instruction for inclusive placements and by providing training and support to the general education staff. The peers are also provided with necessary information and support to encourage meaningful interactions.

Objectives for children with ASD should be observable, and measurable behaviors and skills. They should be written as specifically as possible. These objectives should be accomplished within one year and as one skill is acquired a new objective is added. It is not necessary to display all the goals and interventions being worked on. The child's participation in the community, the family, and in education should improve during the year. Outcomes in several areas help to ensure development all around. Examples of possible outcomes include; development of social skills to enhance participation in family, school, and community activities (e.g. parallel and interactive play with peers and siblings, imitation, social imitations and response to adults and peers), and a functional communication system; expressive verbal language, receptive language, and nonverbal communications skills. These can be broken down further. For example:

Social Skill Goals

1. ________ will develop social understanding skills as measured by the benchmarks listed below.
    a. _____ will raise their hand and wait to be called on before talking aloud in group settings 4/5 opportunities to do so.

b. _____will work cooperatively with peers in small group settings (ie. Share materials, allow peers to share different thoughts) 4/5 opportunities to do so.

Communication Skill Goals

1. _____ will increase social communication skills as measured by the benchmarks listed below.

   a. _____ will initiate communicative interactions with others 4/5 opportunities to do so.

   b. _____ will initiate varied appropriate topics with others 4/5 opportunities to do so. (NASET, n.d.)

Pediatricians are key players in monitoring the needs of children with ASD, but all physicians are part of the initial identification of ASD. The next section discusses Special Education Law and its effects on autism, on parents working with children with autism.

Special Education Law and Autism

Overall, the goal of the Individuals with Disabilities Education Act (IDEA) is to provide children with disabilities the same opportunity for education as those students who do not have a disability. Previously known as the Education for All Handicapped Children Act (EHA), The United States Congress reauthorized EHA in 1990, changing its name to The Individuals with Disabilities Education Act (IDEA). IDEA is a federal law which requires that each state provide a free and appropriate public education (FAPE) to all eligible children who live in that state. Children with disabilities whose parents enroll them in private and parochial schools without the provision of free and appropriate education (FAPE) being an issue, are not entitled to the same benefits as children with disabilities in the public schools. The Public Law 94-142 (PL 94-142), the Education for All Handicapped Children Act, passed in 1975, initially started the change in the way children with disabilities were treated by schools. PL 94-142 which is now known as the Individuals with Disabilities Education Act (IDEA), and which is accompanied by federal funds, is a federal law which requires each state to ensure that a free appropriate public education (FAPE) is available to all eligible children from birth to 22 years with disabilities living in that state.

IDEA's purpose is to improve educational results for all children with disabilities, therefore, it provides benefits and services to children with disabilities in public schools. IDEA also requires school districts to make services and benefits available to children with disabilities whose parents have enrolled them in private or nonpublic schools. School districts and their administrators have responsibility under the law to meet the needs of the special education population residing in their districts by providing diagnosis and a variety of services **(**Murdick, *et al*., 2007). Concerning accessibility to private schools for children with disabilities, IDEA amendments in 2004 expanded upon the reauthorization of 1997. It added requirements to ensure that under local education agencies (LEAs), children with disabilities placed in private schools by their parents, and who meet the participation requirements, are provided with an opportunity to participate equally in programs carried out through the IDEA (https://www2.ed.gov/admins/lead/speced/privateschools/report_pg2.html).

Children with disabilities who are placed in private schools by their parents do not have an individual entitlement to services they would receive if they were enrolled in public schools. The LEA is required to spend a proportionate amount of IDEA federal funds in providing equitable services to this group of children. The amount and type of services available to children placed by their parents differs from that available to children with disabilities who are placed in a private school by a public agency. It is also possible that some children with disabilities placed by their parents in private schools may not receive any services, while some others will. LEAs are obligated to consult with representatives of parents of children with disabilities parentally placed, and representatives of private schools while designing and developing special education services for the children.

Because ASD is all-encompassing in its symptoms and its effects on the child as well as on the family and the school (Iovannone *et al*., 2003), it is necessary for parents to collaborate with the school staff in educational planning and teaching (Cavkaytar & Pollard, 2009). Including parents as members of their child's educational team encourages and affirms parents in taking an active role in their children's education and plays a major role in their educational success (Domina, 2005; Muller, 1995, 1998; Bruder, 2000; Yull *et al*., 2014). Families are indispensable partners in the business of educating children with ASD. The Individuals with Disabilities Education Improvement Act (U.S. Department of Education, 2004), No Child Left Behind Act (U.S. Department of Education, 2001), the Council for Exceptional Children, and the Autism Society of America agree that family-school partnerships are crucial (Azad & Mandell, 2015). Parental involvement in children's schooling would help to ensure that autism remains a substantial part of school reform efforts and federal education policies (Comer, 1992; Epstein, 1985). This is supported by the Individuals with Disabilities Education Act (IDEA). High levels of parental involvement in children's schooling would help to ensure that children diagnosed with autism receive appropriate educational and social interventions and are equipped for independence and for contributing to society.

Challenges to Parents

Parents with autistic children are encouraged to take an active role in their child's education. Some parents do so in varying degrees, but several factors may make parental involvement challenging for others. Some parents of children with disabilities assume responsibility for their child's education by becoming the main educator. Others are challenged by the researching of treatment options. Making decisions about which services are needed, and developing and implementing an educational program which is tailored to meeting the child's needs can be overwhelming.

A qualitative study conducted by Reilly (2004), to discover how Western Australian parents manage the home schooling of their children with disabilities reported that five out of six home schooling families in Western Australia decided to home school in response to a need. A qualitative study done in China to describe the experiences of 43 families of children with autism also cited "a need" as the reason given by parents for choosing to homeschool (McCabe, 2007). Needs constitute challenges for parents of children with ASD. One of the needs identified is that of a safe inclusive environment for the child with autism. This is another challenge for parents.

Negative socialization creates an unsafe environment for children with autism. Five of the six parents who were interviewed in the Western Australian study, gave "negative socialization" within schools as a contributing factor in their decision to home school (Reilly, 2004). Negative socialization includes the fear of bodily, mental, or spiritual harm to a child, and is mentioned by Hunter (1994) as one of the three reasons given for home schooling. Teasing, rejection, bullying, or cyberbullying stemming from the disability put undue stress on the child in a way that hampered their academic progress. This presents a challenge for parents of children with autism. A qualitative study to determine whether ten home school parents taught social skills to their children with attention-deficit/hyperactivity disorder, reported that the vulnerability of the child with the disability to bullying or negative socialization presented one of several challenges that many parents chose to deal with by removing their child from the school environment and working with them at home (Rappoport, 2007).

The rejection of the child with special needs by their teacher presents another challenge for parents and can result in their keeping their child at home. Rejection was identified as one of the reasons parents in China assumed the role of teacher (McCabe, 2007). The parents reported instances where they had actually sent their child out to school, but the teacher sent the child home because of the disability. The rejection of the child contributes to stress for the parents. Evidence from a 15-year study ranging from early childhood to adolescence indicate that parents and caregivers of children with developmental disabilities are at increased risk of experiencing psychological stress from parents of children who are developing typically (Woodman *et al*., 2014).

An article about a disabled boy in India being sent home from school featured a photo of the nine-year-old lying tethered to a bus stop in Mumbai. The boy’s grandmother said that her blind and dumb grandson wanders off and so she had been tying him to the bus stop, where they call home, so she and his twelve-year-old sister could go and sell flowers to make a living. She even tied him to her at night to prevent his wandering away when she was sleeping (http://news.yahoo.com/boy-tied-bus-stop-highlights-struggle-disabled-indians-033223128.htm). This child had been attending a special school but he was sent home. Social agency workers in India said that this incident with this disabled child was not uncommon, but that this case served to highlight the plight of the disabled in India.

Two reasons given for a school's rejection of some children with disabilities were: 1. the teacher felt unprepared to deal with a child who had special needs. 2. The school was unwilling to accept a child with autism (McCabe, 2007). Many teachers believe that they are not able to teach children with autism. They are overwhelmed by the thought of having emotional behavioral disorder in the general classroom. They are nervous because of the very real possibility that the children with autism could lack social skills, display behavioral outbursts, and require modifications to the curriculum and need support staff (Cassady, 2011). The unwillingness of the school to accept a child with autism constitutes rejection. When combined with the teacher's unpreparedness to deal with a child who has special needs, it can be termed a lack of schooling opportunities. This creates a challenge for parents of children with autism. It is helpful for parents and caregivers of children to recognize that many teachers have not been trained to work with children with special needs within the regular classroom. They are often working unaided and this is unsettling. Parents communicating with teachers can ease the teachers' anxiety and build understanding between the two microsystems.

Another challenge is lack of schooling opportunities (McCabe, 2007). A program needed by the child which the traditional options do not provide could constitute a lack of schooling opportunity. Rejection, bullying, lack of schooling opportunities, the child's disabilities, and the lack of trained personnel to teach the student with special needs, all present challenges that may prompt a parent out of desperation to seek or create the best way to educate their disabled child (Goodwin and Gustavson, 2012). In China, while much progress in special education has been made, evidenced by students with disabilities learning in regular classrooms (Deng, Mc Brayer, & Farnsworth, 2001), persons in rural China with disabilities experience lack of schooling opportunities. This is caused by the lack of; transportation, resources, and knowledge of disability rights and education (Deng, 1996). The highly competitive nature of promotion into college, and the high numbers of students drain the teachers of "time, energy, and knowledge" so that students with special needs are often found to be isolated and "drifting in the regular classroom" (Chen, 1993; Quian, 1994). In addition, legislation that calls for 9 years of education for children with or without disabilities is said to be ineffective because there are insufficient specialized schools for children with disabilities. The parent in this study decided to create a program in response to a need as the program she envisioned necessary for her child's success did not exist at the school. Parents' efforts to find resources to meet the needs of their children with disabilities, including autism, support research which says, that there is no single program of intervention which fits all persons with ASD. Rather, intervention ought to be guided by the needs of the individual and the resources available (Ospina *et al.*, 2008).

Another challenge which faces parents is the educational background of the parent. Some parents who have only an elementary level education are intimidated by the educational process, the language of the profession, communicating with the teachers, and the demands of the school. These all have the effect of promoting feelings of inadequacy in the parents which limits their willingness to participate in the educational or social interventions or to provide homework assistance. Parents who feel inadequate to support their children academically can assist them by providing structure. There is therefore room in the literature for research to be done on case studies of a parent coping with the needs of an autistic child such as this study.

Summary

Chapter 2 set a brief historical context within which the present challenge of Autism Spectrum Disorder is inserted to be better understood. Autism or Autism Spectrum Disorder (ASD) names a group of disorders characterized by communication difficulties, impairments in social relating, and rigidity in interests and activities, with onset occurring before age three (American Psychiatric Association, 2013). ASD is a spectrum disorder, manifested differently in each individual as it can occur singly or in combination with other diagnosed learning disabilities or chronic medical problems. This is a lifelong chronic disorder. The Centers for Disease Control and Prevention (CDC) estimates that 1 in 68 children (or 14.7 per 1,000 eight-year-olds) in multiple communities in the United States has been identified with autism spectrum disorder (ASD) (Centers for Disease Control and Prevention, 2014). ASD is increasing in frequency around the world, but can be diagnosed in someone as young as two years old. It occurs in boys more frequently than in girls, and is diagnosed more frequently in boys, but can be more severe when diagnosed in girls as it is often accompanied by retardation.

The review of the literature revealed evidence supporting the various shareholders in the community affected by autism- parents/home and the Individualized Educational Plan Team/school, and the Support Team/community - working together in the interest of the student diagnosed with autism. Parental involvement can take various forms; school involvement, parent-teacher communication, community involvement, and home involvement. While it is true that parental involvement can and does support the learning process, the academic success of the child may be dependent on other factors. The manner in which the parent is involved, which parent is involved, as well as the reason for the involvement can be critical in promoting success (Pomerantz et al., 2007).

The interrelatedness of the home, school, and community lend themselves to collaboration with positive outcomes. These three areas are three contexts within which the students exist and by working together, they positively affect the outcomes for the student with autism. The literature indicates that a combination of the various forms of parent involvement in their child’s education resulted in a generally positive affect on academic achievement. The positive outcomes produced were; improved relating for the student with autism and his/her peers and others, increased academic achievement, and even change of diagnosis in some instances. This was demonstrated in the experience of Carter, the child at the focus of this study, as his communication skills, his academic achievement, and his diagnosis were all positively affected by the working together of his three main contexts.

The literature, while confirming that parental involvement is effective during the elementary school level, has not had enough research concerning the effect of parental involvement at the middle and high school levels to make a conclusion. More research is needed on this period of the development of the young person to be able to determine the relevance of parental involvement. Therefore, this study seeks to fill this gap in the literature as it uncovers the factors which contributed to Carter’s growth through elementary, middle, and high school. The perspective that parental involvement has such a positive effect on academic achievement for the typical student makes it even more essential for parents to participate in the education process to increase the success of interventions for the child diagnosed with ASD.

Indispensable to the progress of the student is the IEP team. This team works together to diagnose the student and to identify the areas of need which must be addressed in order for the student to receive intervention services. The IEP team consists of the school psychologist who can interpret the evaluations, special education teacher, regular classroom teacher if applicable, school social worker, speech therapist, the school representative, and the parents. The IEP meeting provides an opportunity for the IEP team to come together to assess and design an IEP for the educational progress of the children with disabilities. The IEP process has several steps; pre-referral, referral, identification, eligibility, development of the IEP, implementation of the IEP, evaluation and reviews. The IEP team develops the IEP and writes it by collaborating and deciding the large goals as well as the smaller steps through consensus. After implementation, the IEP team meets periodically to assess progress and to set measurable goals for the student. This process evolved out of the Individuals with Disabilities Education Act.

The Individuals with Disabilities Education Act is a federal law which requires each state to ensure that each child with a disability is provided with a free appropriate public education. It also requires that school districts make services and benefits available to children with disabilities whose parents enroll them in private or nonpublic schools. This law has a rich history which helps us understand the law’s intent toward the children with disabilities in the nation. Research shows that many challenges exist in raising a child with autism. Besides dealing with stigmas, financial hardship becomes the norm for many of these families around the world as one of the parents has to remain at home to care for the child. Finding appropriate schooling or classroom placement which is accepting of the child can be another challenge. In 2019, a 13- year-old boy with autism died after being restrained at a school in California. It is said that he was restrained out of fear that he might hurt others (https://www.cnn.com/2019/11/13/us/california-autistic-student-died-charges-trnd/index.html. Incidents like this present additional challenges for parents and caregivers of individuals with autism.

The purpose of Chapter 2 was to review what the literature said about autism; its history, diagnostic criteria, description of possible symptoms, causes, gender differences, the increasing incidence of autism, interventions, autism's challenge for parents, and the provisions of Individuals with Disabilities Education Act (IDEA). The literature review is also intended to provide a background for the study and to enable an understanding of the accomplishments of the family and son in this study in overcoming the challenges of autism. The Chapter 3 introduces the research design, which is used in this qualitative study, giving a description of the research instrument and the data analysis. Data collection, and data analysis, issues of trustworthiness, credibility, transferability, triangulation, coding, and confirmability will be discussed.

CHAPTER 3

RESEARCH METHODOLOGY

Introduction

The present study identified social and educational interventions used in Carter's experience and documented the social and educational interventions employed by several individuals who worked with the child. This study further analyzed the case study to determine whether the educational and social interventions used with him made a difference. Chapter 3 gives a description of the participants, the research instrumentation, the data collection procedures, and the data analysis methods used. It also discusses the research design upon which this study is built. Issues of trustworthiness, credibility, transferability, triangulation, coding, and confirmability will also be discussed in Chapter 3.

There have been numerous studies done on autism, its causes, effects, prevalence, therapy, and parental involvement. However, this study adds to the literature by investigating all of these factors from one case study. This investigation is focused on Meghan's narrative and the first-hand accounts of the participants. Narratives are fascinating, a natural means of communication and can be authentic or composite (authentic stories based on multiple narratives) (Thompson & Kreuter, 2014). Narratives are effective because through their use of detail and thick description the audience is able to be transported and even identify with the characters (Green & Brock, 2002). Mary

Pipher (2006) says that the effectiveness of stories is demonstrated in the bringing about of transformation because stories draw people in to listen to them and this enlivens their recollection of the events. Meghan's narrative which shares the story of her family's working with her son's diagnosis, describes the challenge to find help, her struggle to accept the diagnosis, and the family's commitment to make a difference. The use of the narrative was best served by a qualitative mode of inquiry. It is a case study built from an autobiographical account of Meghan's experience while working with her son who was diagnosed with autism. Autobiographical work transforms those who engage in it as well as the body of the discourse (Pinar *et al*., 2004).

Description of Research Design

This research utilized a qualitative intrinsic case study design. Qualitative research is a broad term which includes several research approaches to investigate social phenomena in their natural settings. In order to study how people interpret their experiences and how they construct their worlds, researchers employ qualitative research which has elements from symbolic interactionism, constructionism, and phenomenological philosophies (Merriam, 2009). Qualitative forms of inquiry are defined by three key elements; the design, the collection of data, and the analysis.

The heart of qualitative research is to make sense of and recognize patterns among words in order to build up a meaningful picture without compromising its richness and dimensionality (Leung, 2015).

On the one hand, quantitative research is primarily focused on numerical data and their statistical interpretation is seen as evidence-based, valid, reliable, and generalizable, while qualitative research, which makes as significant a contribution as quantitative research, has been critiqued for inadequacies in judging its quality of research as well as its robustness. On the other hand, it is believed that qualitative research focused on discovery, insight, and understanding from the perspectives of those being studied, offers the greatest promise of making significant contributions to the knowledge base and practice of education (Merriam, 1998). The following section introduces the Case study as the research model and gives the reasons why this research model was chosen.

The Case Study as Research Model

The purpose of this study was to identify instructional approaches that aided Carter to flourish in all areas of his life and to lose the criteria for further therapy for autism. Identifying the instructional approaches would best be served by the qualitative study approach. Qualitative research is a broad term which includes several research approaches to investigate social phenomena in their natural settings. In order to study how people interpret their experiences and how they construct their worlds, researchers employ qualitative research which has elements from symbolic interactionism, constructionism, and phenomenological philosophies (Merriam, 2009).

One qualitative research tradition used broadly across disciplines is the case study (Merriam, 1998; Savin-Baden & Howell-Major, 2013; Stake, 2005; Yin, 2003). The qualitative case study is an approach that provides tools which equip researchers to study complex phenomena within their contexts using a variety of data sources (Baxter & Jack, 2008). Qualitative Case Study Methodology allows the researcher to interact with research subjects and to study social and cultural phenomenon in action (Murchison, 2010). This is a form of qualitative research which, according to Patton,

> … is an effort to understand situations in their uniqueness as part of a particular context and the interactions there. This understanding is an end in itself, so that it

> is not attempting to predict what may happen in the future necessarily, but to understand the nature of that setting-what it means for participants to be in that setting, what their lives are like, what's going on for them, what their meanings are, what the world looks like in that particular setting- and in the analysis to be able to communicate that faithfully to others who are interested in that setting…The analysis strives for depth of understanding. (1985. p. 1)

The qualitative case study approach ensures that the issue is explored through diverse lenses that enable its various facets to be uncovered and understood. Stake and Yin, the two leading theorists in qualitative case study base their approach to case study on the constructivist philosophy, which says that truth is relative and dependent on the viewer's perspective. Constructivism uses the premise of a social construction of reality (Searle, 1995), which allows the participant to tell his/her story and at the same time enable collaboration between researcher and participant (Crabtree & Miller, 1999). Distinct types of case studies exist and the two research design theorists use slightly differently terminology to describe case study research designs. Yin (2003) discusses descriptive, exploratory, explanatory, instrumental, and multiple case studies. Stake (2005) places case studies into three groups: intrinsic, instrumental, and collective. A brief look at these types of research follows here.

The descriptive case study is used to describe an intervention or phenomenon and the real-life context in which it occurred (Yin, 2003). It provides a detailed account of a topic using a rich, thick description of the case. A descriptive case study is one that is both focused and detailed. This type of research carefully studies propositions and questions about a phenomenon that are posed at the beginning. The detailed account of the known details about the phenomenon is referred to as a descriptive. The researcher investigates, analyzes, and reports details on the context, processes, and interactions, of the case (Merriam, 1998; Yin, 2003). The main goal of the descriptive case study is to assess a sample in detail and in depth, based on an articulation of a descriptive theory. The researcher may or may not use a theoretical framework as a guide (Yin, 2003).

An exploratory case study enables the researcher to assess the possibility of difficulties when selecting a case. Researchers using the exploratory case study decide upon research questions after they have completed exploratory fieldwork and collected initial data. Exploratory case study may be used for exploration only or it can provide the basis for a larger study (Yin, 2003). As suggested by their name, explanatory case studies (Yin, 2003) provide a means for researchers to explain a phenomenon. Explanatory case studies can also be used to explain a pattern of challenges that exist in a specific situation. They can also help researchers make sense of a complex situation or to identify cause-and-effect relationships (Savin-Baden & Howell-Major, 2013).

The instrumental case study allows researchers to develop a better understanding of a situation or phenomenon (Stake, 2005). One can use the instrumental case study design to create, refine, confirm ideas and theories (Savin-Baden & Howell-Major, 2013). In-depth study of the phenomenon using an instrumental case study design facilitates our understanding of many aspects of the case, all the while enabling our grasp of the main issue.

The study of more than one case is referred to as multiples (Yin, 2003) or a collective case study (Stake, 2005). Each of these designs is actually a complex instrumental study linking what could have been several individual studies. Collective case study design provides a structure to gain insight into the issue of interest across settings, individuals, or experiences as it allows comparison within and between cases (Baxter & Jack, 2008). Multiple or collective case studies, instead of providing the in-depth analysis of the single case study, replicates the study’s design and processes across cases. This replication process strengthens the evidence (Savin-Baden & Howell-Major, 2013).

The Intrinsic Case Study is a form of qualitative research that investigates a single, specific case because the case itself is of genuine interest and the researcher seeks to better understand that specific case (Merriam, 2009; Stake, 2005). In an intrinsic case study, the case is selected because of its own merits and uniqueness and not because it represents other cases. This study used the intrinsic case study design because the journey of Carter and his family with autism is unique and, in all its ordinariness, is of genuine interest to me as a researcher. I was interested in studying this case because of my acquaintance with families of children who were diagnosed with autism and because the reported incidence of autism is increasing worldwide. Thus, my choice of research topic substantiates the claim made by Bullough and Pinegar (2001) that many researchers now accept that instead of being disinterested in their studies, they are personally, deeply invested in their studies.

The intrinsic case study design also demonstrates alignment with the purpose of the study and the actual research question. In this particular case study, the analysis focuses on instructional approaches that appeared to benefit Carter in his development and educational growth. In this section, the rationale behind the methodology was stated. Various types of case studies were reviewed and the Intrinsic Case Study which is used in this study was discussed. Detailed study procedures are explained, next.

Detailed Study Procedures

Participants

Participants for this study were selected because of their knowledge of Carter and their experience with him during the time frame of this study. The eight individuals enrolled; the child - Carter, his parents, two siblings and three non-family members who worked with him during this time were invited by letter to participate in the study.

Several forms of data collection were employed. Interviews formed the main form of data. The school psychologist, a teacher, and a therapist were interviewed individually. Focus group interviews were conducted with members of the family, the parents, as well as an interview of the child. As another form of data collection, the mother was encouraged to journal as she reflected on her experiences. Other forms of data included a copy of the IEP as well as a copy of notes from a follow-up IEP meeting. This study used the interview as the primary method to gather recollections and perceptions of those involved.

Merriam (1998) says that there are times when data can only be collected by interviews, like when we want to study past events. Case studies featuring selected individuals are best served by interviews (p.72). Interviewing people enables us to discover things that cannot be observed, such as; situations where an observer would not be allowed, behaviors that took place at a time that is past, feelings that were experienced, thoughts and meanings which were experienced. Interviewing helps us to understand why people do the things they do and the perspective of the other person (Patton, 1999). We will now look at the research procedures used in this study.

Instrumentation

This section lists and includes the research procedure used in this study:

1. Permission obtained from the Institutional Review Board (IRB) to conduct this study involving human subjects.
2. The subject of the study (the child) informed about the details of the study
3. Other children in the family were invited and informed about the details of the study
4. Parents invited and provided with Parental Informed Consent Form
5. Other individuals invited and all participants provided with Consent Form for All Persons Involved in Research
6. Consent forms signed

Obtaining the permission from the IRB involved adding an addendum to the application indicating how the identities of Carter and his siblings would be protected.

The participants are persons who were familiar with the case and who were able to meaningfully contribute to this study. Eight persons were enrolled: the child - Carter, his parents, two siblings and three non-family members who worked with him during this time. These persons were selected purposefully because of their knowledge of the individual and their experience with him during this time. Carter, his parents, and two siblings were informed and invited by letter to participate in the study. They were informed of the potential of risk to themselves and the benefits to be derived from the study. They responded and signed the consent forms. Carter's parents signed the form giving their permission to have him participate in the study. The letters giving IRB permission and securing participants' consent are located in appendix A and B.

Focus Group Interviews are interviews on a topic with a group of people who have shared knowledge of the topic (Merriam, 2009). In a focus group, each participant gets to hear each other's responses and can inform their own memories/opinions or responses.

1. Two focus groups were conducted. One group consisted of the siblings in the family, and the parents and the siblings comprised the other.

2. Separate interviews were also conducted:

   a. The mother was interviewed.
   b. The father was interviewed.
   c. Persons who worked with the child were interviewed: Letters of request were sent to (a) psychologist, (b) speech therapist, (c) violin teacher, and (d) piano teacher

3. All of these individuals signed consent forms. The interviews were recorded on audiotape and transcribed verbatim. All participants' names are pseudonyms. Carter's parents clarified any perceived discrepancies occurring from parental reports during the interviews. Whenever possible interview data was corroborated with that collected via written accounts or other interviews. Detailed notes were taken during the course of the interviews. The next section discusses issues of trustworthiness.

Internal Validity or Issues of Trustworthiness

Introduction

There has been much debate about the merits of qualitative versus quantitative research. The quantitative approach to research has been endorsed by its success in measuring, analyzing, replicating, and applying knowledge gained in this domain

(Streubert, & Carpenter, 2011). However, the merit of qualitative research is assessed by different criteria than quantitative research. The rigor of qualitative research is judged by four criteria: credibility, transferability or applicability, dependability or consistency, and confirmability or neutrality (Lincoln & Guba, 1981). Qualitative research refers to research that does not use statistical processes to determine its findings (Strauss & Corbin, 1990). Rather, qualitative research produces findings from real-life situations where the "phenomenon of interest unfold naturally" (Patton, 2002). Qualitative research aims to shed light upon a subject, and to use one situation to bring understanding to another. This is different from quantitative research, which aims to predict, and to make generalizations from the findings (Hoepfl, 1997).

Trustworthiness or Credibility

Trustworthiness incorporates the idea of the credibility or believability of the research. The Instrumental case study studies the particular case to provide insight into a phenomenon, but the phenomenon extends beyond the investigator's viewpoint (Schmid, 1981). Therefore, while the investigator's viewpoint is important, the phenomenon cannot be so removed from reality that it cannot be corroborated. The trustworthiness of qualitative research can be ensured by addressing its credibility or truth value. This qualitative study took an in-depth look into the experience of a single case to determine what educational and social interventions were used.

Trustworthiness in this study was established by several strategies. Interviews and focus groups were conducted with nine persons who were selected because of their proximity to the subject of the case study and their personal knowledge of the case. The individuals selected were informed of risk, assured anonymity, freedom to withdraw, and recourse should any question or discomfort arise. These interviews were conducted using open-ended questioning allowing each participant the opportunity to present their understanding and experience of the phenomenon. The data were managed using NVivo version 11. The interviewees' own words are included in the presentation of findings in this study, and are compared with statements from other participants. The participants read their responses to see whether their sentiments were expressed.

In this research, bias was avoided and credibility or the truth value ensured by employing the interview technique using open-ended interviews and focus groups. Members of the family shared their memories, perceptions, and group recollections of the phenomenon in focus group interviews. Testimonies by the professionals from the Special Education Department testifying to the work of Meghan with her son were also used to establish credibility and helped to eliminate study bias.

Transferability

The strength of qualitative research lies in its ability to take the particular uniqueness of a case and hold it up in its entirety for our attention. Qualitative research does not try to leave out the unexplainable, or make everything easily understandable. It includes that which may be different- ideologically, epistemologically, methodologically, and humanly. The degree to which the results of a qualitative research can be transferred to another similar situation is referred to as transferability. The one doing the generalization or making the transfer to a different context is responsible for using his/her judgment to ensure that the fit of the transfer is applicable (Lincoln & Guba, 1981). Transferability can be enhanced if the qualitative researcher uses rich, thick, descriptions of the research settings and the assumptions of the research. Research transferability was fostered by preparing dense descriptions of the phenomenon, and then comparing the data and the resultant themes to the data found in the literature. Next, we will look at what triangulation is and what triangulation does for the study.

Triangulation

Triangulation can be very useful in establishing the dependability of the research. It allows for multiple representations of a phenomenon to confirm the accuracy of data. The various data sources can be checked against each other for accuracy and interpretation and to eliminate bias. Dependability was enabled by including a dense description of the research methods used as well as by using data triangulation. The data presented in the case study narrative was checked against the data collected by interviews and that collected by focus groups in order to enhance the rigor of this study.

Confirmability or Objectivity

Confirmability or objectivity can be affected by the prolonged contact between the investigator and the informants. Prolonged close contact between researcher and phenomenon can result in the loss of the ability to interpret the findings. Reflexive analysis or reflexivity, a heightened awareness of one’s self, of the researcher’s biases, of the present, the past, and the future, enables the researcher to assess the influence of the investigator’s own background, perceptions, and interests on the process of the research (Ruby, 1980) In this research, confirmability was assured through triangulation and the use of reflexivity. Next data analysis is discussed.

Data Analysis

Analysis of this case study looked for themes to emerge from the data, the narrative. This is not a quantifiable quality but is rather more interpretive. "Qualitative data analysis focuses on meanings rather than on quantifiable phenomena. It studies in depth and detail without predetermined themes and categories and is sensitive to context in contrast to universal generalizations" (Denzin & Lincoln, 2008, pp. 8-10).

The coding resulted in some themes emerging from the data. Analyzing the data consists of basic steps: preparation, coding, analysis, and reporting. The NVivo software which is designed to analyze qualitative data to assist in this qualitative research process was used. NVivo enabled the creation of categories, the application of these categories to the text, the creation of visible connections between the categories, and the development of comparisons between the categories. First the text was scanned into the program's rich text editor. NVivo created a rich text file. The text was coded by creating categories for portions of the text. The researcher then clicked on a portion of the text and dragged it. As the document was read more codes were created to accommodate the portions of text. Each similar portion of text received the same code. The coding was continually revised by the researcher to develop more accurate categories as needed. Some portions of text were assigned different codes simultaneously. NVivo allows the researcher to recombine categories, count code frequencies, and test hypotheses about relationships between categories (www.sagepub.com/upm-data/43454_10.pdf). Chapter 4 focuses on the narrative as related by Meghan.

CHAPTER 4

CASE STUDY-MEGHAN'S STORY

Introduction

Chapter 4 presents excerpts from Meghan's autobiographical account of Carter's journey with autism related in her voice. Additional data presented include information from IEP reports, observations by the speech pathologist, and examples of educational interventions used with Carter. The social interventions and teaching methods which emerged from the account are also presented.

Meghan Tells Her Story

Meghan began, "Carter was taking an awfully long time to begin talking, compared to my other children. They had each begun talking around the one-year mark, but Carter was now almost three years old and was not yet speaking in sentences. He did seem to be very aware of his surroundings. Since he only seemed to give everything a fleeting glance, I was never too sure about what he actually noticed. However, some things received his full attention. Here is one example:

Carter had always been fascinated by music. The act of lying down on the floor under the CD player appeared to be therapeutic for him. As soon as the other children put on their Suzuki Piano/violin CD to play, Carter would drop whatever he was playing with to crawl close to the speaker. He would lie on his belly, then roll over on to his back and just be so alert and pleasant and smiling as he gave his full attention to the music. It was pure joy for me to observe him so transfixed.

Jordan and I realized early that Carter's interactions with us were purely mechanical. He did not smile with us, play with our faces, or enjoy being tickled as a toddler. We seemed to be simply tools that served the purpose of helping him to get whatever he wanted. Jordan once commented that this child "walked over our faces with no concern other than to reach what was above." Carter took our hands and shoved them to where he wanted to reach. He grunted too, but screaming seemed to be what he did more and more. He was almost three years old and still not talking. He did not make eye contact with us.

Then something happened that forced the issue to the front of my mind. Carter's grandma came to visit and within her first day made the observation that Carter would neither return her kisses nor say, "I love you." She asked, "Don't you teach him to give kisses and to say I love you?" Her words stung, but they seemed to describe something basic about Carter. I blinked and quickly decided to shake the thoughts out of my head until later, thinking that, after I put Carter to sleep, I might be able to pull out those troubling thoughts and try to make sense of the whole mystery of Carter.

That night, after Carter had fallen asleep from exhaustion near midnight, but before he awoke at 2:00 a.m. to keep his nightly vigil, chanting, muttering, and singing to himself – I tried to understand what his grandma's words meant. After turning her words over and over in my mind, I determined that she had meant no harm by her observation. Her question was innocent, but it highlighted a nagging question in my own mind that hurt. "Was my son less than perfect?" "Was that true?" I could not bear the thought.

“What if it was true?” “What did all the little idiosyncrasies mean?” “What could I do?” I groaned from the sheer weight of the thoughts in my head.

I remembered the struggles we had getting Carter to sleep. This was a real problem for me. He had stopped taking daytime naps at around one-and-a-half years old, remaining instead in a state of perpetual motion. I put gates up everywhere to protect him from wandering off. Carter only stopped moving when he was strapped into his car seat and then would promptly drift off to sleep as we drove. At the time it seemed to me that he did become tired but could not shut himself down to sleep. Thankfully, the other children slept on schedule.

Carter would drift off to sleep but would jump up and follow me as soon as I left his room. I realized that he didn’t need anything and I made it a point to not visit with him or entertain him during this time as he should have been asleep. He just puttered around in the quiet semi-darkness or would sit watching me fold clothes. When Carter’s eyes grew heavy with sleep, I would put him in his bed. I then retired to mine, only to be awakened about two hours later to the sound of his voice reciting story lines from one of the audio books he had listened to in the car or from a book that he had been read by one of us earlier in the day. His reciting disturbed everyone and so I resigned myself to sleeping in Carter’s room to manage the noise. Jordan needed to sleep as he had to get up to go to work.

I kept thinking about his grandma’s words. Did all children respond to hugs and kisses? Why didn’t my child? I hugged him. His dad hugged him. But he never seemed to notice. We always said, “I love you.” to him, but Carter was always focused on something else and didn’t even seem to care whether we were there. When we interacted with him by initiating a game, or picking him up, or hugging and kissing him, he behaved as though we were interrupting him. What made her suggest that I had not *taught* Carter to say, “I love you?”

I replayed the other children’s infancy years in my head. Theirs’ were very different. Nothing in my experience prepared me for Carter. How do I get help? Carter was an active child who had to be watched closely. Bordering our backyard was a fairly large pond with ducks and turtles that attracted Carter. He had no fear of its dark water. In front of the house was a fairly busy street. He showed no awareness of the danger posed by the traffic or anything else.

Carter climbed with unusual agility. A skinny pole in the basement became his personal toy. Climbing speedily to the ceiling, he would slide down with great glee. No doubt his slight frame gave him an advantage. The first time his siblings saw Carter in action they looked on with consternation on their faces. It was as though they were saying on the one hand; “What a neat trick?” while on the other hand, they were thinking, “Are we even allowed to do this? The thought of climbing that pole had never entered their heads.

Carter ran on his toes and twirled around with that faraway look in his eyes that said to me that we were not even there. He watched videos while seated with us but did not interact with us. He viewed them with different eyes. Carter’s fingers seemed to have something bewitching in them for he would look them over and over and play with them for hours unless someone distracted him.

Interrupting any activity of Carter’s caused him to lose control, screaming as though he were in great pain. Leaving the house was an issue. Only the presence, example and encouraging words of his siblings helped us to get out of the house. Changing the expected order of activities devastated him. The simple matter of going to church provided a challenge. For example, Carter would scream as if in pain when Daddy stopped the car to let us out. We soon realized that he only screamed if Daddy let us out then drove off to park by himself. If Daddy parked first and we all moved together from the vehicle, he was fine.

Life in our home revolved around Carter in a strange way. I was baffled. Something was not normal, but I could not put my finger on it. I was torn between constantly trying to figure out what had caused the latest outburst and trying to narrate our actions and motives to him. The other children were assigned to play with him and to keep him from getting into a corner and flicking his fingers, playing with the lights streaming between his fingers, playing with any object obsessively, so that I could prepare meals or hang clothes to dry outside on the line in the warm sun. The constant effort to keep Carter occupied was a challenge, but what else could I do?

Carter loved to lie on the floor with the truck or train right up to his eyes studying them forever or putting all the toys in a line and lying down with his eyes trained on that line. I did not think then, that there might be a name to it or that there could be help out there for him, or that it could get worse. We all existed from day to day in a world dominated unwittingly by this small child who had come through a trying ordeal in the hospital during his first year of life.

With his grandma's words ringing in my ears, I became intentional about having Carter slow down and take notice of me. When he screamed, I would take his face in my hands, bring it close to mine so that he could look only at me and say to him slowly, "I love you. I want to help you. I am helping you." By and by, I could see that he began to look at me when I told him those words. At first, Carter would not look at me for a full second. He would give just a fleeting glance, but somehow it felt like progress. Not much, but some.

Carter's speech was unintelligible. His immediately older sibling took on the role of Carter's interpreter. But I had heard him sing the words, *Praise Him, Praise Him, Jesus Our Blessed Redeemer* while lying under the CD player. I knew Carter recited words at night when everything was quiet. He repeated words, so why wouldn't he speak to us? I felt that perhaps he needed to have the words and sentences modeled to him. I knew we would have to start very simply.

As Jordan and I talked, he declared that we must be more intentional about first teaching Carter things that were critical for him to know and then things in general. Teaching him became our nightly family activity for a while. We began by teaching Carter his name. Daddy or I would ask each person at the dinner table their name. In turn, they would answer and I would repeat their response in this way, "His name is …." Then it would be Carter's turn. One of us would say his name for him and I would repeat, "My name is Carter."

Next came his address, just in case. The telephone number followed. Then came names of everyday items. We would ask each person at the table the name of an object on the table, starting with the table itself. Each person at the table would say the name of the object in a sentence. Then we would ask Carter the same question, hoping that he would repeat what he heard everyone say. It took a few tries, but the first time Carter responded, we all erupted in applause, hardly daring to believe our ears. At least we knew that he could learn from our teaching and modeling.

Three-year-old Carter

Carter's drooling was a bit disturbing to me as none of my other children drooled, neither did our friends' children who were his age. The Speech-Language Evaluation conducted by Mrs. M. mentions this concern of mine in the background summary saying,

> Carter is a three-year-old male who was followed by Early-On Services until he turned three, because he was a preemie. He was dismissed as age-appropriate. Carter's mother is concerned about drooling and also unintelligible speech."
> In her summary, Mrs. M. states, "Carter did exhibit excess saliva and drool as he played and imitated phrases and words."

I had always given Carter small amounts of a green powder, called Barley Green Powder© and I observed that the Barley Green helped to keep his immune system functioning well. Even though his sleeping was off, I do not recall him getting sick because of little sleep. At some point, a friend of ours, Paul L., introduced us to Ambrotose© powder from Mannatech corporation. I wondered if the Ambrotose© would help with Carter's drooling? I did not know what to expect, but anything good was worth a try. …

Diet was and continues to be a big part of our program. In the early days, I read a lot on the subject and really tried to improve our family's diet. It was time consuming to fix food for the others and then fix something differently for Carter. We were already dairy-free but had been using meat substitutes occasionally. As we became aware of gluten intolerance and its possible effect on autism, we cut down on the meat substitutes since many of them were actually gluten-based. ….

I carried Carter in my arms a lot during this time. Everything spooked him. Pictures of artwork, eyes of random people in photos lining the halls of the church basement terrorized him. Carter could not walk down those halls without screaming. I would cover his eyes and as quickly as possible, I would weave my way through the crowds of people flowing up or down the hall. It was easier to manage Carter's behavior if he was close to me. He lived in his own world for a long time it seemed, until he was almost five years old.

The Occupational Therapist had been coming and checking on Carter until he turned three. This was part of Early-On, a program for children born prematurely or who had spent an extended stay in a Neonatal Intensive Care Unit. She usually checked Carter's reflexes, his muscle tone, his grasp, his language, and his ability to sit and stand among other things and she felt that he was doing quite well.

Carter was now getting close to three years old and screaming even more. We tried pointing to objects, offering him water, milk, food, snacks, or even his favorite toys. Sometimes he would stop screaming to look at our offerings. At other times nothing seemed to help. Perhaps, I thought, if Carter learned sign language, he would be able to say how he was feeling, or what he wanted. I wondered, "Could I request classes in sign language?" One day, in desperation, I asked the Occupational Therapist who was making a regular house call, whether sign language might be an option for helping him to communicate.

The Therapist felt that Carter had a large enough vocabulary of understood words. Despite her confidence that Carter was doing fine, to her credit, she gave me the contact information for the local Intermediate School District (ISD) office and suggested I call for an appointment if I still felt concerned. I am so grateful that she gave me permission to do what I thought was best. With the nagging dread hounding me, I contacted the ISD office to request a sign language class. Instead an appointment for an IEP meeting was made. I was told to take Carter with me.

Carter and I attended the IEP meeting. I had my tote bag of tricks with me. As usual, it was loaded with soft toys. In it was a soft multi-function car which taught fastening a button, fastening with Velcro fasteners, and zipping a zipper. There were flash cards with textured patches on them to imitate the feel or sound of several textures, such as the rabbit's soft fur or the crinkly sound of fire. There was play dough for when the flash cards lost their appeal. My big bag also carried a beautiful three-dimensional animals-of-the-world-puzzle; paper and pencil; crayons and storybooks. These helped occupy the older children.

Figure 1. Soft Multi-Skill Teaching Car

Figure 2. Textured Flash Cards

Figure 3. Spelling Word Puzzle

At the end of our meeting, the staff all commented on how quiet Carter was. How well I was able to sit and field their questions while managing his behavior, and how well he was managed. It felt that these people were really saying something else to me, but I chose to focus on how well he had behaved while in their presence. Of course, it had been a nerve-wracking experience. It required a lot of mental energy for me to focus on their questions while simultaneously monitoring Carter so that he did not lose all control and start screaming. I wanted to hear that he was fine, but I felt that their comments were in fact saying something different.

The staff said that they needed to visit Carter in his natural setting and observe him. After that he would be tested by the speech therapist, then Dad and I would have to fill out a paper and pencil form about our experiences with him. I had concerns about having Carter diagnosed and how that diagnosis would affect his future, but I agreed because I did want to know if indeed my hunch was right and something was wrong, and more importantly, how I could help him. Strangely, I felt increasingly anxious, but at the same time somewhat confident that I was doing the right thing.

The psychologist and the social worker came to our house and asked me to allow them to observe Carter without interference from me. They knew that I had a system of managing him and that with me in charge it would be difficult for them to make an assessment. For my part, I did not know how to do as they asked because I was so accustomed, so attached to managing his environment that I felt that everything would fall apart if I was not allowed to stay, but I did not have a choice in this matter. In order for them to evaluate him, I had to draw back.

Immediately, I could see everything going downhill. Behaviors that I did not allow and some I had never seen before were in full swing. I was chagrined. Carter galloped around on all fours, drooling profusely, and screaming joyfully at the others. The psychologist called Carter’s name, trying to get his attention and to have him sit and interact with her. She got down on the floor with him. He was oblivious to her efforts.

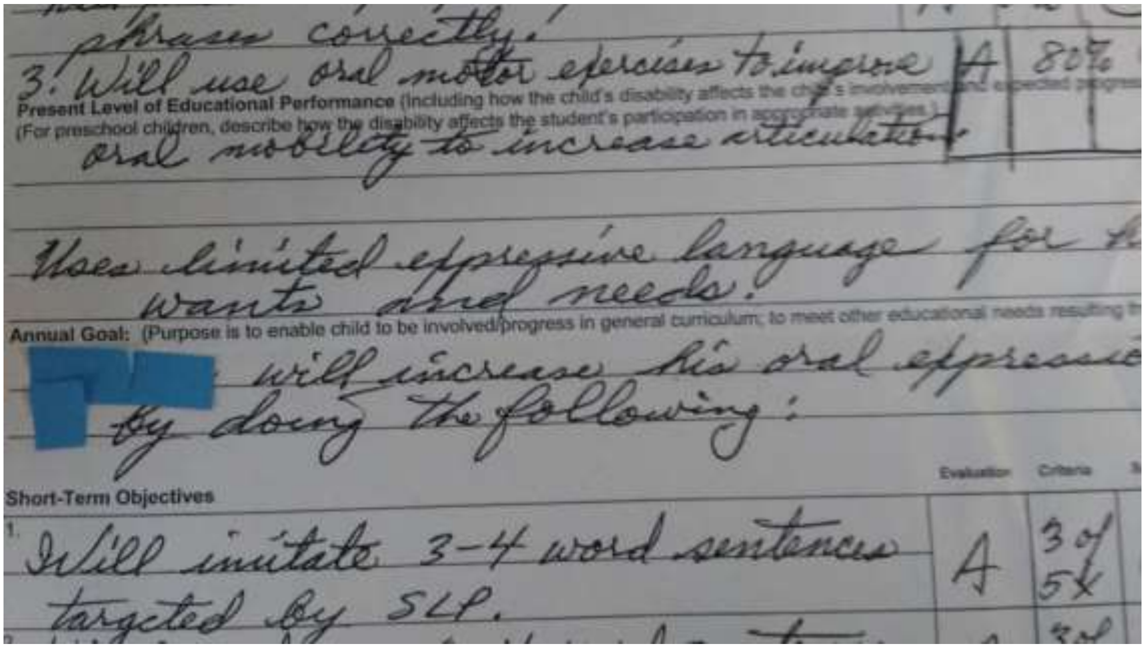
She put out a piece of paper and enticed him with a crayon to join her. She said to Carter, “Draw a face.” He stopped and looked at her blankly.

She drew a circle on the sheet of paper and drew in a mouth. She said, “Draw the eyes on this face.” The word “eyes” triggered in Carter’s mind a memory of a line from a book that we had read from our local library. Instead of drawing, he repeated the favorite line from the book in a monotone, “She made cookies for the eyes, a carrot for the nose and a great big banana for the smile.”

The psychologist had no idea what those words signified, since they were uttered out of context. But compared to Carter’s speech a few months earlier, they signified a great measure of progress to me. In a way, I had seen God answering a prayer of mine by giving him words. During that time his behavior began to improve also. Over the next few months, he changed a lot. He memorized everything he was taught to memorize. It was just that his words were pointless. He did not use words for any purpose.

Watching Carter with the psychologist, I felt helpless and so sad for him. He still did not play with others. He still did not make eye contact. I made a mental note to myself to add that to my prayer. Yes, he needed to play with others, to make eye contact, and to have words and use them intelligently, and to follow directions. The social worker tried to start a conversation with me, I guessed, possibly to distract me, but I could not focus. I felt keenly that it was all so hopeless. I loved each of my children and this particular child needed help and I could not help him.

The Speech Therapist tested Carter in her office. From the test, she figured out that he knew the names of several items around the house; could count to twenty and knew the alphabet in English, Spanish, and French; and had memorized poems that his older siblings had been learning for homeschool. However, he did not speak in sentences. He did not use the words that he knew for any purpose. He pointed for whatever he wanted, and he moved constantly. The following excerpt from an IEP meeting shows that initial tests found Carter to use limited expressive language for his wants and needs:



phrases correctly.

3. Will use oral motor exercises to improve oral mobility to increase articulation. A 80%

Present Level of Educational Performance (Including how the child's disability affects the child's involvement and expected progr

(For preschool children, describe how the disability affects the student's participation in appropriate activities.)

Uses limited expressive language for wants and needs.

Annual Goal: (Purpose is to enable child to be involved/progress in general curriculum; to meet other educational needs resulting fr

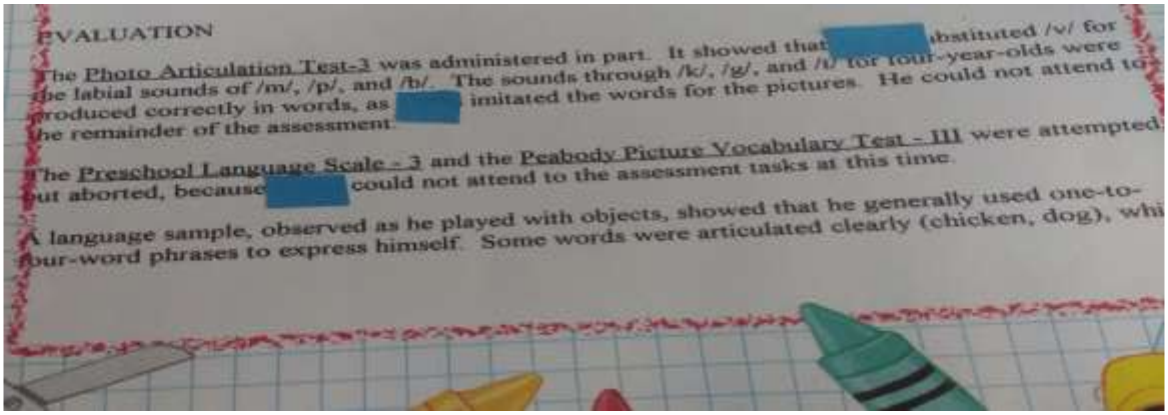
[redacted] will increase his oral expressio by doing the following:

Short-Term Objectives

	Evaluation	Criteria
1. Will imitate 3-4 word sentences targeted by SLP.	A	3 of 5x

Figure 4. Excerpt from Carter’s Individualized Educational Plan (IEP) Progress Report dated 1/16/04

In addition, Carter’s long stay in the hospital being fed by tubes had its own effect. He did not produce initial and medial sounds, such as ‘mm,’ ‘b,’ ‘d,’ ‘p,’ ‘t’ and ‘v’ as indicated in the excerpt below from his Speech-Language Evaluation.



EVALUATION

The Photo Articulation Test-3 was administered in part. It showed that [redacted]bstituted /v/ for the labial sounds of /m/, /p/, and /b/. The sounds through /k/, /g/, and /t/ for four-year-olds were produced correctly in words, as [redacted] imitated the words for the pictures. He could not attend to the remainder of the assessment.

The Preschool Language Scale - 3 and the Peabody Picture Vocabulary Test - III were attempted, but aborted, because [redacted] could not attend to the assessment tasks at this time.

A language sample, observed as he played with objects, showed that he generally used one-to-four-word phrases to express himself. Some words were articulated clearly (chicken, dog), whi

Figure 5. Excerpt from Carter’s Initial Speech-Language Evaluation

He drooled copiously because the muscles around his lips were weak from his not sucking enough. The funny thing about Carter was that he was very observant about some things. He needed to wear a bib to help keep his clothes dry from the drooling, however, after he turned two or thereabouts, he objected to the bib very strongly. It was my observation that he wanted to fit in with his siblings and since they were not wearing bibs, he refused to have one placed on him. I resorted to carrying an extra shirt and keeping a cloth diaper handy to mop up with.

One evening shortly after the psychologist’s visit, my husband and I completed some worksheets in the social worker’s office. I had a strong feeling that the consensus was pointing toward autism based on what I had been reading in the literature, but I just knew that it couldn’t possibly be so. Carter was smart. I knew that he knew a lot of things. Although by now I had read a bit about autism and its symptoms, I tried to convince myself that he did not have it. Or did he? In the nights when it was quiet, I would lay awake and argue with myself about why he acted the way he did.

"Could he possibly be a late bloomer?" "But how do I account for the screaming?" The ISD called and asked me to come in for a meeting once all the relevant testing had been done. They were all very pleasant, but the evidence was irrefutable- We were dealing with autism. In addition, he had scored so low on the IQ test that he was considered uneducable.

"But he does know words", I countered.

"Whatever talking he does amounts to parroting. His speech consists of words he has heard others say. The talking late at night, that is called echolalia." this comment came from the psychologist.

"But he memorizes poetry." I said.

"Yes, he memorizes poetry, but he cannot respond to simple questions like what is his name. He does not engage in any form of play. He is not even showing parallel play. He is almost four. Children of this age are making friends and showing interest in others and what they are doing. What we are seeing here are the classical signs of autism." The psychologist reminded me.

The Director of Special Education said, "There is a lot of work to be done, but it will be tackled in small amounts. We will set small goals and we will meet at the end of --------- to assess the progress. There is a school for children with these challenges. We recommend this school as the best placement for your son."

I felt numb, but managed to nod my head to acknowledge what had been said. Before I rose to leave, I asked if I could visit the recommended school before making a decision and was encouraged to do so. Walking out to the parking lot I felt like I was walking in a dream. I buckled Carter in and reminded the other children to do the same. It was back to the familiar routine, but so much had changed in that short space of time since I walked into the office. There was no going back, and no time to prepare for the future.

They loaned me a book from the department. I tried to read it through objectively, but every page seemed to describe my son. In the book, a woman named Laura Wing of the UK, an authority on autism, discussed many challenges these children face. To my mind each symptom she described signaled a call to battle. I simply could not accept that my son had a diagnosis of autism. I worked even more feverishly with him at home trying to reach the developmental milestones for his age. I probably was in denial.

My visit to the recommended school was heartbreaking. Under normal conditions, I would have been impressed by the work the teachers and aides were doing. As a classroom teacher, I would have great appreciation for their contribution to the lives of these children. On this visit, however, I was looking with an eye toward what my own child would be doing when he is there all day. How would this school help him to function in the society outside of the classroom?

The teachers were fine, but as I saw them work with the other children, I thought of how much Carter copies his older siblings. I envisioned him coming home copying the behaviors of the students in his room and I shuddered. Some of them sat on the floor and rocked all the time, it seemed. Some wore weighted shirts. A couple of them had adult helpers holding them all the time as they screamed or were disruptive. I was distraught. Is this all there was to look forward to? I cried on the inside.

On my second day observing there, the teacher to whose room he had been assigned said to me, “Your boy is doing so well at home; you need to keep working with him. Look at him. He is mellow and calm. He already knows much more than these children. Being here will slow him down.”

That was precisely what I had been thinking, but had not found the words to express. Immediately an idea formulated in my mind. What was needed was language of a certain level. Perhaps if a number of persons could help me provide Carter with purposeful speech, it might make a difference. But paying students to play with him was out of the question. I had read of a parent doing so in another book. If I was going to pay, perhaps the piano teacher who was already being paid to teach the older children might provide more of the help I envisioned.

I felt this thought emerge - Instruction was needed that would grip Carter’s attention and lead him to action – that would enable him to participate in society on all levels. That was it. I did not want a repeat of his performance with the psychologist. Language has a purpose and Carter just did not seem to get it. He needed to understand when he is spoken to. I was convinced that Carter must learn to use language appropriately, to respond to others, and to initiate conversation.

I approached the piano teacher and asked her whether she minded being part of an exercise that may or may not bear musical fruit. She agreed. I asked the violin teacher the same question. Carter’s team grew to include the Piano Teacher, Violin Teacher, Gymnastics Coach, the Swimming Instructor, and the Speech Therapist with whom he was already working. When he was not attending one of the classes, he was being taught at home. I taught each older child a violin lesson and a piano lesson every day. I also taught them Reading, Spelling, Math, and English at the beginning and added other subjects as they got older. Carter was taught Reading.

We visited the Speech Therapist each Thursday. Carter soon was able to read small books with her help. He did sequencing and matching exercises on paper, and practiced sounds using flashcards among other exercises.

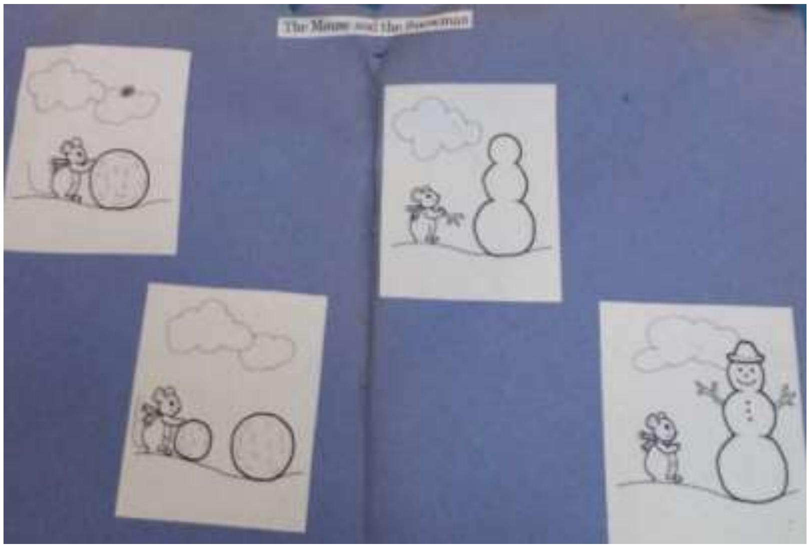


Figure 6. A Sequencing Exercise

Figure 7. A Matching Exercise

Figure 8. Flashcards for identifying initial, medial, and final letter sounds

Figure 9. Touch and Feel Flashcards

Carter was encouraged to exercise the weak muscles around his mouth by blowing a feather across the table, blowing soap bubbles, pulling air up a straw, and using a straw to blow on objects. Each day of the week we worked with a different teacher starting with twenty minutes per session and progressing to about half an hour, then, much later, such as during fourth-grade, increasing it to forty-five minutes per lesson. Our beginning schedule included swimming and gymnastics on Mondays and Wednesdays, music on Tuesdays, etc. No promises were made regarding outcomes.

Books on autism loaned to me from the ISD office taught that autism is characterized by communication difficulties, impairments in social relating, and by rigidity in interests and activities, with onset occurring before age three (American Psychiatric Association, 2000). Faulty executive management was mentioned as a critical factor. This spectrum disorder impacts each individual differently.

Going to the supermarket was a challenge. As soon as we got inside, Carter would propel me to the banana stand. Taking my hand, he would push it to the bananas, intending for me to get him one. I had learned from experience that he would lose all self-control if I tried to do otherwise. Paying the cashier right away for a single banana meant that Carter could eat it immediately. Once he was eating the banana, he became happy and relaxed and grocery shopping became possible.

The library, our second home, was a venue of possible embarrassment, but I had learned how to manage him there as well. Carter would come alive at the library door hurrying me to the section with the DVDs. He would put my hands on the DVD of his choice and if I pretended not to notice or if I made a mistake and put my hand on another DVD, he would fold over as if in excruciating pain and scream all the while holding onto my hand. Luckily for us the local library carried the DVDs he wanted. These were Baby Einstein, Baby Mozart, Baby Bach, Baby Beethoven, and P.B. Bear. This was not a problem at all since our entire family enjoyed these delightful videos. We were just fascinated by Carter's obsession. He was not pampered nor was he manipulating, but it seemed there was something inside of him that made him do this. What was it?

Was Carter addicted to the Baby Einstein videos? He demanded (screamed) to see them constantly. He could not get enough of them. It was the thing of the time. Whenever someone put the video in for him, he would sit with rapt attention; but at those times, it was as though only part of him was engaged, because somewhere inside his eyes had a look as though he was not really focusing on the screen but was actually somewhere else. Later, it dawned on me that it was the music. The music was really captivating him. He would rock himself and he would twirl his hands, for hours if given the chance, even falling asleep under the trance of the music.

I kept Carter’s fingers occupied with putty dough, play dough, picture cards, vocabulary cards, small soft toys, paper and pencil activities, and small books. Some of these sat in my ever-ready tote bag and I relied on them to get me through visits to the doctors for the older children, any office waits, or driving long distances. The book by Laura Wing in describing the symptoms of autism, said that children with autism rocked themselves or twiddled their fingers, playing with the light. I immediately thought of my son. Could that, really be it? Right away, I told myself that I should find a way to stop Carter from playing with his fingers. In the process of thinking about possible options, I eliminated some ideas as hopeless. Putting mittens on his hands did not seem practical. That could be a form of torture or a form of pleasure. They would have to be a certain texture for Carter to tolerate them or he would not have it...velvet, velour, or soft knits. The mittens may defeat their purpose by causing him to pay more attention to his hands than before.

Carter loved to stroke certain fabrics, touch others, run his fingers over them, and touch his face with them over and over in a tireless manner as though he was committing them to memory. Then again, I could imagine him looking at me in that disappointed way, with his little head slightly tilted to one side, as if he had expected better of me and was somehow ashamed of my behavior, as if asking me why I was doing this to him. No, telling Carter to be still would not work. I have had to hold him to me or sit and rock him. Simply telling him to sit still in church did not work.

Several years later sitting quietly for a bit, I recalled how Carter displayed an uncanny feel for music. I remembered how one night, years earlier, when he was about four and a half, and his siblings were asleep, my husband and I were trying to get him to sleep that he walked over, touched the piano keys and began feeling around – touching them hesitantly. As we watched, his fingers quickly found the notes and played a song, *"Jesus Loves Me This I know*" with two hands. Then he played another song, and another. It sounded familiar. "Oh, it must be a piece from the Baby Bach DVD." We looked at each other in disbelief. Carter was playing with two hands and harmonizing. What else did he know? What else could he do? It was too much for us to digest. We could not speak of this until he fell asleep.

It was funny that people complimented me on the fact that Carter did not disturb the church service with crying or walking up and down like other children his age. What they did not know was that the only reason they did not hear him, was because he fell asleep as soon as I sat down and put him on my lap with my arms around him. That Carter slept right through to the closing hymn without fail each week was to be expected in a way, because of his sleeping pattern. He hardly slept during the nights and kept moving all day. He fell asleep when he was held immobile, such as in his car seat, in his stroller, or being carried in my arms.

I decided to focus on the outcomes that I felt would most enable him to become a contributing member of society. One such outcome was that Carter should use his hands in a constructive way. But how could he learn to use his hands meaningfully? I gave him pencils and paper and encouraged him to use them. There was no time to instruct him in the proper way to hold a pencil. He looked at his teachers, his siblings. He made marks and scratches on the paper. What else could I find to occupy his hands? Every time I dashed into T.J. Maxx® (simply because it was close by), it was to look for whatever new manipulative toy I could find.

From these short forays, I armed myself with crayons, play dough, soft putty, flash cards, picture cards, soft books, and small soft toys. My bag of supplies was always ready. It became an obsession with me to keep Carter's hands occupied so that he did not flap them or wiggle them in the air over his head. A wooden train set, Kiddie computer, Lego game set with table, map of the world puzzle, spelling word puzzles, helped to keep him engaged in the present. He was given more electronic equipment than the older children simply because he needed them to keep him occupied.

I felt deep inside of me that Carter had some form of language, but finding it was taking so long, and everything else seemed to trigger the dreaded screaming. It was a relief to start work with Mrs. M____, the speech therapist. She showed genuine interest in my son and treated him with such respect. Going to Mrs. M's room was anticipated with pleasure. He smelled each book, touched everything, raced from one object to another with glee while we named them for him. Then the Speech Therapist would ask Carter to sit. He would sit and she would show him cards on a flip chart asking him to name the pictures.

By now Carter had grown to the place where he was ready to work with her. Mrs. M called the name of the object and he had to point to it correctly. Then he was asked to find the picture that matched the one shown. These activities that she used with him were particularly interesting to me for they showed me where I needed to focus my teaching.

Carter's siblings accompanied us to these sessions and were often included in the therapy as they were invited to encourage him to respond. A question would be asked of them and after they each answered, the same question would then be directed to Carter. A correct response was rewarded with applause and smiles. He always enjoyed doing whatever his siblings did. We had been doing this very activity with our family at home. These sessions proved to be helpful to Carter and the siblings thought it was great fun. They enjoyed participating and being leaders and Carter began to pay more attention to our words and actually began to use words to name objects at home. I prayed constantly for God to give him intelligent speech.

Decision for Kindergarten

Going for a walk with Carter was fine if he was in his stroller. Having him walk on the road was a nightmare. He wanted to walk freely like the older children he was looking at, but unlike those children, he was oblivious to the presence of the motorists and even the vehicles on the road. I would have to take hold of one of his hands and inevitably have a wrestling match with him to keep that hand in mine. It was so much easier to carry him up in my arms against my chest or in his stroller. He would have to learn to walk on the street and, later on, how to cross it. Aware that I could not fight every battle at once, I did whatever was convenient for the occasion.

There was a lot to deal with. His obvious lack of speech, limited vocabulary, his lack of awareness of himself, of his personal space, and of traffic when walking on the side of the road. We had to be deliberate about teaching Carter that the roads were for vehicles as well as for people, that he needed to be alert to danger, that he needed to eat with utensils, and so much more. I had read somewhere that there was a small window of time within which to work before his brain would lose its plasticity at around age seven. This drove me to conquer as much as was possible knowing that in a few short years he would be seven. In that case, he needed to learn how to make friends and how to be a friend.

Always taking stock of Carter's progress, I reasoned that maybe a regular classroom might be the place to immerse him in social life. We discussed it on the IEP team. They were pleased with Carter's progress so far. The I.E.P. team agreed that his vocabulary had increased to the place where he could attend regular school if I so wanted. They informed me that Carter would be able to have therapy sessions with the social worker as part of a small group while in school, and keep his appointments with the speech therapist as he could be taken out of class.

I had been trusted to read several textbooks and had done so. The speech therapist loaned me several children's story books which I read to Carter. In fact, each week she allowed him to select a book that he liked and we took them home, read them, and brought them back the following week. She was aware of my working with him with the flash cards, play dough, and other things.

I decided to take the plunge and put him in school. I reasoned that if it did not work, Carter could be withdrawn. Should we keep him from trying school, we would probably never know what could have been accomplished. He turned five that summer. I registered him with some trepidation when I thought of the very real challenge this would be for Carter. However, having experienced working with the I.E.P. team, I could not help but feeling a little more assured that I was doing the right thing. These people were my strong allies. They shared my excitement about Carter's every victory. Each small achievement of his was a cause for celebration. The classroom experience should not be that far off the mark, but still I did not want him stigmatized, bullied, or made to regress.

Thanks be to our All-wise God who is always at work even when we don't see it, or have forgotten what we prayed. When asked if I had a preference for a Kindergarten teacher, I quickly said, "Mrs. V____". One of my friends had recommended her to me as an experienced, but fair teacher. She was very supportive and understood that there may be some challenges. She welcomed my precious Carter and me into her classroom. This was just fine because if Carter was going to be there, so was I. No, I did not attend class the whole time. I volunteered to assist the teacher for the first two weeks of class but I ended up being there all that year. I stayed around long enough each morning to make sure that Carter was making a smooth transition into his school day.

Every morning when the kindergartners came in, they went to a wall chart and put something there to indicate that they were present. Just seeing that many children was overwhelming for Carter. Putting his backpack into his locker, finding his table, and looking for the instructions for the day were unbelievably stressful. By the time I gently nudged him through the routine, he invariably forgot about the wall chart. Carter moved like he was in a daze.

I tried to be alert and on the lookout for situations that might cause Carter to have a meltdown. Emotionally, he was very fragile. He could become overwhelmed in an instant and cry uncontrollably. I tried to anticipate triggers and to step in to calm him. I still do. I am always on alert concerning what is going on in his environment, gauging whether it is safe to leave him and go on to other duties. With Carter in this new situation, it was important for him to feel safe and in control of himself. Having a meltdown in front of a roomful of strangers would cause him to feel self-conscious and embarrassed. I also did not want the teacher to have to manage him and a meltdown in addition to a classroom of kindergartners.

I did so want for this experience to be successful for Carter as well as for the teacher. A negative experience could well influence the school or the teacher's willingness to accept another student like him. I also felt that a successful Kindergarten year could determine his attitude to school. Being conscious of these things, I reminded him nightly of things that he needed to attend to like the attendance chart. I reviewed homework with him and worked on his Speech and IEP goals. Every night as I put Carter to sleep, I would pray for him, then I would repeat what he was going to do the following day, but I would say it in the first person as if I were, he. Carter has always needed to know in advance what was going to take place.

Around the time that Carter started Kindergarten, I made a good friend in a young woman who also had a son with autism. We shared our experiences with each other, commiserated at times, then smiled at other times. Her son was a very picky eater with a list of twenty or so items that he would eat, but I only remember that it seemed as though he lived on peanut butter and bread. There was no deviation. He liked to play with my children and sometimes came over for a play date. It did not matter how long he stayed at our house, how hungry he became, or what food we offered him, he would not eat. His parties were very simple to organize since he could not tolerate more than two friends at a time. My two children were honored to have been his party guests for a few birthdays. They got along just fine. They played individually since that was what he did.

This young mother and I shared information we had read in books, gleaned from articles or from the therapist. As she saw me go for help and heard me share how respectful and helpful and resourceful the IEP team was, she began to think that maybe she could get help for her son, as well. She had tried to obtain support before in another state and found them ill-informed, judgmental, and quick to stereotype. An RN, she was very informed about Autism and its challenges and handled all her son’s needs but was sensing that he was very smart and that he not only would need to be challenged academically, but that he needed to form relationships with other children.

I encouraged her to go in to the Special Education Department and have him assessed. She came back very favorably impressed with their knowledge and their openness and the fact that they were interested to hear what she had to say. They, on the other hand, were impressed by her thorough knowledge of the disability, and how clearly, she articulated her son’s needs. She did place her son in school and quickly realized that she could trust the staff to provide her boy with good support. Later on, it was her turn to encourage me to place my boy in school.

Carter and Music

Carter continually amazed us by playing the piano pieces his older siblings were practicing. We knew that he was auditorily keen, but we did not want to push him into anything that he could not handle, particularly since he was not yet speaking. We knew that he could learn, but we did not know whether he could follow the directions of the teacher, and whether he could satisfy the demands of the teacher. We felt that frustrating the teacher could be a real possibility. As time passed and he made small steps towards being verbal, I became more hopeful, and began to wonder what part his music could play in his progress. When he began picking up his siblings' instruments, touching the strings, listening to their individual sounds, I made a decision to push on and see what was possible.

A Few Years Later

There were many wet eyes in the auditorium the day that Carter spoke, mostly those of people who remembered his early days. Others who had not known about his early start on life, said that hearing him share it really helped them get the concept of service which he had chosen as his topic. His speech was one of several speeches that day. It was not a long delivery, but to our family and to our friends it was momentous. I experienced a mixture of emotions as I watched him deliver his speech. I was super happy for him. I was so proud of his accomplishment. Yet I was sad, in a way, because this signaled to me the end of an era of life with this child.

At the same time, I felt relief for I sensed that he was on his way and that the efforts made to help him overcome his challenges would not go unrewarded. My heart felt so full of immense gratitude for the many people who have intentionally or unintentionally provided opportunities for him to develop and explore avenues of growth, such as presenting the speech. Today, Carter no longer screams. He does not play with his fingers over his head. He holds the gaze of whomever he is conversing articulately with.

In fact, he tested out of the Special Education program a few years ago, not needing any services at that time based on the progress he had made in every area. Since autism is lifelong, we were told that should we feel it necessary, we could bring him back later for further evaluation. Carter is friendly; always looking out for the interests of others, especially the unpopular. He is a youth leader-in-training, a great communicator, and a motivated student making the honor roll in high school and managing college assignments as an early college student. I feel humbled that I have been allowed to have a small part in the development of this remarkable young man.

Key Themes from Meghan’s Narrative

The key themes from Meghan’s Narrative share the Learning Activities which emerged as being helpful to Carter. These are Speech-Language Evaluation and Therapy, Modeling and Carter, Music and Carter, Academic Activities and Videos, and Work with Instructors and Teachers. A short description of each theme is given here. These themes will be addressed further in Chapter 6.

Speech-Language Evaluation and Therapy

Working with the Speech Therapist was a major theme emerging from Meghan’s Narrative. Because Carter had been fed by tubes during his long hospital stay the muscles around his mouth were weak and this affected his ability to produce initial and medial sounds. The Speech Therapist targeted this and several other areas to focus attention on. She encouraged him to exercise the weak muscles. She provided him with several exercises. For example, the muscles around his mouth were strengthened by blowing a feather across the table, blowing soap bubbles, pulling air up a straw, and using a straw to blow on objects. Working with the speech therapist also yielded definitely positive results. Carter made progress in producing the sounds that were targeted. He made progress with speaking in sentences, in pronouncing words, and in reading.

Modeling and Carter

Meghan said,

I felt that he had to have the words and sentences modeled to him.

She said,

Teaching Carter became our nightly family activity for a while. We began by teaching Carter his name. Daddy or I would ask each person at the dinner table their name. In turn they would answer and I would repeat their response in this way, ‘His name is …’ Then it would be Carter’s turn. One of us would say his name for him and I would repeat, ‘My name is Carter.’

She continued,

Next came names of everyday items. We asked each person at the table the name of an object on the table, starting with the table itself.

Each person at the table would say the name of the object in a sentence. Then we would ask Carter the question, hoping that he would repeat what he heard everyone say. It took a while, but the first time Carter responded, we all erupted in applause, hardly daring to believe our ears. At last we knew that he could learn from our teaching.

Music and Carter

Carter was fascinated by music. As soon as the other children put on their Suzuki music to play, Carter would drop whatever he was playing with to crawl close to the speaker. He would lie on his back, roll over on to his belly and just be so alert and pleasant and smiling. It was pure joy for me to observe him so transfixed.

I heard him sing, Praise Him, Praise Him, Jesus Our Blessed Redeemer while lying under the CD player.

Whenever someone put the video in for him, he would sit with rapt attention; but at those times, it was as though only part of him was engaged, because somewhere inside his eyes had a look as though he was not really focusing on the screen but was actually somewhere else. Later, it dawned on me that it was the music. The music was really captivating him. He would rock himself and he would twirl his hands, occupying himself for hours if left alone, even falling asleep under the trance of the music.

One night, when he was about two and a half, and his siblings were asleep, Jordan and I were trying to get him to sleep when he walked over, touched the piano keys and began feeling around – touching them hesitantly. As we watched, his fingers quickly found the notes and played a song, *‘Jesus Loves Me This I know*’ from his kindergarten Sunday School room with two hands.

Then he played another song, and another. His dad drew closer and asked him to play *Lift up the Trumpet.* Carter complied. Daddy requested that he play *Redeemed, How I Love to Proclaim It*, then *Praise Him, Praise Him, Jesus Our*

> *Blessed Redeemer*. Those requests were granted. Carter was playing with two hands and harmonizing. Then Carter played an unsolicited piece – a classical piece. It sounded familiar. 'Oh, it must be a piece from the Baby Bach DVD' I said.

Academic Activities and Videos.

Meghan kept soft toys, flash cards with textured patches on them to imitate the feel of the rabbit's soft fur or the crackly sound of fire, for example; play dough for when the flash cards lost their appeal, a beautiful 3-D animal-of-the-world-puzzle; paper and pencil, crayons and storybooks, picture cards, and vocabulary cards in a large tote bag and used them to keep Carter occupied and to prevent him from twiddling his fingers. These manipulatives were a helpful resource to get Meghan through visits to the doctor with the older children, any office waits, sitting in the car, or riding long distances. Spelling word puzzles and games were added as we went along. Carter not only stopped twiddling his fingers through the use of these manipulatives, but he also learnt a lot of educational material from these academic activities.

Commenting on their visits to the local library, Meghan said,

> The library was another venue of possible embarrassment, but I had learned that I could manage him there. It was our almost-second home. My children owned library cards at an early age. Carter would come alive at the library door hurrying me to the section with the DVDs. He would put my hands on the DVD of his choice and if I pretended not to notice or if I made a mistake and put my hand on another DVD, he would fold over as if in excruciating pain and scream all the while holding onto my hand.
>
> Luckily for us the library carried the DVDs he wanted. These were Baby Einstein, Baby Mozart, Baby Bach, Baby Beethoven, and P.B. Bear. This was not a problem at all since our entire family enjoyed the videos. We were just intrigued by Carter's obsession. He demanded to see them constantly. He could not get enough of them. It was the thing of the time. Whenever someone put the video in for him, he would sit with rapt attention; at those times, it was as though only part of him was engaged. Somewhere inside his eyes had a look as though he was not really focusing on the screen but was actually somewhere else."

Work with Instructors and Teachers

Carter was fortunate to have instructors for swimming and gymnastics. These were the same instructors his siblings had. The instructors gave him instructions that had been proven to be successful with other students. These instructions were verbal and had tangible results. Carter was able to experience the force/energy/transforming power of words. Their instructions caused him to pay attention more and more to the words as he realized that the words were creating a reality for him. If he followed the swimming instructions, he was able to swim to the rope and back, or he was able to touch the bottom of the pool. In addition, he was able to watch his swimming requirements being checked off the sheet and learn that he was promoted to the next level. This helped him to feel more in control of his results.

Working with teachers on academic subjects was challenging requiring a different degree of focus. It proved to be very stressful for Carter to follow multiple step directions. This proved to be frustrating for him. More than once Carter had to step away from the class and regroup. Even doing homeschool on line through the Virtual program became too demanding and stressful and had to be stopped after one semester. However, he enjoyed learning facts and became a really conscientious student. One day a teacher explained to Carter how to compute his G.P.A. That has been a most useful tool for him.

CHAPTER 5

FINDINGS FROM MEGHAN’S NARRATIVE AND INTERVIEWS

Introduction

Chapter 5 presents a thematic analysis of data collected through focus group interviews with Carter’s siblings, all members of his family, and an interview of his parents. Three persons who participated in some way during Carter’s experiences –a school psychologist, a teacher, and a therapist – were also interviewed individually on their recollections of his journey. Finally, Carter himself was interviewed. An interview with Carter’s grandma was desired, but impossible as she had developed major memory loss by this time. A semi-structured interview protocol was followed to allow the participants the opportunity to share their memories of the process and to provide an in-depth view of the methods used to help Carter. Interviews were conducted in the months of October and November of 2016 and January of 2017.

The interviews took place with the School Psychologist in the board room at her office; the Speech Therapist in her office, and the Piano Teacher at her studio. The family focus group interview and Carter’s individual interview were conducted in the event room downstairs in Bell Hall, Andrews University – Room 018. Carter’s siblings were interviewed in the cafeteria. The only persons present at these efforts to collect data were the interviewer and the interviewees. These venues provided privacy and freedom from distractions.

Chapter 4 documented Carter’s journey. First, there was the description of Carter’s symptoms of autism in the words of the Psychologist, the Speech Therapist, and Carter himself. Next, Carter’s progress was documented. Third, Carter’s Developmental Support Team of parents, siblings, Therapist, and teachers was presented. Next, educational and social interventions used to advance Carter’s Development which emerged from the analysis of the data were grouped under content and processes. Carter’s desire to progress and some of the ways he indicated this followed, and ended with a summary.

Carter’s Symptoms and Diagnosis of Autism

The School Psychologist shared that she actually remembered visiting Carter in his home and noting the classic autism symptoms that he displayed.

Psychologist:

> I first met Carter when he was three. He had been referred for a Special Education Evaluation due to the behaviors he was exhibiting. I would say at that point in time; he was exhibiting “quote, unquote,” Classic autistic child; where he had a lot of those sensory issues, a lot of the language deficits, the behavior-social deficits that made it difficult for him to interact and communicate his needs and wants to other people.
>
> My earliest memories of him were actually what I like to bring up as one of those good success stories. I remember coming to his home, and like I said earlier in the interview, some very classic symptoms, a lot of the chortling going on; a lot of the sniffing, oral-motor, licking, tasting, kinds of things going on and he did not want to talk. He did not want to communicate. He did not want to look at me. It was interesting to watch him because you could tell his mind was working, but you just could not reach into that mind at that point in time. (Psych I)

Because of the diagnosis arrived at as a result of the assessment, Carter was able to receive Speech Therapy. The Speech Therapist interviewed for this study was the second therapist to work with Carter. She had worked with Carter for at least two years and had signed him out of the speech program. She said:

> So, for Carter, the worst part for him was the socialization issue and understanding humor and analogies…In Carter's case, a child with autism, they are very literal and they need visual [cues]. They are very regimented in certain things.

The therapist also noted that certain muscles around Carter's lips were weak and needed to be strengthened. Because of that weakness, Carter had difficulty producing certain sounds like the initial sounds of words beginning with /m/, /b/, /d/, /n/, /p/. He also had difficulty with certain medial as well as final sounds. In his interview, Carter was asked the following question

Q:

> What, if anything, do you remember about your behavior when you were young? It doesn't have to be as far back as you can remember.

Carter:

> I used to think very literally about things like, for example if someone was to talk to me to dialog with me with a figurative expression I would answer literally. They would say, "Hit the road, Jack and never come back." And I would say, "But I'm not Jack. Who is Jack?" I would think that way.

As a result, the Speech Therapist had Carter do many exercises identifying analogies, and figurative speech which proved to be helpful.

Carter's Progress is Documented

This interview is different because it involves the subject of the study. The young man, Carter, shared his recollections on his experience growing up in the Carter Interview. He talks about his literal thinking and his inability to maintain eye contact and activities that helped him overcome.

Q:

> What, if anything, do you remember about your behavior when you were young? It doesn't have to be as far back as you can remember.

Carter:

I used to think very literally about things like, for example if someone was to talk to me to dialog with me with a figurative expression I would answer literally. They would say, “Hit the road, Jack and never come back.” And I would say, “But I’m not Jack. Who is Jack?” I would think that way.

Q:

How did that change over time and what do you think helped that change?

Carter:

I think I was enrolled in a Speech Therapy Class. I think this was when I was in Kindergarten. Yeah. Through the public schools. I can’t remember exactly where. I think I. ...yeah, I was in ___ Elementary. And I went to Kindergarten and then I left and then I came back in Second Grade. My mother had me learn all of these speech expressions, figurative expressions from this book then I had to answer questions correctly. That really helped to get me out of thinking of everything too literally.

Q:

What would you say were your greatest challenges growing up?

Carter:

I guess expressing myself. Because I think there was a time, I don’t remember everything, but my brothers tell me; when I wasn’t speaking, and then they were praying that I would be able to speak and then I guess that I started talking. But then I was talking a lot of gibberish I wasn’t saying, how do you say, I wasn’t saying, I wasn’t speaking inappropriately, but my thoughts were not well put together.

Q:

So, it was real words, but it was kind of jumbled.

Carter:

“Yeah, it was confused. After a while I began to think more clearly and express myself in a way that other people would understand.

Q:

“I remember the first time I met you. I don’t know if you remember the first time you met me. It was just outside here in the hallway and you had your head

> down. Your mother told you to say, “Hello”, greet Dr. B. And so, you said hello. And then she told you to shake my hand and to look me in the eye,

Carter:

> “Oh Yeah! And that was another thing when I would greet people, I would look at the ground because I don’t know, I don’t know. Maybe it was being scared. That was another thing that I had to do; Look people in the eye when you’re speaking to them.

Q:

> “Do you know what helped you get to the place where you could, look we’re maintaining eye contact? You seem to be pretty comfortable with it. You know what helped you move along that pathway to get to this place? You have any ideas?

Carter:

> “I’m not sure. I guess pressure from my mother – “look me in the eye; look people in the eye, look people in the eye.” And then you go to school and the teachers are; “why do you have your head down? There is nothing to be ashamed of. You’re not in trouble. Look me in the eye”. (CI)

While Carter was too young to be aware of everything he experienced, he was able to respond to direct questions from the interviewer about some changes he experienced and what methods were helpful.

Carter’s parents and siblings responded to questions about their experiences with Carter in the Family Focus Group Interview.

Meghan:

> One day the music teacher told Carter when playing, ‘Put your eye on the ___.’ Immediately I knew that was not the thing to say. She was shocked and she apologized and apologized because he literally put his eyeball on the ___. She said she has never had anybody do that before and she apologized some more.

Kayden:

> In the beginning, he wasn’t able to maintain eye contact with other people. He would look away or he wouldn’t respond, or he would always mumble; now he’s very comfortable with all kinds of people. He can hold really intelligent conversations with all kinds of people. So, I feel that the progression from not

> being able to talk to people to now being able to completely hold conversations with people that at first, he'd be very awkward with and not even want to talk to, is something that just shows growth. (FFGI)

The Speech Therapist, speaking from her experience with Carter said:

> "So, we constantly, by the time we finished telling him, he was much better at looking at the person when he was talking opposed to looking away or looking down.
>
> Q:
>
> Describe, well you haven't seen him for a while, but from the time you began to the time you stopped working with him, what improvements did you see?
>
> Sp. Th:
>
> Oh huge. The improvements, and I was an integral part, but a small part (STI).

The School Psychologist responds to this question:

> Q: Th:
>
> "How would you describe the difference between how he was then and how he is now?
>
> Sch. Psych:
>
> How he is now? I haven't seen him for a few years. I think maybe it was his twelfth birthday that was the last time I actually got to see him. I would say from the time from the initial assessment when he was four and when we needed his reevaluation there was a huge difference. He was speaking in sentences. He was making sense. He was, the eye contact that was nonexistent before, he was sustaining eye contact. He was social, he was engaging, and it was like, Oh, my goodness, is this even the same kid?" because there had been such a huge difference in about two and a half years, I think. No more than three years certainly. (PsycI)

Meghan in giving her perspective on Carter's progress summarized her thoughts this way as she said;

> Carter no longer screams. He communicates well and is now a youth leader. He works enthusiastically making the honor roll in high school and managing college assignments as an early college student. He has dreams and aspirations of his own. Carter will go places in life. (MN)

In summarizing Carter's progress, it was apparent that Carter was initially very literal in his thinking and for a long time did not express himself clearly. He did not maintain eye contact with other people. He now speaks clearly, maintains eye contact and understands literal and figurative expressions. The next section will identify and describe the work done by Carter's Developmental Support Team in the direct words of the interviewees.

Carter's Developmental Support Team

Parents as Teachers

Meghan's work in developing a curriculum was of great importance. In the words of the Psychologist:

> I would say … the work that parents, i.e. Mom did at home to provide him with so many opportunities, especially appropriate socialization where the expectations were really set that he would interact and be part of this family just like anybody else. We weren't going to treat him differently just because he has autism. We weren't going to think he couldn't do anything just because he has autism. He got involved in the music just like the rest of the family. He got involved with social church things just like the rest of the family so he was really brought along as if these are the expectations and you will meet these. (Psych I)

The Speech Therapist commented that the work done by Carter's mother effected the biggest improvements in him:

> Mrs. ____, his mother was very much an integral part of that (specific activities to help Carter) because she followed through with my recommendations. (STI)
>
> Oh huge. The improvements, and I was an integral part, but a small part. Mrs. ___ (Carter's mother) did the biggest work which was to expose him, to develop a curriculum for him where he was exposed to situations where he had to deal socially with other human beings.
>
> He's gifted in music, so having him in swimming, in music, creating an academic curriculum using bi-neural feedback with music to enhance his ability to focus. All these things together worked to improve his overall ability

to socialize and be part of a community. So, it’s all based on the curriculum that was developed for him and I was just a part of that curriculum. (STI)

Kayden:

I think there is a fine line between catering to somebody’s diagnosis and helping them. It’s a very fine line and I think my Mom did a very good job of not catering to but helping. As my brother was saying she had a lot of puzzles, but she read to him constantly, always reading to him. And it wasn’t catering to him, you know, cause maybe he cried or made a fuss, and he cried a lot, he cried a lot, probably more than I thought, than I deemed normal. He was always crying for something. Maybe he was in pain, I don’t know. But like she would read the story to him over and over again. She always had. I think she was good at coming up with different things to occupy his mind.

She played classical music in the house all the time. We practiced in front of him. She took him to recitals. Just anything that she read that had anything to do with growing your mind she would expose him to it, doesn’t matter what. We had so many games. I don’t know how many mind-building games we had in the house. It’s around those lines. There are countless other things that I can’t remember that she did to try to help him. She exposed him to a lot of stuff that helped him because he wouldn’t talk for the longest.

Caleb:

Yes. It progressed for a long time and I could see my Mom getting tired. She won’t give up, but she was …

Kayden:

Yeah, He was five and not talking.

Kayden:

She wasn’t giving up, it’s just, she was just wanting to see something that would work.

Older Siblings as Instructors and Role Models

Meghan also felt that his older siblings were critical to his success.

Meghan:

Seeing the other children do what we wanted them to do, he (Carter) followed suit, so that was helpful.

> We took him to the speech therapist and the older children went with us. Going with us, they were not idle. They were part of the therapy. The Therapist worked through them to help him. At home, they were helpful in keeping him occupied, keeping him engaged so that he would not sit down, get lost, and have his mind go off into that place where he would go.
>
> Then as he got older and he could play with them, they were his playmates. They played and that was helpful. So, going with them to swimming, going with them to music, going with them to piano, to ___, art classes, they were his role models. They were ahead of him and he always wanted to catch up with them. I think they kind of set a standard for him and they raised the bar for him and he wanted to get into their activities.

Speech Therapist, Teachers, and other Professionals

Carter's program began with a diagnosis from the professionals in the local department of Special Education. The Director of Special Education, psychologist, social worker, and speech therapist did more than diagnose. They provided Meghan with reading material, encouragement to try homeschooling, support for each transition, and rejoicing over each victory of Carter's. She dialogued with them continually during the time Carter was receiving therapy and has great regard for the work they did with him. Even now, Meghan keeps them informed of his progress because she knows that they would share her joy since they know how far he has come in his journey with autism. Meghan felt that her working together with the teachers, therapists, psychologist, social worker, and the Director provided Carter with the support he needed and helped her to help him.

Educational and Social Interventions used in Carter's Development

Themes begin to emerge early on during analysis of data identifying the educational approaches that aided Carter's development. Many nodes were developed from the analysis of Meghan's Narrative and the interviews conducted. These were too many to be mentioned individually. Instead, some of the smaller nodes were merged and some which did not extend across most data sources, were considered non-substantive and eventually dropped. Using Axial Coding techniques similar nodes were grouped and placed under themes. For example; music was a strong node but it overlapped with art activities so frequently that music and art activities were combined. Several prominent themes emerged: Music and Art, Speech Therapy, Memorization, Social-Religious Activities, Physical Activities, Older Siblings as Teachers and Role Models, Family Activities which included Parents as Teachers, and Academic Interventions which included visual aids, videos, and attending school. These themes were seen as presenting two natural groupings: Processes and Content. Processes

Modeling and Imitation

The responses from the participants in the interviews indicate that one of the instructional approaches emerging from the study was having Carter's siblings provide him with models to imitate. Carter was taught names of several people and items and even his own name through his siblings modeling and his imitating them starting at the family dinner table. Carter continued to exercise the observation skills developed at the dinner table to help himself in areas of interest to him (FFGI). In the beginning, his siblings were his unwitting role models, but they later became willing leaders. This worked particularly well when he worked with the Speech Therapist. The older siblings followed the Therapist's instructions and modeled exercises intended for Carter to practice. They continued leading and modeling for Carter after leaving the Speech Therapy sessions. Meghan said concerning the older siblings, that

> They were his role models in swimming, gymnastics, music lessons, eating, and art classes. They were built-in knowledgeable playmates, keeping him engaged and they set the bar for him. (FFG)

Learning by observing others has significant educational, economic, and social implications. If one can learn by observing the consequences delivered to another, it can reduce instructional time and financial costs related to intensive instruction, and lead to intensive acquisition of socially relevant behavior, thereby increasing social integration opportunities (Ledford *et al.*, 2008). This is supported by Albert Bandura, whose Social Learning Theory proposes that people learn from each other through observation, imitation, and modeling. “Most human behavior is learned observationally through modeling: from observing others, one forms an idea of how new behaviors are performed, and on later occasions this coded information serves as a guide for action” (Bandura, 1977, p. 22).

Carter watched his siblings intently, overtly, and covertly, being sure to mimic what was needed. As he grew, so did his ability to discriminate between positive behaviors and behaviors, which were non-productive and negative in others. Much of Carter’s progress proceeded from learning activities that were based on modeling and imitation. This is seen in his work with the family around the dinner table, his work with the Speech Therapist, and his imitation of his siblings. Music, Social and Religious Activities and the memorization portion of the Religious Activities, Physical Activities, drew heavily on the desired behaviors being modeled for him and his imitating them. Some of this modeling was intentional.

Memorization

Memorization was a key process in the early curriculum developed for Carter. Carter decided that he wanted to participate in the Bible memorization competition after having viewed a competition meet. This was slow, painstaking work as Carter was not reading that fluently and more than anything, he was apt to be distracted and lose his focus.

Caleb:

> Eight, he had to memorize eight chapters.

Meghan:

> So, how was he going to memorize it? Now this was more work for me. Every morning I'm reading a verse three times because they said to memorize morning and afternoon. And he would work with me. I would read and he would say it after me because he wasn't reading that fluently. And so, bit by bit we went through, week by week and memorized.

Dad:

> And when he was in Bible competition, he put enough time into learning and memorizing all his chapters so he could recite chapters upon chapters on end from memory.
>
> I remember specifically when the team missed three questions and they made 92 out of 100 and he was so upset that they missed six points. That was too many for him.
>
> That memorization that work of memorization did a lot for him did a lot in his head and then he got up there answering the questions. And as soon as he was done one year, he was ready for the next year. So, I think that memorization did more for him than schoolwork. It had his brain primed for school and everything even high school. (FFGI)

In Carter's words,

> At the time, we had a different coach. The coach was always telling us, 'Walk, walk and read out loud.' That is what I think really helped me get my thoughts together at that time. And then like how you memorize properly. So, when the meet/competition comes you can just answer the questions. The answer is at

> the tip of your tongue, just like that. And experimenting with those things like different ways of learning – I think that helped me a lot. So, I was able to memorize my schoolwork in similar ways. I used the same ways I memorized scripture to memorize my schoolwork. It helped me get good grades, too.
>
> Q:
>
> You mentioned starting to memorize scripture at an early age. Do you remember how early, how old you were when you first started memorizing scripture?
>
> Carter:
>
> I think I was five. I was, I think I was in Sunday School with Mr. Fine at church. Oh, but I was memorizing at home before then:
>
> ‘Drive the nail aright, boys. Hit it on the head.
> Drive the nail aright, boys, while the iron is red’
>
> My mother always encouraged me, memorize your memory verse. This was on the back of the quarterly. They always had an incentive or a prize – a gift card. I think that also helped. That was a very important factor for me – memorizing things. (CI)

Memorization of poetry and memorization of scripture was something that the family engaged Carter in outside of the activities directly related to Speech Therapy and Carter’s family members have expressed that it seemed to have had a significant impact on his progress.

Visual Aids

Videos made up a big part of Carter’s program. He became attached to them and would select the Baby Einstein, Baby Mozart, and other videos in that series from the library, while Meghan and the other children would take out videos on science, history, biographies of famous people, languages, and fun kid stuff.

Content

Schooling

Schooling first emerged as a sub-category within the Academic Activities Category taking various forms; starting first with home school, then public school for Kindergarten. Homeschool again for First Grade through fifth and eighth, then sixth, seventh, and ninth grade in regular school. In her narrative, Meghan relates how in making her decision to place him in school, she reasoned that,

> …maybe a regular classroom might be the place to immerse Carter in social life…I decided to take the plunge and put him in school. I reasoned that if it did not work, Carter could be withdrawn. The classroom experience should not be that far off the mark, but still I did not want him stigmatized, bullied, or made to regress.

Carter commented:

> I think I was enrolled in a Speech Therapy Class. I think this was when I was in Kindergarten. Yeah. Through the public schools. I can't remember exactly where. I think I ...yeah, I was in Mars Elementary. And I went to Kindergarten and then I left and then I came back in Second Grade.
>
> I was really excited about the idea of going to school because I think my preschool years I was at home. I was excited about the idea but I do not think I was ready emotionally to be separated from my mother at that time, so sometimes I would cry because I was homesick. (CI)

Meghan:

> He went to Kindergarten. Going to school was another big thing that helped him because at that time he didn't know his - he didn't understand personal space. I remember him standing on line following the teacher's instruction to get on line. He would go and stand just anywhere in the line and the other kids would protest. He didn't understand that he had to stand in a certain place and things like that. It was more than learning to stand in his place. Carter was unaware that that space existed.

Q:

> "That was one of the next things I was going to ask was, "What kinds of experiences and activities do you think contributed to his ability to succeed in academic learning environments like school?

Caleb:

> "All the above. When he did go to school, he did go to Kindergarten, then he was homeschooled. Was that Second through fifth?

Meghan:

> "Uh-huh. First through fifth.

Caleb:

> "Then he went to school for 4th Grade?

Meghan:

> He actually stayed for a month.

Caleb:

> Carter went for 6th and 7th Grades and then he was homeschooled for 8th and then went to high school for 9th Grade. I think we were leading him, then he was leading himself away from relying on us completely. He was independent. He is a sophomore this past year in school and I feel he is independent. He is very independent. He relies on us for some things like some really basic stuff, but for the most part I feel like he's extremely independent. He can go to the store; he can do his own laundry. (BHI)

Carter was homeschooled for a large part of his childhood. He attended regular school for kindergarten and was homeschooled for first and second grade. Carter then requested that he attend school but specified that it be the private school in town. He attended that school briefly for third grade as a part-time student, then when it became too stressful, he returned to homeschool and completed third, fourth, and fifth grades. Carter next attended school with temporary support (mother initially present in the classroom) for sixth grade and stayed for the seventh grade. He returned to homeschool for eighth grade when regular school became too stressful but was allowed to reenter school in ninth grade when he felt he was better able to deal with the school environment.

Academic Content

This theme is labeled Academic Content because it includes activities which are educational. However, all the activities did not take place in a classroom. Each category or activity in this theme delivered some knowledge or set of skills. The Academic content theme emerged as the broad theme which covered many categories of activities which were used with Carter.

It included playing educational games; table games such as Uno and Checkers, puzzles, manipulatives such as Legos and Play Dough; watching videos featuring foreign languages, science, or history, and also included attending school, and other activities. Many of these activities were grouped in a subgroup under the title of Informal, while attending school fit under the Formal subgroup and is mentioned as a separate activity which was helpful for Carter.

The manipulatives got Meghan through long waits such as doctor visits with the older children, any office waits, or riding long distances in the car. They provided diversion, held the children's interest, gave Carter's fingers exercise, engaged him and kept him from having meltdowns or flicking his fingers in the light. Spelling word puzzles and games were added as they went along. Carter not only stopped twiddling his fingers through the use of these manipulatives, but he also learnt a lot of educational material from these academic activities.

The family interviewer asked:

"What do you think are the kinds of experiences that Carter had or the kinds of activities that you did at home with him whether they were informal or structured or planned kind of thing?

The immediate response from Caleb was,

> We always played these kinds of puzzle games. They were more like shapes and things and you had to make certain shapes out of them. We had like a couple circles and some trapezoids or whatever. You're supposed to organize them together and make shapes, and I think that he, that right off, he was good with it, in a way, like he could make whatever he wanted with the shapes you know, whatever animal, whatever and more. And we drew a lot. Carter and I would just doodle around. (Interview FGS)

Kayden said,

> I think there is a fine line between catering to somebody's diagnosis and helping them. It's a very fine line and, I think my mom did a very good job of not catering to my brother's diagnosis, he cried a lot. But she would read the story to him over and over again. She had videos and she played classical music in the house all the time. We also had lots of Legos. We would build a lot but while helping him. We had lots of puzzles, but she read to him constantly, always reading to him. She always had, I think she was good at coming up with different things to preoccupy his mind; she had videos – they're called Baby Einstein videos, I'm not sure if that is exactly the name.. (FGS)

These responses from the siblings' interview indicate what was done in the home to help Carter. The siblings were very involved in Carter's care and they also observed their mother. Kayden also mentioned several activities; speech, music recitals, and games saying,

> Just anything that she read that had anything to do with growing your mind she would expose him to it, doesn't matter what. We had so many games. I don't know how many mind-building games we had in the house. It's around those lines. There are countless other things that I can't remember that she did to try to help him. She exposed him to a lot of stuff that helped him because he wouldn't talk for the longest." (Interview FG1))

Kayden provided information about what was done for Carter at an early age. Playing Educational games emerges as one of the many activities that was used with Carter.

Playing games included outdoor games and puzzles. One of the siblings said,

> We had the puzzles, the map of the world puzzle, spelling word puzzles, crossword puzzles you could separate. This is not like paper and you could put them together; so, he was primed in that way. (FGS)

> There were also Lego and other games requiring mental focus such as word puzzles, Connect Four, and Uno. Playing Checkers and Scrabble was something the family engaged in with Carter as he got older.

The Speech Therapist had this to say,

> … so, having him in swimming, in music, creating an academic curriculum using bi-neural feedback with music to enhance his ability to focus. All these things together worked to improve his overall ability to socialize and be part of a community. (STI)

The following responses come from the Siblings Focus Group:

Caleb:

> Carter would come out and I would say, Hey, O Yeah, that's a good idea. Let's play a game. My Mom always had a cache of these, these puzzles and stuff and Legos, Yes Legos were crucial. O Yes, and Connect Four, those magnetic puzzles. She had these magnetic rods and balls that you just stick together, yes, I forget what they were called, but they (R) they had a little metal base ... you can build them up. And I, I don't know, Carter and I used to sit down and just play with Legos; play whatever, build castles and forts, or whatever, cars, trucks, tanks or whatever, you name it. I remember that Kayden got his first Lego set and I was there, and Carter was there, and I got this sudden interest in this thing, and after Carter saw that Oh, Oh, you could build stuff with it, he said. Oh! He saw too, that you could build more and not just once – stick them together and make stuff – and he caught on. He got into them too.
>
> He continued, 'She would read the story to him over and over again. She always had. I think she was good at coming up with different things to preoccupy his mind; she had videos – they're called Baby Einstein videos. (FGS)

Meghan decided to focus on the result she wanted for her son and then deciding on an appropriate activity to achieve that result, working on a kind of backward design. Meghan was convicted in her heart that Carter needed to use his hands appropriately and to stop flapping his hands and twiddling them in the air above his eyes. She felt that using his hands in a constructive way would help him to stop. She then gave him pencil and paper, and various manipulatives to achieve that end.

She says,

> I armed myself with crayons, play dough, soft putty, flash cards, picture cards, soft books, and small soft toys. My bag of supplies was always ready. It became an obsession with me to keep Carter's hands occupied so that he did not flap them or wiggle them in the air over his head. He was given more electronic equipment than the older children because he needed them to keep him occupied. A kiddie computer, Lego game with table, map-of-the-world puzzle, spelling word puzzle, even his own train set helped to keep him engaged in the process. (Meghan's Narrative)

Kayden, Caleb, the Speech Therapist, Meghan's Narrative all credit the playing of educational games with being a part of Carter's growth and progress. In addition to paper and pencil activities, videos, manipulatives, crayons, soft toys, games namely; Lego games, puzzles, Connect Four, and Checkers, and pets; live goldfish and finches, all were used as forms of learning activities. Carter did stop twiddling his hands in the air over his eyes, and in the process gained a bonus; he learned a lot educationally from interacting with all of the manipulatives, books, games, puzzles, toys, and videos.

Carter's siblings, his parents, the psychologist, and speech therapist, all held the perception that mental games, table games, puzzles of all sorts, home school, attendance in regular school, educational videos, foreign language videos, reading of books to Carter, and other academic activities were part of Carter's daily program.

Art Activities

The term 'Art' is used to include art activities such as drawing, coloring, and creating books. In the Family Focus Group Interview, Carter's Dad responds to a question about what activities proved helpful to Carter.

Dad:

> I think Art was an activity that helped. What Carter wasn't able to express verbally, he was able to express in drawing. He would draw endlessly. He would have multiple sheets of art; pictures of cartoon figures and stuff like that, and at a different stage of his life he would also write comments; he would have people communicating like a comic book; one person saying one

> thing and the other person responding in bubbles. As a matter of fact, he wrote a whole cartoon book. I don't know if we still have it, but that was one of the ways that he would express himself. (FFGI)

Music

Music emerged as another theme and included sub themes such as - classical music, Carter taking lessons, Carter teaching himself to play instruments; Carter listening to his siblings practicing their music, and Carter playing in music groups.

Carter's brother responds:

Caleb:

> He will teach himself all kinds of stuff. He taught himself the ____instrument. He taught himself the ___. He's taught himself so many instruments. He taught himself the ____. Said 'Oh, Mom I'm going to play ____,' and he just got it. He's really smart and he got this drive and this motivation that I don't know, sometimes I just wish I had some. (SFGI)

Music lessons emerged as an activity for Carter, which provided another sub theme. The music teacher was asked the question, "was there anything in particular that helped Carter to make progress in his lessons? To which she responded,

> 1."First of all, I think what helped him was the love that he has for the music. That is the most important thing, I think.
>
> 2. And he was very interested in everything that I would give to him as far as assignments.
>
> 3. He would always try his best to do and I just treated him as though he was going to accomplish that goal. And he would always do that." (Interview IPT))

Caleb:

> I think music for one, it was important, it provided an outlet, helped him to develop part of his personality, in a sense, it also provided a getaway maybe. When he learned about playing instruments, he adopted it into part of himself to help to express feelings. I feel he just learned it and now it's kind of evolving with him as he grows. (FFGI)

Meghan:

> I think music was key. (Interview FFG)

This response to the research question led to the creation of a smaller node which indicated an additional theme – Carter's focus. Carter's love for music, his interest in it, and his desire to try his best, altogether termed focus, contributed to his progress in music lessons.

Caleb:

> She (Mom) played classical music in the house all the time. We practiced in front of him. She took him to recitals. (Interview FFG)

Hayden:

> I think one thing I haven't touched is music. I think that music really helped him, immensely. Probably the most crucial part other than the puzzles, the books, and the games, and the reading, and the human interaction, and the speech work, I think that music was, probably did 70% of the work because, we don't, can't explain it, but people say classical music has a specific effect on the mind, I don't know how, but it just has to because it has helped him, I think personally. Like the Baby Einstein videos, I previously mentioned, they're purely classical, it's all classical. They show like pictures, moving pictures to classical music. I think that helped a lot. Playing instruments helped, I think, helped stretch some part of his mind. He really got into instruments. (SFGI)

Hayden:

> I mean, the key was really he saw us playing instruments and he wanted to play instruments, too. (SFGI)

Speech Therapist:

> …. So, having him in … music, creating an academic curriculum using bi-neural feedback with music to enhance his ability to focus. All these things together worked to improve his overall ability to socialize and be part of a community. (STI)

Carter was asked this question:

> What got you started being interested in playing the ____?

Carter:

I think it’s because I saw my Dad play on it. I saw my siblings play it. I saw my siblings take lessons on it. I guess I just wanted to try it and see. (CI)

I started when I was about four and I picked up the ____ when I was about five…. My mother, you know. I wanted to play but for some reasons when I went to lessons, I didn’t like it a lot because the teacher is always ...my mother tells me at the time that the teacher was always trying to fix my positions, and I didn’t like the teacher, you know, touching me like that. So, I think. (CI)

I also didn’t like having to sight read notes. I was a very auditory learner so I really enjoyed listening because we learned through the Suzuki, that curriculum… I’ll see the notes on the page, but I didn’t really like ... I just thought, O, but what I heard resonates with what’s on the page in front of me. I’ll just play what I heard. And I really enjoyed that because it seemed easy for me.

And then, I guess I had a lot of interest in the ____, but then I think I heard someone play the _____ on the radio, I think it was WAUS or one of those stations, my interest grew, and I think it was on my seventh birthday, my mother bought me a _____. I started to play around with it and then, the next month, the month after my birthday I started lessons. My interest in _____ grew until it was kind of a balanced. I liked the _____, but I really liked the ____ more so I kind of gravitated toward the ____. (CI)

Q:

So, what other kinds of instruments do you play?

Carter:

I also play the ____. That I started I think when I was seventh grade. Yeah. I did not have lessons until late last year. I took lessons for like three weeks. But up until then I was you know, doing what the teacher said, what Mr. G said, following his instructions about what to do with your mouth, the notebooks and playing the songs. I was always auditory until high school. Now in the _____ band we have warm-up books, like sight-reading books. It is not playing from a radio system. You have to learn how to play. I guess my brain liked it, but I myself, I still don’t like sight-reading.

Q:

But you do it. Right? (Laughs) Because you have to. Any other instruments besides this?

Carter:

I play a little bit of guitar, but not very seriously. (CI)

Meghan:

> I think the music videos helped him. We had a lot of different music videos and they played a role in helping him to connect. Do you remember that music video we had where the lady would do the actions of what she was saying?
>
> We had a lot of videos; music videos, bible verse videos, exercise videos.
>
> He got his (musical instrument0 at age 7. When he got it, he wanted to play in the ___. The older siblings were playing in the_____, so he wanted to play __ __ ____, too. I would sit with him at the back in the ___ and I would point to each note and I would say the name of the note. I don't know how he knew, but he knew exactly where the note was on the instrument. So, I was reading for him and he was playing. I read music for him like two months in the ____ and that was it. So, all of these things just provided, just helped him. The music was helpful not only in the reading and the listening but even in the performing because he knew how to stand in front of a group, how to bow and even though it was uncomfortable for him to have the people staring at him, this is what all the children were doing so he could not do anything different and so he would go and do it. Before he performed, he was always very anxious, very anxious, but we calmed him and encouraged him. This was another family effort.

Siblings' Focus Group – two of his siblings, Music Teacher, Speech therapist, Carter's Dad, Meghan, and Carter all testify to Carter's involvement in music being a strong contributor to his growth as a person. These statements coming from various respondents provide triangulation and thus credibility.

A question to Carter asked:

Q:

> So, of all the things we've talked about, what kind of activities do you think were most important in helping you grow to the current person you are that nobody would recognize as ever having been diagnosed as having autism?

Carter:

> I think music is one of the most important. That opened up many avenues for me to meet that many different people from many different walks of life. I won't have come in contact with them if I was just doing soccer or if I was just doing something else. (CI)

Dad:

> That was an activity – listening to classical music. I remember specifically that we would put on classical music in the home. That was even before they got into actual playing of music. She (Carter's mother) used to play classical music even before he was born.

Meghan:

> I used to play classical music for my students when I was in the classroom and could see the calming effect on the kids. I continued with my older kids when I had them and played classical music for Carter from the time he was born.

Dad:

> We made a conscious effort to expose him to classical music and that did not change when he came home. When he did reach home after being in the hospital all those months, we continued to let the whole house listen to classical music. I got into classical music as a result of the children listening to all that classical music and one of the things that I forgot to mention it is that he would kind of hear things in the classical music that I would not hear.
>
> And then at some stage, (we always had a piano in the house), he would go and he would play these lines that he had heard coming from the classical music on the piano. He would play these lines and I would always wonder what is he playing? What is it? It wasn't the melody. He was hearing another line in the music like he was hearing this distinctly. Let's say it was the alto, not the soprano. He was hearing what I wouldn't normally pick up. He would try to play it on the piano. And it was only after a number of years that I realized that it was the same music that he was playing but he was hearing something different than what I was hearing. That played a role. And shortly after we realized that his pitch was good. He had a very good pitch (perfect) perfect pitch. Somebody helped us pick up that when he was like four or so. That helped us to put together the fact that he was actually listening and trying to play things that I wasn't hearing. He was hearing, he was hearing those things. (FFGI)

Meghan saw the music as performing another function in developing poise and an awareness of being on stage which was important to his becoming more rounded and less stilted.

Meghan:

> The music was helpful not only in the reading and the listening but even in the performing because he knew how to stand in front of a group, how to bow and even though it was uncomfortable for him to have the people staring at him;

> since this is what all the children were doing, he could not do anything different and so he would go and do it. (FFGI)

Dad:

> He has been in many different organizations. He was in the _____ orchestra, he was in the Lake ___ Youth Orchestra. He was doing youth clubs. He was in a lot of different things. He was in music. He did stuff in leadership. He was doing things in many different categories, not just music or just leadership or just creativity. He was doing things that were well rounded and it was stuff he chose to do. The things that he wanted to do, he did good in. Whatever he did, he did to the best of his ability. He liked to engage. But when he was in ___, he turned himself into the best possible player in his section not just to be the best but because he put effort into it. When he was in ___, he made sure to put effort into it teaching himself the _____ so that he could be his best...

Speech Language Evaluation and Therapy

Speech and Language Therapy provides evaluation, diagnosis, and treatment for disorders affecting communication. It specializes in voice disorders, swallowing disorders, and cognitive-communication disorders. Speech and Language Therapy is an integral part of diagnosing and treating autism spectrum disorders. Carter needed Speech Therapy because during his long hospital stay, he had been fed by tubes and not by bottle, weakening the muscles around his mouth and affecting his ability to produce initial and medial sounds. The response of the Speech Therapist in the interview introduced, defined, and enlarged several sub-activities comprising the Speech theme and which helped our understanding of the theme.

The Speech Therapist answered,

> The blowing of the straw is to strengthen the orbicularis oris - that is the muscles in the lips that encircles the mouth - and is one of the activities that stimulates the movement and it creates muscle memory. I do a lot of tactile, a lot of activities like this with children so I know that in his case those activities enhance his ability to produce the sounds.” (IST)

She continued saying,

> In Carter’s case, a child with autism, they are very literal and they need visual … and they are very regimented in certain things, so if you prepare them and give them a visual aid … for our learners you have different modalities for learning. For a child with autism that’s the best modality. They learn through pictures. They are much regimented, so to help them with flexibility you use what we call social stories, but actually an illustration of the steps of the things we’re going to do during the day. The book of analogies had pictures and had a passage and questions related. In the passage, there were analogies and or abstract thinking sentences, and the pictures helped him get to the answers and become more familiar with the minutiae of analogies so he could better grasp at jokes and what was going on in the passages. (IST).
>
> I would constantly ask him, ‘Look at me.’ So, would you. You reinforced that. ‘Look at me when you’re talking to me.’ ‘Who are you talking to?’ when he was looking away and not having eye contact - and that’s autistic behavior. That’s modification of behavior. So, we constantly, by the time we finished telling him he was much better at looking at the person when he was talking as opposed to looking away or looking down. (Interview IST)

The School Psychologist shared her opinion when asked about how the Speech Therapy was helpful to Carter:

> I think it was probably a combination of multiple things. Within the schools he qualified to get some Special Education help which meant some very direct services some very direct therapy - Speech Therapy. I think. He had some classroom help where they had specific goals to increase those skill deficit areas. (PsyI)

Meghan:

> It was a relief to start work with Mrs. M_____, Carter’s first Speech Therapist, and a pleasure to work later with Mrs. O____. Mrs. M____ showed genuine interest in my son and treated him with respect. He grew to anticipate going to her room with pleasure. It was the one place where I did not have to restrain him. Carter smelled each book, touched everything, raced back and forth from one object to another with glee while we named them for him. Then she would ask him to sit and show him cards on a flip chart asking him to name the pictures. She called the name of the object and he had to point to it correctly. Then he was asked to find a picture that matched the one shown. Mrs. O____ connected with him immediately.
>
> Carter would sit on my lap for a few minutes at a time until he could sit without my holding him to encourage him to be still. I learned to stroke his back and to hold him close to help him burn off some of the high energy. On his own he would run back and forth in the little office and not show that he was hearing her. These activities were particularly interesting to me for they

> showed me where I needed to focus my teaching. Carter was not making connections. He did not generalize a concept. His thinking was very literal. He was showing a lot of progress. He was more aware of us and of his surroundings. He knew the names of many things. But, how do I get him from here to making connections and understanding abstract concepts?
>
> Carter's siblings accompanied us to these speech therapy sessions and were often included in the therapy as they were invited to participate, so he could be encouraged to respond. A question would be directed to them and after they each answered, the same question would then be directed to him. A correct response was rewarded with applause and smiles. He always enjoyed doing whatever his siblings did. These sessions proved to be helpful to him and the siblings thought it was great fun. They enjoyed participating and being leaders and Carter began to pay more attention to our words and actually began to name things at home. I prayed constantly for God to give him intelligent speech. (MN)

From the interview with Carter comes his response to this question on his speech improving and the impact of speech therapy. Carter's response supports the previous responses from his siblings, parent, psychologist, and speech therapist.

Q:

How did that change over time and what do you think helped that change?

Carter:

> I think I was enrolled in a Speech Therapy Class. I think this was when I was in Kindergarten. Yeah. Through the public schools. I can't remember exactly where. (CI)

Family members elaborated on the extent to which Carter benefitted from the Speech Therapy

Meghan:

And he even spoke at the ____.

Caleb:

> Oh yeah, I remember. It was for ____ a few years ago he had to do something like a testimonial or a speech at the ___. He sat down and he wrote his speech. At _____, he got up and spoke for everybody. I was a bit nervous cause that was, you know, that was like a really large crowd of people. How is he going

> to handle it? He handled it very well. It wasn't very long, you know. He was very professional. I know he wasn't comfortable up there, but he told himself, "Yeah, I have to do this. I'll get this done. I chose to. And so, I'm going to do it". And he went there and he did it and he did it really well. It was really nice. It was a really good speech though. It was about his progression and how God helped him in his life. It was very well thought out. It was a really good speech.

> He was taken to Speech Therapy weekly and worked one on one with the Speech Therapist who helped him with strengthening the muscles around his lips, pronunciation, naming of objects, word identification, and communication. Another sibling said, 'All the toys we got for him were given with the intention of helping him develop speech.'

Meghan:

> I was actually thinking of speech; going to the speech teacher/therapist as being one of the key activities that helped him because she helped him to slow down and think and it was a safe place to be. (FFGI)

The School Psychologist added,

> "I don't know if I remember a specific activity. I would say probably two main keys just based on his history: one was the speech therapy where the therapist really targeted his ability to communicate with others … (PsycI)

In response to this question on which types of activities helped Carter the most, the Speech Therapist commented that,

> "...For Carter, the worst part for him was the socialization and understanding humor and analogies. And so, we worked on that. And another part is that the home did their part too in doing as much as they were supposed to do to build on the strengths that Carter already had to help him overcome the areas that he needed to work on."

The Speech Therapist thought of an activity that helped Carter the most. She added that,

> The whole interaction and reading and understanding going directly to his area of weakness to enhance his learning was the key factor for him. (STI)

Kayden:

> And some of the things from the Speech Therapist like; he should form his words properly and enunciate and not only that but think about the person's questions, think about the topic; be able to give his own say on what he

> learned, so I feel that it was a bunch of things that happened that came together to help him learn how to socialize. He was not much of a socializer earlier in his life, like at first, he was scared of talking to people and I think that our efforts and his own personal efforts came together to teach him how to socialize. (FFGI)

Meghan:

> I think that Speech Therapy was one of the things that helped him (he could not say/pronounce certain sounds) (FFGI)

Dad:

> We thought it was muscle issue.

Meghan:

> We would model for him expecting him to imitate and he would try but he just couldn't get some words. When we went to the Speech Therapist, she gave him exercises to strengthen different muscles, because she immediately knew which muscle it was, what was the name of the muscle and how it worked and so on. She gave him this exercise with the straw. He had to practice blowing a feather across the table with the straw. He had to practice bubbles; he had to drink – pulling up with the straw different things, and then she would send us home to practice these things (38:29) with him, strengthening the muscles because he couldn't get out the medial sounds, and the "p" and "b" and "m". (FFGI)

Working with the speech Therapist had a profound impact on Carter's ability to express himself and thus affected his ability to socialize, thus it was one of the most helpful learning activities and this is supported by statements by one of his siblings, the Speech Therapist, the School Psychologist and Meghan.

Physical

All children benefit from physical activity (Fedewa & Ahn, 2011). Former First Lady Mrs. Obama promoted movement as an important part of a healthy lifestyle, helping children fight childhood obesity, and as a result, related health problems. Physical activity is beneficial also to individuals with autism (Lang, et al., 2010).

Q:

There are a couple of things I want to ask Carter. Now I know that you did some gymnastic classes, and you had some swimming lessons – do you think those experiences helped you and if so, how?

Carter:

Oh yes, swimming experiences: I am happy I was able to learn swimming at a young age. By the time we got to ___ for different things and we had to do the Swimming Honor, and I think that if I hadn't learned those lessons at that time, I probably wouldn't have been able to do the honor or be able to swim decently at least to survive.

Speech Therapist:

So, having him in swimming, creating an academic curriculum using bi-neural feedback with music to enhance his ability to focus. All these things together worked to improve his overall ability to socialize and be part of a community.

Psychologist:

Wow! So, he could pick up the concepts, but had he not been taught… I think it's that specific teaching, that direct teaching, and like you said in multiple environments; not just only in the classroom, and not just only in the swimming class, but you're learning it in swimming, (PsycI)

Caleb:

We also did sports with him.

Dad:

I remember teaching him how to catch. I would throw the softball at him and he would try to catch and that's how he developed his catching ability. He was older, but he did develop the art of timing it and grabbing it. That was it. (FFGI)

Meghan:

Well, there was swimming. The older kids were taking swimming, so we added him to the swimming. And then we probably were not going to be doing gymnastics, but then, you know what, we needed to do gymnastics, because my thinking was, he knows words, but somehow, he doesn't connect words with the activity and the action. And if he doesn't understand what the purpose of words are, then he'll never make it in life. So, I felt that a way to help him understand that words were critical to his well-being was to practice swimming

> at the pool. If he didn't follow the instruction if he didn't get it then he would go down in the water. We did that (swimming) and then there was gymnastics and he caught on.

Caleb:

> When I was homeschooled in 10th grade, he (Carter) saw my friend playing his favorite sport, soccer. Carter didn't like the fact that he didn't have a favorite sport. So, he decided to teach himself soccer. He watched soccer videos and watched the pros. He became an expert at soccer and he taught himself all the moves and the different ways to kick, different ways to dribble, and soccer ball handling and how to outsmart players on the field. So, at first when he was younger, he wasn't extremely dexterous, but he was dexterous but not with his feet. and used to trip over things. But now he's very dexterous. He can do things with a soccer ball that I could never see myself doing. He can flip the ball over his head with his feet. He kinda did that also as a means to get into the "in crowd" at school. There was a very large group of soccer players that loved soccer. And he said, "You know what? I'm gonna join their soccer team." And he got good and practiced until he felt that he was good enough to join their team. He made the team. (FFGI)

Carter learned many skills from swimming, soccer, marching, and gymnastics. However, more than those skills, he developed discipline, focus, work, and an understanding of the purpose of words.

Social Skills

Social skills can be defined as specific behaviors that result in positive social interactions (Elliot & Gresham, 1987). It includes verbal as well as non-verbal behaviors which facilitate interpersonal communication. Social skills in childhood have been consistently linked to positive developmental outcomes, including peer acceptance, academic achievement, and mental health (Hartup, 1989). Children with Asperger's Syndrome or High Functioning Autism may lack the behaviors needed to interact successfully with others. Smiling, making eye contact, asking questions, making appropriate responses, interpreting social cues – both verbal as well as non-verbal, appropriate emotional responses, understanding the perspectives of others are all social skills necessary in forming friendships and developing relationships with family, peers, and other adults (Krasny *et al*., 2003; Beidel *et al*., 2000).

Carter's family intentionally included him in the social activities of his older siblings. Carter's dad urged that the role of the children's club which Carter used to attend when he was very young not be minimized. This grew to include ____, and church-related social events such as hay-rides, snow-tubing, canoeing, etc.

Carter's Dad comments:

> We can't minimize the role of the club which he used to attend when he was little. First, he used to attend not being a member, but because his mother would be there with the other kids and she would take him along with her. The activities that the kids were involved in, he wanted to do those things too. I am sure, that involvement helped him to develop his skills with his hands and stuff like that.

Meghan:

> And for a while I wrote for him. Even when he started to attend the club, he could not write fast enough and so I would write for him.

Caleb:

> Another thing that was important to his development was to help him to become comfortable with things he was uncomfortable with at first – like before when he hated talking to people. If I remember correctly, and we kinda weaned him into it. We made sure that he got used to things that he didn't like, that were, that had to be part of his life later on. I feel that we made sure that he became more rounded as we went along.

Meghan:

> Yeah, that was a way to get him out into groups of people. The older siblings were in the choir, he went along with us, and then of course, he wanted to be in the choir, too.

Carter was asked this question about the impact of the children's club and the youth club on his progress:

Q:

> You know we talked about the Bible memorization competition; talk to me about the _____ and ____ clubs in general and how you think those youth organizations helped you if they did.

Carter:

> They did help. They helped a lot in fact. Because in my early childhood I was homeschooled, being in ____ and _____ clubs exposed me to being around different children or people my age and interacting with them – not that every single interaction was always pleasant, but you know how it works with people; this kid is a little annoying, you know what to do to make him stop. If this kid wants you to help him with something you know how to accommodate or help him. (CI)

Carter's sibling related that being around other people was helpful

Caleb:

> One thing that helped him was – it wasn't just music. I think socializing with other people. That helped him. Before he wasn't much of a socializer. He would hide from people, but as he progressed, he would watch how people socialized with each other. Now he taught himself. We taught him, but he also taught himself how to socialize. He wasn't able to maintain eye contact with people before. He would walk away and just mumble. He would look away or he wouldn't respond, or he would always mumble. Now he's very comfortable with all kinds of people. He can hold really intelligent conversations with all kinds of people.

The Speech Therapist said:

> Carter's mother did the biggest work, which was to expose him, to develop a curriculum for him where he was exposed to situations where he had to deal socially with other human beings. A child with autism tends to be by himself wanting to be by himself and in a world alienated from reality and so for him that was the integral part…

Religious Activities

Activities included in this theme are memorization of scripture, prayer, and church attendance. Carter credits his academic success in part to his being made to memorize scripture at an early age. Carter was asked, "What other kinds of personal strengths do you think helped you in your development?"

Carter replied:

I think being taught how to memorize scripture at a very early age. I started - By the time of my last year in ___ Club and I was really excited about being in the Bible competition so I begged my mother, I really want to do this. I really want to be in this. So, she got me to the program and to their system.

At the time, we had a different coach. The coach was always telling us, 'Walk, walk and read out loud.' That is what I think really helped me get my thoughts together at that time. And then like how you memorize properly. So, when the meet/competition comes you can just answer the questions. The answer is at the tip of your tongue, just like that. And experimenting with those things like different ways of learning – I think that helped me a lot. So, I was able to memorize my schoolwork in similar ways. I used the same ways to memorize scripture to memorize my schoolwork. It helped me get good grades, too.

Q:

You mentioned starting to memorize scripture at an early age. Do you remember how early, how old you were when you first started memorizing scripture?

Carter:

I think I was five. I was, I think I was in ____. I was in the ___ class with Mr. ___ at church. My mother always encouraged me, "memorize your memory verse." They always had an incentive or a prize – a gift card. I think that also helped. That was a very important factor for me – memorizing things. (CI)

Meghan:

Another thing that I thought was helpful for him was the Bible competition, because as a parent you just can't think of everything that could be done. So, we're having worship. We do our story. We memorize our Bible Verses and so on. But when he was nine, he heard somehow about the Bible competition and decided he wanted to go and see it. (BHI)

Caleb:

Eight, he had to memorize eight chapters.

Dad:

I think at one time he wanted to be a preacher, too. What was the name of the one he listened to?

Meghan:

C.D. Brooks. That memorization, that work of memorization did a lot for him, did a lot in his head and then he got up there and answered the questions. And as soon as he was done one year, he was ready for the next year. So, I think that memorization did more for him than schoolwork. It had his brain primed for school and everything, even high school. (BHI)

Concerning prayer, Meghan commented,

We prayed and asked God to give him words. God granted our prayers. (ICP)

Meghan:

Well, I think we also had a lot of prayer. We prayed. We prayed when he was just garbling when we weren't getting words. We prayed and asked God to give him words. And then when the words came and they were just parroting words, we would pray. When he would just say things randomly or repeat what he heard from a book, we would pray.

My prayer was, 'God, put the words in order. Put order in his brain. Cause him to speak sensibly.' I was not embarrassed, but I was concerned about his future. And we saw his speech come around and help was sent and I want to feel that behind everything our prayers were part of the action that helped to make the change. And there were other people praying for us. (FFGI)

In Meghan's Narrative, she reiterated:

I prayed constantly for God to give him intelligent speech. (MN)

And then again,

Thanks be to our All-wise God who is always at work even when we have forgotten what we prayed for or even that we prayed.

Caleb:

We were always praying for Carter, whatever. We were always asking God to help or whatever, and, and, but He did.

Family Activities

Teaching Carter became our nightly family activity for a while. We began by teaching Carter his name. Daddy and I would ask each person at the dinner table their name. In turn they would answer and I would repeat their responses.

And Daddy would say, "Kayden, what is your name?" And Kayden would say, "Kayden". "Caleb, what is your name?" Caleb would say, "Caleb." Then Daddy would say, "Mommy what is your name?" Mommy would reply, "My name is Mommy." Carter, what is your name? Then one of us would speak for

> him, “My name is Carter.” At first, he would look and he wouldn’t say anything, but after a while he caught the idea and would say his name. We taught him several things like that, sitting at the table; his name, then we taught him his telephone number, because we realized that this kid was not progressing at the normal pace. We realized that we had to do something so there were things that we, after dinner in the evening, we just sat down and we would work with him around the table as a family - like teaching him his address (FFGI)

The psychologist added,

> “And another part is that home did their part too in doing as much as they were supposed to do to build on the strengths that Carter already had to help him overcome the areas that he needed to work on.” (PsycI)

Caleb:

> May I say something? Some people buy their children lots of Legos. We didn’t have a lot but we did have a couple sets. When my older brother grew out of his set, I grew into them. When I grew out of them, then Carter grew into them. He got his creativity by building things. I think being able to put out what’s inside your head using Legos, drawing, and music; it helped him grow.

Even in writing on paper, writing is not really a problem for him now. And he had to do a lot of writing for Biology this year, and he did work like a trojan. But I think all of those activities helped him, so its normal. It’s nothing that is new. This year he has always said that Bible Competition helped him know how to study for Biology. (FFGI)

Carter:

> My mother had me learn all of these speech expressions, figurative expressions from this book then I had to answer questions correctly. That really helped to get me thinking out of everything too literally. (CI)

Speech Therapist:

> Mrs. (blank) his mother was very … an integral part of that because she followed through with my recommendations.

When asked about his experience learning to communicate with different people, Carter had this to say,

> My mother also had a role in teaching me this. She explained to me, … It's about being respectful. I think I learned that from her - learning to be respectful to my parents and respecting them. I would treat other people the same, yet not exactly the same respect I give my parents, but similar.
>
> Q:
>
> What helped you get to the place where you could maintain eye contact.
>
> Carter:
>
> I'm not sure. I guess pressure from my mother – "look me in the eye; look people in the eye, look people in the eye.

Concerning other activities that his family was engaged in, Carter had this to say;

> Carter:
>
> "We were able to, our parents helped to put us, helped organize us into a performing group. We would play together at different venues; we would play like at churches, play for different events like a benefit concert the church was having. We were fortunate enough to go and play at the blank. (CI)

Meghan mentioned using food supplements such as Ambrotose powder from Mannatech and Barley Green Powder which helped with concerns such as anxiety and maintaining Carter's immune system. She also said concerning their dietary supplements and choices that;

> "Carter's drooling was a great problem for me. He was eating solids at this time and still drooling profusely. I made a decision to keep a bib on him for as long as it was necessary. I do not exactly remember when, but Paul L. introduced me to Ambrotose powder from Mannatech. I had always given him Barley Green Powder. I observed that the Barley Green helped to keep his immune system well. Would the Ambrotose help with the drooling? I did not know what to expect, but anything good was worth a try. We noticed that it helped keep him calm.
>
> Diet was and continues to be a big part of our program. In the early days I read a lot on the subject and tried to improve our family's diet. It was too time consuming to fix food for the others and then fix something differently for my boy. We were already dairy-free but had been using meat substitutes

> occasionally. Since we became aware of gluten intolerance and its possible effect on autism, we cut down on the meat substitutes since many of them were based on gluten. We turned to tofu and used a lot of ground provisions (yam, plantains, and cassava or yucca) in addition to rice, and in place of pasta (gluten), and green vegetables. (MN)

Psychologist:

> I would say … the work that parents, i.e. Mom did at home to provide him with so many opportunities, especially appropriate socialization where the expectations were really set that he would interact and be part of this family just like anybody else. (Psych I)

The theme of Family Activities emerges from statements made by the Psychologist, Carter, Meghan, Carter’s siblings and the Speech Therapist. It appears as though much of what was accomplished with Carter came about as a result of the work done at home through the many activities which fit under this theme; family music activities, family expectations, family diet, dietary supplements, concerted family efforts to teach and instruct Carter, each parent individually teaching Carter, and Meghan following up on the Therapist’s instructions. Statements from the Psychologist, Speech Therapist, Carter, Carter’s siblings and Meghan support each other in verifying the work done with Family Activities.

As can be seen in Table 1, the nodes developed from the analysis of the data were useful in addressing this question. Thirty-two nodes were developed; very similar nodes were combined; nodes which occurred less than ten times were dropped unless each mention was with such emphasis that it was actually very important. Attention was given to nodes with double digits in occurrences as it would have been too time consuming to address every node.

Table 1

Educational & Social Interventions Used with Carter Based on Interviews

Physical Activities	Social Activities	Academic Activities	Religious Activities	Music & Art	Speech Therapy	Family
Swimming Gymnastics Playing ball Learning to Catch	Children's Club Children's Choir Youth Club- Sunday School Teachers Other People Helped: Neighbor	Formal Academic or Attending School Kindergarten Home School Brief 4th Grade stay 6th Grade 7th Grade Informal Academic Playing Educational Games: Chinese Checkers, Connect Four, Uno Scrabble Puzzles Map of the World, Spelling, Pictures, Giant Floor Puzzles Kiddie Computer Videos: Music, Science, History, Foreign Languages	Memorizing Scripture Attending Church- Praying	Drawing Coloring Painting Listening to Classical Music Listening to Siblings' Practice Instrument Lessons: Piano, ___, ____, and orchestra	Therapist's instructions Reading the book of Analogies Bible memorization competition Memorizing: poetry, verses, scripture	Teaching Carter his name Dad teaching him skills: e.g. catch Siblings modeling for Carter: Responses Behavior Diet Food Supplements Carter's Mother's Contribution Planning of Carter's Curriculum Volunteering in Carter's classroom, Teaching Carter, assigning Siblings to teach/support Carter. Reading many books to Carter

Carter’s family teaching Carter, Spanish language tapes, French Tapes, card games, memorization, and prayer were all part of their program for him. Further analysis of the data allowed the activities to be grouped according to type of activity. The activities appeared to be clustered in certain ways and were therefore grouped under some umbrella terms or emerging themes. Table 2 demonstrates the emerging themes of educational interventions used with Carter and the activities that comprise the emerging themes.

Table 2

Triangulation Matrix of Sources

Sources Themes	Narrative	Family Focus group Interview	Siblings Interview	Psychologist’s Interview	Speech Therapist Interview	Piano Teacher Interview
Family Activities/Parents as teachers	X	X	X	X	X	
Academic Activities	X	X	X	X	X	
Music & Art Activities	X	X	X	X		X
Speech Therapy	X	X		X	X	
Physical Activities	X	X	X	X		
Social & Religious Activities	X	X	X	X	X	
Carter’s Drive	X	X	X	X		X
Support Team Intentions	X	X	X	X		X
Memorization	X	X	X			

Carter's Desire to Progress

Caleb:

> "I think a big change that I noticed now is that when he was a lot younger, we used to have to help him to improve, like how to talk properly or how to enunciate or be calm. But now he's finding things that he may see in himself that he wants to change or fix and he just changes them. It has progressed more from us finding ways to improve him to just him finding ways to improve himself. (FFGI)

Caleb:

> "I think it was not only us but also himself, because I know he liked to imitate so we did help him a lot, because we (mumbling)… but then he began to take over. I think he can teach himself stuff. Like right now he is teaching himself how to code. He also taught himself how to play the ___. So, I think it was a combination of us helping him; in the beginning, it was mostly us but now it's shifted more to him doing things ... (FFGI)

Carter's father summarized Carter's progress in this way, saying:

Dad:

> "He has been in many different organizations. He was doing ____. He was in a lot of different things. He was in sports, in music. He did stuff in leadership. He was doing things in many different categories, not just music or just leadership or just creativity. He was doing things that were well rounded and it was stuff he chose to do. The things that he wanted to do, he did well. Whatever he did, he did to the best of his ability. He liked to engage. But when he was in ____, he turned himself into the best possible ___ player in the ____ section not just to be the best but because he put effort into it. When he was in ____, he made sure to put effort into it teaching himself the ___ so that he could be his best... And when he was in Bible competition, he worked hard to be his best. He has kinda taken over now. He has learned how to get what he wants and as a result of that he can take over things. We don't have to show him a whole lot of things that he wants to accomplish, but initially we had to get him going. (FFGI)

Summary

"*What do you think were the Educational and Social Interventions that helped him grow and exceed the expectations of those first psychologists who tested him and wrote him off?"*

Chapter 5 discussed the responses to the research question for this study taken from the Interview Protocol and asked of each interviewee in their setting. Descriptions of the research findings were provided which included the respondents' perceptions about the Educational Interventions in their own words. The responses from the interviews showed that a wide variety of activities had been engaged in with Carter. Analyzing all of the interviews by coding using NVivo revealed the activity themes used with Carter as indicated in the interviews. The activity themes have been organized into tables as seen in Table 2.

Outline of Chapter 6

Chapter 6 presents a discussion of the overarching themes with the literature. It starts with an introduction, background, statement of the problem, purpose of the study, method, design, and then presents the themes which were uncovered in the study. The themes discussed are: Carter's drive to succeed, Meghan's intentionality, and concludes with Every Child is an Individual. Recommendations for further practice and research are also presented.

CHAPTER 6

FINDINGS, DISCUSSIONS AND RECOMMENDATIONS

Introduction

This study examined the case of a young boy named Carter who was diagnosed with Autism Spectrum Disorder (ASD) to uncover the educational and social interventions which were helpful to him. ASD is a disability covered by the Individuals with Disabilities Education Act (IDEA) whose purpose is to improve educational outcomes for every child with disabilities by providing them with services through the public schools. IDEA's amendments in 2004 broadened the reauthorization of 1997, and increased the requirements to ensure that children with disabilities who have been placed in private schools by their parents are provided with an opportunity to participate equally in programs provided through IDEA (https://www2.ed.gov/admins/lead/speced/privateschoolreport_pg2.html). IDEA also requires that each child with a disability be provided with the Least Restricted Environment (LRE). IDEA's provisions facilitated the other factors that contributed to Carter's growth and development.

Responses from the interviews conducted for the study, Journey with Autism: Emerging Educational and Social Interventions from a Single Case Study, outlined a broad array of educational and social interventions indicating that Carter, the child in the study, was provided with the Least Restricted Environment and had a rich and diverse experience. Each strategy identified in this study targeted a different facet of Carter’s life. Thus, the entire collection of educational and social interventions developed for Carter resulted in a curriculum which presented opportunities for holistic, all-around development for Carter which presented opportunities for holistic, all-around development for Carter facilitated through his family. These interventions provided Carter with a variety of experiences, service opportunities, and opportunities to learn academic subjects. These experiences taught him skills helpful in meeting a variety of situations. Carter’s program of interventions included the organized, the planned and focused as well as the spontaneous learning activities. Carter’s education targeted his appropriate development physically, mentally, and spiritually (White, 1903). The chart shows the social and educational interventions impacting each other and all being affected by the family activities.

Background

This case study highlights the educational interventions emerging from the analysis of the case of Carter, a young boy diagnosed with autism. Meghan decided to work with him herself because she had confidence that he possessed the ability to change and grow if given the appropriate interventions. Meghan felt that it was more suitable to work with him at home, initially, without the limitations of a classroom. Different settings were used for varying lengths of time: home school, public school, and private school. This approach was supported by the Individuals with Disabilities Education Act (IDEA). IDEA is a piece of American legislation which guarantees Free and Appropriate Education (FAPE) which is customized to the individual needs of students with disabilities and also requires that all students with disabilities be educated in the Least Restrictive Environment (LRE) (https://en.Wikipedia.org/wiki/Individuals with/disabilities). The Least Restrictive Environment enables the student to receive the services they need to realize success. This study revealed several interventions that enabled Carter's growth. Two additional themes emerged which were critical to Carter's recovery: Carter's Drive to Succeed and Meghan's Intentionality.

Statement of the Problem

Parents and caregivers of children diagnosed with autism are under severe stress (Picardi *et al*., 2018), and need examples of interventions which have been tried successfully. Some studies have identified examples of successful interventions. These include Early Denver Start Model, Lovaas Model, and Applied Behavioral Analysis. However, additional interventions which prove successful for ASD need to be identified so that parents can have access to a variety of methods.

Purpose of the Study

The purpose of this qualitative study is to explore the interviewees' perceptions of the educational and social interventions used with Carter. The purpose of this qualitative case study is to identify from the data gathered, the educational interventions used and their impact on the child, Carter, who had been diagnosed with autism. This study aims to discover and describe and elaborate the educational interventions employed by several individuals who worked with Carter and helped him move beyond his diagnosis.

Method

This intrinsic case study gathered data from Meghan's narrative and through interviews with persons who were purposefully selected because of their work with Carter or their familiarity with the case. Data was also gathered from focus group interviews with family members, a copy of an IEP, and some artifacts. This data was processed using the NVivo software which is designed to analyze qualitative data.

Design

Qualitative Inquiry

Qualitative forms of inquiry are defined by three key elements; the design, the collection of data, and the analysis. One qualitative research tradition used broadly across disciplines is the case study (Merriam, 1998; Savin-Baden & Howell-Major, 2013; Stake, 2005; Yin, 2003). The case study design allows the researcher to interact with research subjects and to study social and cultural phenomenon in action (Murchison, 2010). The Intrinsic Case Study was the specific design used in this research and is a form of qualitative research that investigates a single, specific case because the case itself is of genuine interest and the researcher seeks to better understand that specific case (Merriam, 2009; Stake, 2005). In an intrinsic case study, the case is selected because of its own merits and uniqueness and not because it represents other cases. This study used the intrinsic case study design because the journey of Carter and his family with autism is unique and, in all its ordinariness, is of genuine interest to me as a researcher.

Participants

Eight persons were enrolled: Carter, his parents, two siblings, and three non-family members who worked with him during this time were interviewed. These individuals were selected purposefully because they knew Carter and had personal experience with him during this time. Their familiarity with the case enabled them to contribute meaningfully to this study. They were invited by letter to participate in the study. The names of the family members were changed to protect their identity.

Data Collection

Four kinds of data were gathered. The narrative and journal, interviews, documents, and artifacts. First, data was gathered mainly by use of Meghan's Narrative and Meghan's Journal, semi-structured interviews, focus group interviews, documents, and artifacts. Individual semi-structured interviews were conducted with: Carter, the school psychologist, a teacher, and Speech Therapist. Focus group interviews were conducted with Carter's siblings, then with his parents, and with the family in a group. In addition, data was gathered from a copy of Carter's IEP, and a copy of notes from a follow-up IEP meeting. Merriam (2009) says that there are times when data can only be collected by interviews, like when we want to study past events. Case studies featuring selected individuals are best served by interviews.

This qualitative research sought to pinpoint the educational and social interventions which were employed in working with Carter and to that end used the semi-structured interview as the primary method to gather recollections and perceptions of those involved. To identify the educational and social interventions that aided Carter in his journey out of autism - would best be served by the qualitative study approach. Conducted as an Intrinsic Case Study, data was gathered using Meghan’s Narrative, Meghan’s journaling found in Meghan’s Journal, an Individual Interview protocol of the child at the center of this case study, as well as the Interview Protocols of the school psychologist, therapist, and teacher. The Focus Group Interview Protocol was used to gather data from the family members in two focus groups. Data in the form of an IEP as well as a copy of notes on the IEP were used. Interviews were used to gather data. Individuals who knew Carter, or who worked with him during the time of his early development were invited by letter to participate in the study. They were informed of potential risk and their freedom to withdraw from the study at any time and each of these individuals signed consent forms.

A semi-structured interview protocol was followed to allow the participants the opportunity to share their memories of the process and to provide an in-depth view of the methods used to help Carter. Interviews were conducted in the months of October and November of 2016 and January of 2017. The interview with the School Psychologist took place in the board room at her office. The Speech Therapist - in her office, while the Piano Teacher - at her studio. The family focus group as well as Carter’s individual interview were conducted in Bell Hall, Andrews University – Room 018. The only persons present at these efforts to collect data were the interviewer and the interviewees. These venues provided privacy and freedom from distractions, and were conducive to the interview and free from intrusions.

Data Analysis

Analysis of this case study, looked for themes to emerge from the data and the narrative. Qualitative data analysis is rather more interpretive and focuses on meanings. It studies in depth and detail without predetermined themes and categories and is sensitive to context in contrast to universal generalizations (Denzin & Lincoln, 2008). Analyzing the data consists of basic steps: preparation, coding, analysis, and reporting. The NVivo software which is designed to analyze qualitative data was used.

NVivo enabled the creation of categories, the application of these categories to the text, the creation of visible connections between the categories, and the development of comparisons between the categories. First the text was scanned into the program’s rich text editor. NVivo created a rich text file. The researcher then clicked on a portion of the text and dragged it. The text was coded by creating categories for each portion of the text. As the document was read more codes were created to accommodate the portions of text. Each similar portion of text received the same code.

The coding was continually revised by the researcher to develop more accurate categories as needed. Some portions of text were assigned different codes simultaneously. NVivo allows the researcher to recombine categories, count code frequencies, and test hypotheses about relationships between categories (www.sagepub.com/upm-data/43454_10.pdf). The nodes proved to be too many to be mentioned individually. Smaller nodes were merged and those which did not extend across most data sources were eventually dropped. Using Axial Coding techniques similar nodes were grouped and placed under themes. For example; music was a strong node but it overlapped with art activities so frequently that music and art activities were combined. The coding resulted in some themes emerging from the data.

Ensuring High Quality Results

The first thing I did to ensure dependability was to include a thorough description of the research methods. Various data sources were checked against each other to evaluate accuracy and interpretation and to eliminate bias. Triangulation of the data presented by the various sources; the narrative, the journal, the interviews, focus groups, and artifacts proved useful in establishing the dependability of the research and eliminating bias. All of these processes enhanced the rigor of the research. Focus groups were conducted with two of Carter's siblings, with Carter's parents, and with his family. Individual interviews were also conducted with the Psychologist, Speech therapist, Piano teacher, Classroom teacher, and Carter.

Carter's Drive to Achieve

Carter flourished in the program created for him by his developmental team, however, his growth was not achieved by his being merely compliant with the adults in his life. They had goals for him but he also had goals for himself. One goal of Carter's was that he wanted to be like his siblings. Meghan said, "It appeared to me that he wanted to fit in with his siblings and since they were not wearing bibs, he refused to have one placed on him." (MN)

Carter paid close attention to his siblings as he was

> …going with them to swimming, going with them to music, going with them to piano, to ___, to art classes. They were his role models. They were ahead of him and he always wanted to catch up with them. I think they kind of set a standard for him and they raised the bar for him and he wanted to get into their activities.

Having older siblings and being in an environment where they were expected to play instruments fueled Carter's drive to succeed at music. Carter saw his siblings practicing on the piano. Meghan mentioned that “Carter continually amazed us by playing the piano pieces his older siblings were practicing.” (MN) He decided that he wanted to play the other instruments too and he said so. He played them effortlessly because he played what he heard, but he practiced extra until he got very good.

Earlier he participated in planning his activities, but he later took over the setting of goals. He discussed the elementary school he wanted to attend with his mom and presented reasons why he should be allowed to do so. One year he begged to be allowed to join the youth club and spent the summer drawing pictures of the uniform he was hoping he would wear. When asked by Mrs. B___ what he wanted for his tenth birthday, he was so focused that he promptly responded, “My youth club uniform”. He was focused on the goals he had set for himself.

One of his siblings commented,

> He’s really smart and he got this drive and this motivation that I don’t know, sometimes I just wish I had some. (SFGI)

Another example of this was shown when Carter insisted that he and Meghan attend a Bible memorization competition. He liked what he saw and decided immediately that he wanted to participate the following year. This was beyond his present level of functioning since he was not yet reading at the level of the competition. With Meghan’s help, he studied for the qualifying test. He passed the test, qualified for the team and took part in the competition. The competition season lasted four months. He made the team for five consecutive years. Carter’s setting of goals, planning, and reaching those goals all contributed to his development and to his no longer meeting the criteria as outlined in the DSM V for receiving services for

ASD. The dynamic way Carter grew developmentally despite his diagnosis demonstrated his drive to succeed.

Importance of Meghan's Belief

The findings revealed that Meghan held certain beliefs and that these beliefs undergirded her behavior toward Carter, her goals for him, her manner of setting out to organize the support team, her selection of new and unusual toys for him, and the curriculum she developed for him. Meghan's basic beliefs which influenced this study were:

1. Carter could learn.
2. Carter needed to learn to communicate.
3. Purposeful language was what Carter needed to be engaged in.
4. Improved instruction results in improved outcomes (Barber & Mourshed, 2007).
5. Every child can learn and it is the teacher's responsibility to find the way that works for the child (Marzano *et al*., 2001).
6. An individual teacher can have a significant effect on student achievement, even if the school does not (Brophy & Good, 1986; Wright *et al*., 1997).

These beliefs provided fuel for Meghan's drive to help her son. She was convicted that Carter could learn and that communication was the key. She first asked for sign language lessons, but Carter did not qualify for sign because his vocabulary was adequate. Meghan believed that Carter needed purposeful language, and she set about assembling a team of interventionists to assist her in the project. Because she believed strongly that purposeful language was needed, she enrolled him in

Kindermusic (music classes for babies), swimming and gymnastics classes for infants. These classes provided purposeful language. Following the instructions meant success, getting to do as the others, even staying afloat. Believing that improved instruction resulted in improved results drove her to look for ways to engage her son's attention and to teach him. Because Meghan believed that the teacher was key to the student's success, she took on the task of working with him herself, believing that she was the best suited for the task since she was so heavily invested in him.

Meghan believed that Carter would at some time grow and change to some extent, and thus he was included and expected to participate in the activities of his siblings. He was not treated differently because he had autism. For example, the children were all taught by their mother in their homeschool, each child working at their grade level. Carter memorized the same poetry and sang in the same choir as his siblings. Meghan's beliefs informed her intentionality.

Curriculum: Outgrowth of Meghan's Intentionality

One of the factors affecting the results demonstrated in this study is Meghan's intentionality. To be intentional means to have a goal in mind, create a plan and set out to accomplish it. Meghan was determined that Carter would learn to communicate, engage in purposeful language and become productive. She conceived a plan to involve others to help her to achieve these goals and set out to accomplish them. The effect of Meghan's intentionality on Carter's interventions is discussed here.

Meghan said,

> "There was no time in the entire experience that I felt that Carter was going to remain the way he was. I was always working toward the goal of his becoming whatever he was going to become even though I had no idea what that looked like, but I was sure it was not what he was presenting at that time.

> This outlook is part of my thinking that every child can learn. I was going to find what worked for my son." (Mother's Journal)

Psychologist:

> "I would say … the work that parents, i.e. Mom did at home to provide him with so many opportunities, especially appropriate socialization where the expectations were really set that he would interact and be part of this family just like anybody else. We weren't going to treat him differently just because he has autism. We weren't going to think he couldn't do anything just because he has autism. He got involved in the music just like the rest of the family. He got involved with social church things just like the rest of the family so he was really brought along as if these are the expectations and you will meet these. (Psych I)

While Meghan held the conviction that Carter could learn, she did not know how much he could learn, or when he would learn it, because each child is different, even identical twins (Ghose, 2012). Believing that he could learn, Meghan said that she was going to find what worked for her son. Unsure of which avenue to use to reach Carter; linguistic, musical, mathematical-logical, visual-spatial, bodily-kinesthetic, intrapersonal, interpersonal, naturalist, or existentialist (Gardner, 1991), Meghan developed a multiple-intelligence-based curriculum for him. This program utilized different intelligences through content from languages, music, mathematics, geometrical puzzles, gymnastics, swimming, games, structured social groups such as the children's choir and the youth Club, audiobooks, videos, writing, and drawing. This unique multiple-intelligence-based curriculum used with ongoing assessment yielded great results. Carter blossomed. He stopped screaming, learned to; communicate, hold someone's gaze in conversation, respond appropriately in social situations, carry on conversations, follow directions, observe personal space, use purposeful language; teach others, speak in public, contribute to organizations in which he participated, and become productive demonstrating that Carter could learn and that the teacher is key.

Meghan’s intentionality was the glue that held together the curriculum she designed for him. Convicted in her heart that Carter could learn given the right circumstances, she set out with the intention that he would progress. Each of the educational interventions under the categories of Carter’s Developmental Support Team, the Processes, and the Content came to be part of the curriculum for Carter because Meghan felt that it would be helpful and she included it. Carter’s support team, which consisted of his parents, his siblings, the Speech Therapist, and his teachers were encouraged by Meghan’s intentionality to provide him with every possible opportunity to learn. Everyone who worked with Carter shared Meghan’s attitude that he would do as he was asked. This was their expectation and Carter lived up to it. This intentionality that Carter must improve enabled Meghan to appreciate working with the professionals and fueled her commitment to cooperate with the speech therapist to maximize the results and was demonstrated by her efforts to get him to understand figurative speech. He was not excused because he had autism. My findings indicate that Meghan’s beliefs fueled her intentionality. My findings indicate that Meghan’s vision for Carter influenced the broad spectrum of educational and social interventions used with Carter.

Diagnosis of Autism used as Guidepost

Carter’s diagnosis of autism served as a guidepost for Meghan outlining skills which needed to be worked on, for example; following directions, Meghan involved her family in building these skills in Carter. She enlisted his siblings to keep him engaged, to model for him, to read to him, and to keep him calm. Everyone who worked with Carter shared Meghan's attitude that he would do as he was asked. This was the expectation and Carter lived up to it. Rather than excuse his behavior to others, Carter was encouraged to greet people, make eye contact with them, and behave appropriately. His teachers gave him homework like everyone else and expected him to have it done. Carter's Developmental Team, Processes, and Content all grew out of Meghan's use of the diagnosis as a guidepost.

Family's Role

Meghan's involvement of her family in early intervention treatment for ASD is recommended (Wallace & Rogers, 2010); however, early intervention in autism produces varied results based on a number of factors. One factor is knowing which intervention will work for a particular child. Family involvement is another factor in ASD treatment which should be studied to ascertain the characteristics associated with responses to treatment (Vivanti *et al.*, 2014). Treatment programs may utilize a form of treatment requiring some commitment from the family. Stahmer, Schreibman, & Cunningham, (2011), indicate that some issues which could potentially impact intervention response are: family system or philosophy, family commitment, family culture, and family educational beliefs.

An early intervention program may employ a format that may not be a match with the cultural values, social norms, or educational beliefs, of the family. Family stress level, positive paternal involvement, and positive family expectations for outcome of intervention, family support, and ability of parent to work cooperatively with therapists have the possibility to impact intervention (Stahmer *et al*., 2011).

Families of children with developmental disabilities experience greater stress than families with other problems due to behavior such as cognitive delay (Baker *et al*., 2002; McStay *et al*., 2013; Vivanti *et al*., 2014). Mothers of children with ASD also report higher levels of distress than those with no disabilities or even other disabilities (Brobst *et al*., 2008) making the family's role in facilitating interventions a necessity.

Teaching skills to children is enhanced when the skills are generalized across various settings. Importantly, the concept of family involvement is consistent with the recommended broader best practices that support working with young children in natural environments. Zwaigenbaum *et al*., (2015) reviewed current evidence for autism spectrum disorder (ASD) interventions for children aged less than 3 based on peer-reviewed articles up to 2013 and concluded that family involvement is also likely to be cost-effective and increases the sense of empowerment on the part of parents and caregivers. Under Meghan's supervision, Carter's family engaged him in a continuous all-day program of teaching him, redirecting him, playing games with him, reading books to him, modifying his diet, supplementing his diet, family outings and reinforcing Speech Therapy techniques introduced and recommended by the therapist. The success of this form of intervention is noted through studies conducted by Wieder & Greenspan, 2005) which suggest that relationship-focused intervention is effective when working with young children who appear relatively high on the spectrum and parents who appear to have the resources and energy to become intensely involved in the intervention activities (Case-Smith & Arbesman, 2008). New research and anecdotal evidence suggest that some alternative therapeutic choices that include sports, exercise, and other physical activities can be a useful adjunct to traditional behavioral interventions, leading to improvement in symptoms, behaviors, and quality of life for individuals with autism. https://www.autismspeaks.org/science/science-news/sports-exercise-and-benefits-physical-activity-individuals-autism

Everything that Carter was exposed to, everything that he was privileged to be a part of, was accomplished through the efforts of his family and orchestrated by Meghan. Carter's speech therapy sessions, swimming sessions, music lessons, children's choir, youth group, gymnastics, orchestra, and other activities took place in the company of his mother and siblings. Carter was accompanied in his activities by his mother and siblings and in doing so, they learned a variety of ways to work with him. There is consensus that effective early intervention includes a family and/or caregiver component (Johnson & Myers, 2007).

Parents as Teachers

The power of involving parents in their child's intervention cannot be underestimated. Parents can be provided with training and supervision to facilitate their being involved as co-therapists. The National Research Council Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education (2001) recommends that "specifically, parents should help set goals and priorities for their child's treatment, identify and locate needed support for themselves, and teach or reinforce their child's new skills at home and in the community." Zwaigenbaum *et al*., (2015) reviewed current evidence for autism spectrum disorder (ASD) interventions for children aged less than 3 based on peer-reviewed articles up to 2013 and concluded that family involvement is also likely to be cost-effective and increases the sense of empowerment on the part of parents and caregivers.

The second year of life is a period that is developmentally critical for children with ASD. During this time, the brain exhibits increases in brain volume, and atypical neural connectivity related to ASD takes place. This is the time when some children with ASD demonstrate regression and changes in behavior. The potential for setting the course developmentally for these children is great at this time as timely interventions can halt the downward snowballing of regression and behavior change (Zwaigenbaum *et al*., 2015). Interventions should be developmentally appropriate. Teaching skills to children is enhanced when the skills are generalized across various settings. Parents can be valuable resources because they have unlimited access to their children and can teach and reinforce at all times. Importantly, the concept of parental involvement is consistent with the recommended broader best practices that support working with young children in natural environments.

New research and anecdotal evidence suggest that some alternative therapeutic choices that include sports, exercise, and other physical activities can be a useful adjunct to traditional behavioral interventions, leading to improvement in symptoms, behaviors, and quality of life for individuals with autism. https://www.autismspeaks.org/science/science-news/sports-exercise-and-benefits-physical-activity-individuals-autism.

Parents can facilitate their child’s participation as Meadan (2016) and her colleagues explain:

> …a few hours of therapy each week does not result in the type of developmental gains for children compared to those achieved by teaching

> intervention strategies to families and encouraging them to take advantage of the ‘teachable moments’ they have with their children in home and community environments. (3, p. 103)

The collaboration between professionals and parents provided Carter with the best possible teaching and teachers. In some instances, Carter’s parents included activities that built on his strengths. His interest in music provided an avenue to help develop his social skills and to introduce him to being a part of groups like the children’s choir and the orchestra. Committed teachers and parent-educators are to keep in view what the students may become and seek to develop all of their powers even when the outlook is dubious (White, 1903).

Most children with autism are generally diagnosed while still very young and spending more time with their parents than elsewhere. Therefore, having parents and caregivers included as part of the intervention team increases the amount and the frequency of the intervention.

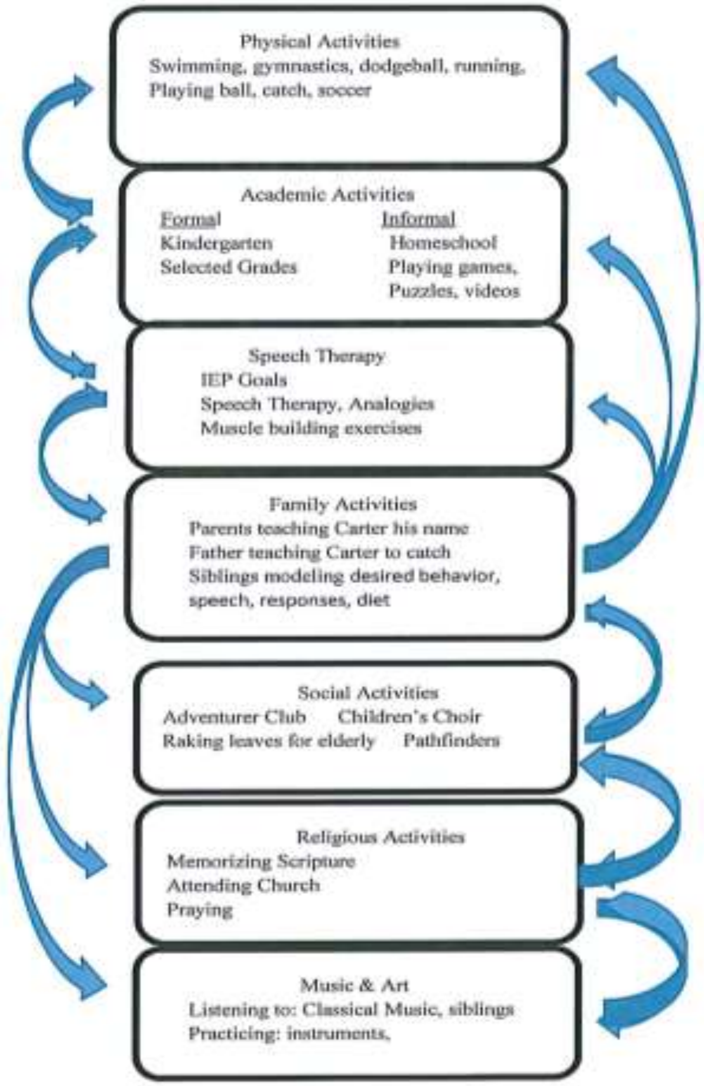


Chart showing interrelatedness of activities

Figure 10. Interrelatedness of Activities

Parents have the added advantage of being able to seize teachable moments and to make the most of them to provide learning opportunities on the go. This will facilitate transfer of knowledge across subject areas and impact developmental outcomes positively (Carter *et al*., 2011).

Meghan said,

> I felt that he had to have the words and sentences modeled to him. Teaching Carter became our nightly family activity for a while. We began by teaching Carter his name. Daddy or I would ask each person at the dinner table their name. In turn, they would answer and I would repeat their response in this way, 'His name is …' Then it would be Carter's turn. One of us would say his name for him and I would repeat, 'My name is Carter.'

She continued,

> Next came names of everyday items. We asked each person at the table the name of an object on the table, starting with the table itself.
>
> Each person at the table would say the name of the object in a sentence. Then we would ask Carter the question, hoping that he would repeat what he heard everyone say. It took a while, but the first time Carter responded, we all erupted in applause, hardly daring to believe our ears. At last we knew that he could learn from our teaching.

The Speech Therapist commented that the work done by Meghan effected the biggest improvements in him:

> Oh huge. The improvements, and I was an integral part, but a small part. Mrs. (Carter's mother) did the biggest work, which was to expose him, to develop a curriculum for him where he was exposed to situations where he had to deal socially with other human beings. A child with autism tends to be by himself wanting to be by himself and in a world alienated from reality and so for him that was the integral part and also enhancing his skills which was music. It's music. He's gifted in music, so having him in swimming, in music, creating an academic curriculum using bi-neural feedback with music to enhance his ability to focus. All these things together worked to improve his overall ability to socialize and be part of a community. So, it's all based on the curriculum that was developed for him and I was just a part of that curriculum. (STI)

Research findings indicate that the progress made with Carter depended in a great part on the involvement of his parents. Both parents worked with Carter to teach him; for example, to say his name, to identify his siblings, to name objects around the house, among other accomplishments. Carter's Dad made a point of working on Carter's eye-hand coordination. He enabled his wife to stay at home and homeschool Carter and take him to his many appointments. Carter's development would have been less complete without the full support and participation of his father.

The Psychologist said that Carter progressed because his mother's intention was,

> We weren't going to treat him differently just because he has autism. We weren't going to think he couldn't do anything just because he has autism. He got involved in the music just like the rest of the family. He got involved with social church things just like the rest of the family so he was really brought along as if these are the expectations and you will meet these. (PI)

The Psychologist and the Speech Therapist said that the curriculum developed by Meghan was of great importance. The Speech Therapist noted that the work done by Meghan effected the biggest impact on him (STI). Once Meghan realized that Carter did not grasp figurative speech, she requested help in that area. The therapist then set about to remedy that situation by adding the illustrated book of sayings to the curriculum. According to the Psychologist, Meghan set the expectations that Carter could do anything and even involved him in church activities just like the rest of the family (Psych I). Meghan was the coordinator of specific activities to help Carter and she followed through on the recommendations of the Speech Therapist. Carter's siblings concurred that their mother's efforts to keep Carter engaged, to read to him, to have an arsenal of activities at the ready, to anticipate his needs, and to assess and plan for his growth, were critical to his progress.

Siblings as Teachers

At the beginning of the journey with Carter, at the dinner table, Meghan initiated a style of teaching him which involved his older siblings as instructors. At Speech Therapy the siblings encouraged Carter to follow the Speech Therapist's instructions; repeating her exercises, modeling exercises intended for him to practice, and encouraging him to imitate them. They kept him engaged and cheered him on providing positive reinforcement during the therapy sessions encouraging him to practice desired behaviors.

Carter's siblings caught their mother's vision and became his willing leaders. They were his role models in swimming, gymnastics, instrument playing, piano lessons, and art classes demonstrating the educational aspect of the family interaction pattern where the younger or less knowledgeable family members learn from those older or more knowledgeable (Cicirelli, 1975). This intervention is closely related to another instructional approach - modeling and imitation. In various cultures older siblings provide care, model appropriate behavior, teach valuable knowledge about life to younger siblings (Zukow, 1989).

Another documented advantage of having older siblings is that including them as role models and aides positively influenced the group dynamics because of their familiarity with their sibling's behavior (Case-Smith & Arbesman, 2008). Typically developing peers exerted a positive influence in encouraging cooperation and social interaction while peers with behavioral disorders had the opposite effect (Legoff, 2004). Vygotsky taught that a student can with speech and supportive conditions from a knowledgeable person participate in and extend his/her present skills and knowledge to a high level of competence (Donato, 1994). Carter's siblings modeling correct responses was a method of teaching. This demonstrated that responsive, supportive relationships which promote social-emotional development have the ability to facilitate the child's social-emotional growth and to encourage the growth of key behaviors which are important for learning (Greenspan & Wieder, 1999; Mahoney & Perales, 2005; Wieder & Greenspan, 2005).

Interview responses indicate that one of the teaching methods used with Carter was having his siblings provide him with models for him to imitate. Beginning by imitating at the family dinner table, his siblings were his role models and teachers (FFGI). The older siblings followed the Therapist's instructions and modeled exercises intended for Carter to practice. Meghan, in recognition of the role of his siblings said, "They were his role models in swimming, gymnastics, ____ playing, piano lessons, and art classes. They were built-in knowledgeable playmates, keeping him engaged and they set the bar for him." (FFG, STI)

Speech Therapist

Working with the Speech Therapist was a major theme emerging from Meghan's Narrative. Meghan's concern for Carter's developmental progress led her to seek sign language instruction. Her desire to have him progress propelled her into the Special Education program and working with the Speech Therapist. Because Carter had been fed by tubes during his long hospital stay, the muscles around his mouth were weak and this affected his ability to produce initial and medial sounds which affected his ability to communicate. The Speech Therapist targeted this and several other areas to focus attention on. She encouraged him to exercise the weak muscles. She provided him with several exercises. For example, the muscles around his mouth were strengthened by blowing a feather across the table, blowing soap bubbles, pulling air up a straw, and using a straw to blow on objects. These activities were planned to provide a specific outcome. Speech evaluation and Therapy formed a big part of the curriculum designed for Carter.

> The most widely used behavioral intervention programs focus on developing communication, social, and cognitive skills. However, new research and anecdotal evidence suggest that some alternative therapeutic choices that include sports, exercise, and other physical activities can be a useful adjunct to traditional behavioral interventions, leading to improvement in symptoms, behaviors, and quality of life for individuals with autism. https://www.autismspeaks.org/science/science-news/sports-exercise-and-benefits-physical-activity-individuals-autism

Speech therapy emerged as a key component in the curriculum developed for Carter. Responses from 100% of the interview respondents indicate that speech therapy gave Carter significant tools that facilitated his progress, namely, strengthening oral muscles. Speech therapy trained those muscles to produce “p,” “b,” and “m” sounds and thereby enabled his pronunciation of initial, medial, and final consonants, and thus enhanced his communication. Speech Therapy helped Carter slow down his thinking and organize his thoughts and put into practice the strategies he was being taught. It focused on literal thinking by providing him with workbook practice in discerning literal from figurative speech. It targeted his ability to communicate by providing activities that developed his understanding of humor and analogies. Working with the Speech Therapist profoundly facilitated Carter’s ability to express himself and thus positively affected his ability to socialize. This is supported by statements by one of his siblings, the Speech Therapist, the School Psychologist and Meghan.

Conceptual Model

The research questions asked whether social and educational interventions contributed to Carter’s experience. What educational interventions used with Carter contributed to his no longer meeting the criteria for receiving services for ASD? What social interventions contributed to his no longer meeting the criteria for receiving services for ASD? The study set out to garner the responses to those questions from the case study utilizing interviews, focus groups, and other forms of data. It was the intention to allow the variables contributing to Carter’s experience to emerge from the study and as such the study did not employ a conceptual framework or attempt to predict the variables at the onset.

The analysis of the responses answered those questions and pinpointed several key factors working together with social and educational interventions which contributed to Carter’s growth and development. These key factors formed the conceptual model. The conceptualized model of this research is positioned in the variables affecting Carter’s growth. This model sets out six main variables, which emerged in the study as the main pillars or supports of the research. The six variables also called factors, which impacted Carter’s growth were identified as; the school district office; Carter’s support team which consisted of the speech therapists, teachers, and instructors, the interventions used, Carter’s parents as facilitators of all interventions, the Individuals with Disabilities Education Act, and Carter himself.

The study found that these factors interacted to create the broad system of support that delivered a successful outcome for Carter. The first factor – the school district office is the originator of the support provided for Carter. The school as it operated under the district office followed established guidelines. These guidelines provided Carter with the Individualized Education Plan meeting, which facilitated the diagnosis of autism that started the process of intervention for Carter.

The second factor was Carter’s support team. This team was comprised of all the adults and family members who participated in some way to facilitate Carter’s interventions; the Speech Therapist, swimming instructors, gymnastic instructors, social worker, classroom teachers, piano teachers, IEP team, and Carter’s family.

The third factor in the system was Carter’s parents. The study revealed that Carter’s parents not only initiated contact with the school, but that they were the point of contact for the other factors. They facilitated and maintained Carter’s working with each factor. They were also his first teachers and they maintained a home environment that contributed to his development (Richardson & Rothstein, 2008). Parental involvement is a significant strategy for effectively educating learners with special education needs (Afolabi, 2014).

The fourth factor was the educational and social interventions used with Carter. These interventions took the forms of specific subject matter, activities, clubs, and associations, which facilitated social interactions and growth, academic stimulation, and spiritual development.

The fifth factor was the Individuals with Disabilities Education Act which undergirded the previous four factors with the law supporting responsibility towards children with disabilities. This factor provided the basis for the existence of the interactions between the school and the support team and the other factors as well.

Carter himself was the sixth factor as he demonstrated a drive for progress. The study found that Carter’s progress was the result of all the factors working together.

These findings are depicted in the conceptual model. One of the objectives of a conceptual model is to enhance our understanding of the purpose of the research. The conceptual model provided a visual depiction of the inter-relatedness of the variables. It showed that Carter's progress grew out of the interaction between the variables and their working together through the parents' efforts.

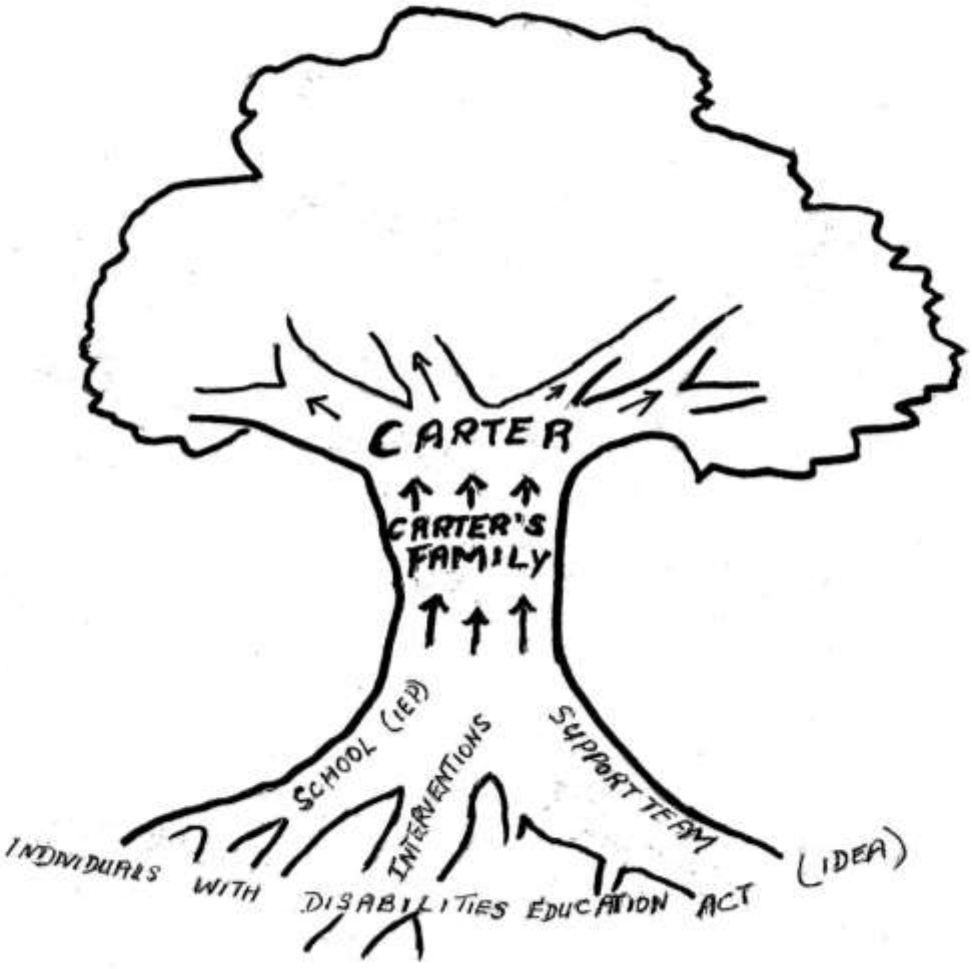


Figure 11. Diagram Showing Conceptualized Model of the factors affecting Carter's Growth

Conclusions of the Study

Each child is an individual. Parents with a child diagnosed with autism should recognize that their child is a unique individual with their own strengths, interests, preferences and weaknesses. From the story of Meghan working with Carter, some suggestions emerge for families working with a child who has autism. Each parent or caregiver should:

- Study their own child and their particular set of circumstances.
- Seek services from the local school district.
- Become knowledgeable on the subject of autism.
- Use a variety of educational and social interventions which are relevant and available or which engage their child’s interest.
- If feasible the parent may want to develop a method for incorporating the interesting or relevant activities into the curriculum for their child.
- Involve the family members as teachers, models, and companions.
- Work with the intention that there will be improvement.

In the process of working with Carter, Meghan discovered that music resonated with him. She encouraged his interest and his ease with music by providing him with instruments, lessons, performances, music organizations, and other opportunities. Had his interest or giftedness lain in another field, she would have focused the work there. This initial research suggests that greater cooperation between parents of affected children and professionals is the best approach for managing this disorder.

Recommendations

This study has revealed many of the intervention approaches used with Carter. While it is clear that the techniques used were effective as evidenced by the change in Carter’s mannerisms and subsequently in his no longer meeting the criteria for autism therapy, further study of these approaches as interventions is recommended to determine their individual effectiveness. The findings indicate that while Carter benefitted greatly from the personalized program created for him by Meghan and the professionals, further study is recommended to ascertain which techniques would be applicable to children in general and how much of each intervention is needed. The findings suggest the following areas for further research:

The findings of this study indicate that manipulatives such as play dough, Legos, and Connect bits were used to help Carter. These manipulatives were found to be successful as he stopped twitching his fingers in the light above his head. Instead he became adept at writing, drawing, cutting with scissors, and using his hands productively. However, it is not known exactly how much time was needed with the use of each manipulative to effect a change. Therefore, further study of manipulatives as an intervention is recommended to determine their individual effectiveness in treating symptoms of autism.

In this study music played a prominent role in Carter’s life and was found to be a key to Carter’s progress. He loved it and expressed an affinity to it. Because of his environment, Carter experienced music every day through studying instruments in a variety of ways such as; listening to classical music, attending Kindermusic classes, singing in the children’s choir, playing instruments, and as he grew older performing in various groups and practicing music every day. However, it is not known how much of the time and effort devoted to music would have been actually adequate to affect a difference in Carter’s life.

Further study is therefore recommended to ascertain how much music is needed to make a difference in the life of students diagnosed with autism. Further study is recommended to determine which behaviors were positively affected by specific music activities. Further study is also recommended to determine whether music is effective for only some students or whether it is effective for all students with autism; and, if music is effective in making a difference in only some students, what would be the characteristics of these students?

APPENDIX A

IRB APPROVAL LETTER

APPENDIX B

CONSENT FORMS AND RESEARCH INSTRUMENTS

Andrews University

CONSENT FORM For All Persons Involved in Research

My name is Kwame De Jonge-Moore. I am conducting a research study as part of my dissertation, in partial fulfillment for my Doctor of Philosophy degree at Andrews University, Berrien Springs, Michigan. I would greatly appreciate your participation in this study.

Research Title: Journey with Autism: Emergent Educational and Social Interventions from a Single Case Study

Purpose of Study: To find our which social and educational interventions were useful for helping someone diagnosed with autism.

Duration of participation in study: I understand that I am being invited to participate in an interview or focus group for approximately thirty minutes, and that follow-up interviews may be requested.

Procedures: I will be giving permission for the researcher to interview me and use my responses.

Benefits: The study will be helpful for students, parents, and teachers. It will help everyone to learn how parents, schools and communities can work together to improve the diagnosis of autism.

Risks: I will not experience a risk of being harmed in any way during the research study above normal risk.

Voluntary Participation: My participation in this study is completely voluntary. Refusal to participate will involve no penalty or loss of benefits to which I am otherwise entitled. I may discontinue participation at any time without penalty or loss of benefits to which I may othewise be entitled.

Confidentiality: I understand that the child's identity in this study will not be disclosed in any published document. The researcher will keep the records in a secure computer, used only by the researcher and advisors for a period not less than 3 years. I understand that my responses will be treated confidentially in the research report.

Contact: I am aware that I can contact Dr. Larry Burton, the research supervisor of Kwame De Jonge-Moore at (burton@andrews.edu) or 269-471-3465 or the researcher Kwame De Jonge-Moore at kmdmoore@yahoo.com 269- 277-0317 for answers to questions related to this study.
I have read the contents of this Consent and received verbal explanations to questions I had. My questions concerning this study have been answered satisfactorily. I hereby give my consent to participate in this study.

____

Participant's Name (Subject) **Date**

____

Participant's Signature (Subject) **Date**

____________________ ____________________ ____________________

Researcher Signature **Phone** **Date**

Andrews University

PARENTAL INFORMED CONSENT FORM

My name is Kwame De Jonge-Moore. I am conducting a research study as part of my dissertation, in partial fulfillment for my Doctor of Philosophy degree at Andrews University, Berrien Springs, Michigan. I would greatly appreciate your child's participation in this study.

Research Title: Journey with Autism: Emergent Learning Strategies from a Single Case Study

Purpose of Study: The purpose of this study is to identify which social and educational interventions were helpful to someone diagnosed with autism.

Duration of participation in study: I understand that my child will be required to participate in an interview or focus group for approximately thirty minutes.

Procedures: I will be giving permission for the researcher to use a copy of my child's IEP for 2004-2007. I will be giving permission for the researcher or her representative to interview my child.

Benefits: The study will be helpful for students, parents, and teachers. It will help everyone to learn how parents, schools and communities can work together to serve children given the diagnosis of autism.

Risks: My child will not experience a risk of being harmed in any way during the research study above normal risk.

Voluntary Participation: My child's participation in this study is completely voluntary. Refusal to participate will involve no penalty or loss of benefits to which she/he is otherwise entitled. The child may discontinue participation at any time without penalty or loss of benefits to which she/he may othewise be entitled.

Confidentiality: I understand that the child's identity in this study will not be disclosed in any published document. The researcher will keep the records in a secure computer, used only by the researcher and advisors for a period not less than 3 years.

Contact: I am aware that I can contact Dr. Larry Burton, the research supervisor of Kwame De Jonge-Moore at (burton@andrews.edu) or 269-471-3465 or the researcher Kwame De Jonge-Moore at kmdmoore@yahoo.com 269- 277-0317 for answers to questions related to this study.
I have read the contents of this Consent and received verbal explanations to questions I had. My questions concerning this study have been answered satisfactorily. I hereby give my consent for my child ____ to participate in this study.
(Write Child's Full Name)

__________________________________ __________________________

Parent's Name (Subject) **Date**

_____________________________ __________________________

Parent's Signature (Subject) **Date**

Parent's Name (Subject)_______ _______**Date**______________

_____________________________ __________________________

Parent's Signature (Subject) **Date**

_____________________ ____________________ ________________________________

Researcher Signature **Phone** **Date**

STUDENT ASSENT FORM

My name is Kwame De Jonge-Moore and I am conducting a research study as part of my PhD at Andrews University. This study has been explained to you previously. The purpose of the research is to try to understand which learning activities are useful for helping someone diagnosed with autism. I am asking you to be part of this research by participating in an interview or focus group. The items will be short questions about your observations.

You are free to stop taking part at any time. There is no penalty for withdrawing. Participating in the interview or focus group does not present any risk or harm to you. Your identity and responses will be kept secure and private. This should be an enjoyable experience for you.

I ______________________________ agree voluntarily to take part in the research study.

Date: ________________

Flow of Subject Interview **Process**
Introduction and explanation of the study
Test recording device
Begin recording: Now we are recording”
Consent form review
Begin interview
Thank you and request permission to contact again (if additional questions arise later)
Complete interview
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Introduction

The purpose of this qualitative study is to identify social and educational interventions which aided you in your journey out of autism; to describe the impact of the educational interventions on you, from the perspectives of the interviewees, and to identify and elaborate the educational and learning processes employed by several individuals who worked with you and helped you move beyond the diagnosis.

The purpose of this study is to identify the learning activities that contributed to your subsequent designation who had been formerly diagnosed as autistic. Results from the research will help to improve the experience of parents working with their children diagnosed with autism and help us as a group of educators to better understand which activities shifted the diagnosis of autism and how they did so. We would like you to share your recollections of your journey with us.

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I would like to begin by asking about your recollections of childhood.

1. What are your earliest memories of childhood?
2.1 Why do you think these memories are still with you?
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2.2 What do you remember about how others, family members and others, responded to your behavior when you were very young?
2.3 Did the types of responses to your behavior change over time? If so, how?
2.4 How did these experiences influence you? (behavior, thinking/learning, outlook/perspectives, desires and goals)
3. What kinds of feelings or emotions do you remember experiencing as a young child?
3.1 Do you see any connections between your feelings and your earliest memories?
3.2 How have your emotions changed or stayed the same as you have matured?

4. What would you say were your greatest challenges growing up? What were the toughest things for you to learn or do?

    a. Speaking clearly was a challenge for you. What activity or activities helped you to pronounce words clearly?
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    d. There was a time when it was difficult for you to look a person in the eye when you were speaking to him or her. That does not seem to be an issue now. Tell me about an activity that aided in your being able to look at the person you are talking to directly in the eye.

5. What kinds of activities do you think were most important in helping you grow and develop to the place where you no longer fit the description of a person with autism?
If not mentioned, follow up with additional questions.
5.1 I know you were very active in a variety of activities over the years. Which of these do you think helped your growth the most?
5.1.1 Speech Therapy
5. 1.1. a. What do you remember about going to the Speech Therapist?
5. 1.1. b. What was done there and how did it help you?
5.1.2 Gymnastics
5.1.3 Bible Competition
5.1.4 Swimming lessons

6. Did you attend Gymnastic classes?
a. How did those classes help you?
b. How old were you at the time?
7. What do you remember about challenges with communicating?
a. We can’t imagine you ever having difficulty communicating, so tell us what was that like? Describe for us.
b. How is your communicating with others now?
c. What could have possibly made the difference?
8. Was swimming helpful and if so, how so?
9. What are some of the things that you have accomplished in your life by yourself or together with your siblings?
10. What is your greatest accomplishment?
11. What have you done that has given you the most pleasure?
12. Do you remember when your love for music began? Has music played a part in your improvement?
12. What is it about music that it made such an impact on you?
13. You play several instruments. Please name them. Can you say if playing several instruments has been helpful to you? If so, how so?
14. You have been active in the ___ club and in the ___club. Has either of these contributed to your progress? If yes, how so?
15. Was the Bible Competition an activity that proved helpful? If so, how?
16. Was attending school a factor in your progress?
a. Explain. How has attending school been a factor in your development?

17. You have proven that you are an excellent student. Studying requires a lot of focusing. Did you always have good focus or was there a time when you were very easily distracted and had difficulty focusing? What do you think has helped you to be able to focus so that you can turn your assignments in and produce quality work?
18. Describe your home environment. Did your home environment enable you to grow? How?
19. In reflecting upon your personal experience in growing out of the diagnosis of autism, what recommendations would you make to parents and families of children with a diagnosis of autism?
a. What activities would you recommend as absolutely necessary in the curriculum of a child with autism?
20. What have your teachers done that have facilitated your growth as a student and as a person?

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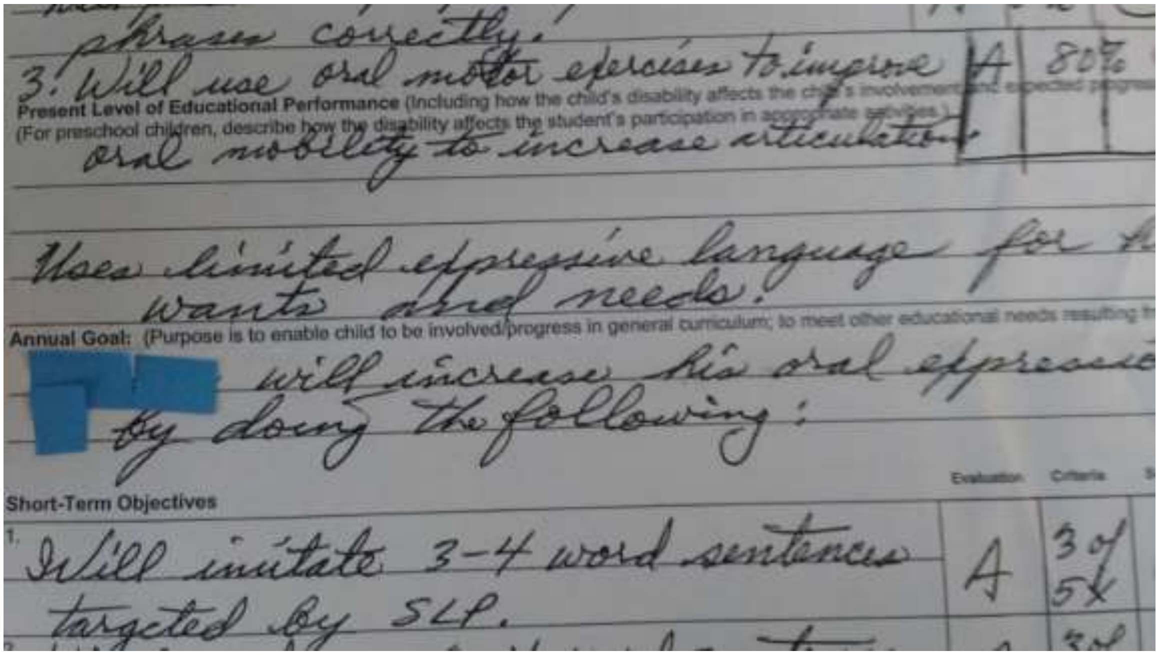
APPENDIX C

ARTIFACTS

Soft Toy – Multi-function Car



phrases correctly.

3. Will use oral motor exercises to improve oral mobility to increase articulation | A | 80%

Present Level of Educational Performance (Including how the child's disability affects the child's involvement and expected progress

(For preschool children, describe how the disability affects the student's participation in appropriate activities.)

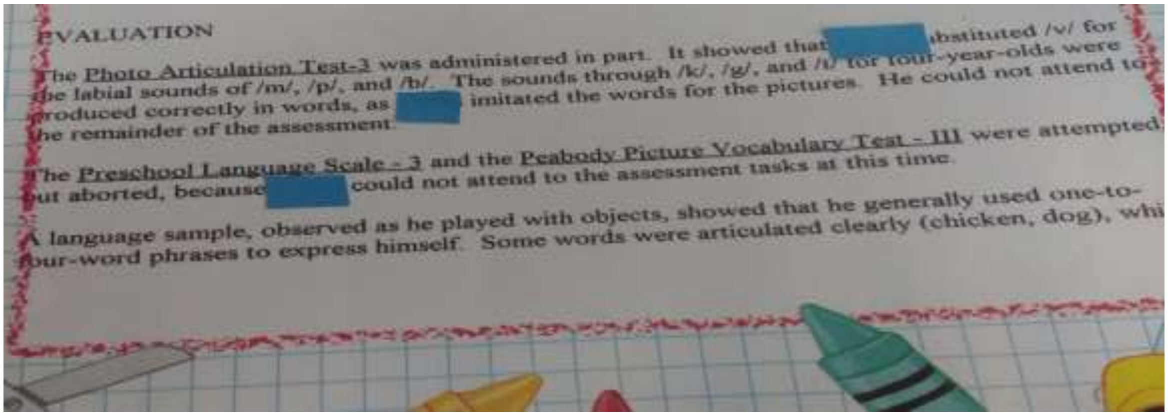
Uses limited expressive language for h
wants and needs.

Annual Goal: (Purpose is to enable child to be involved/progress in general curriculum; to meet other educational needs resulting fr

[redacted] will increase his oral expressio
by doing the following:

	Evaluation	Criteria
Short-Term Objectives		
1. Will imitate 3-4 word sentences targeted by SLP.	A	3 of 5x

Excerpt from Carter's Individual Educational Plan



EVALUATION

The Photo Articulation Test-3 was administered in part. It showed that [redacted] substituted /v/ for the labial sounds of /m/, /p/, and /b/. The sounds through /k/, /g/, and /t/ for four-year-olds were produced correctly in words, as [redacted] imitated the words for the pictures. He could not attend to the remainder of the assessment.

The Preschool Language Scale - 3 and the Peabody Picture Vocabulary Test - III were attempted but aborted, because [redacted] could not attend to the assessment tasks at this time.

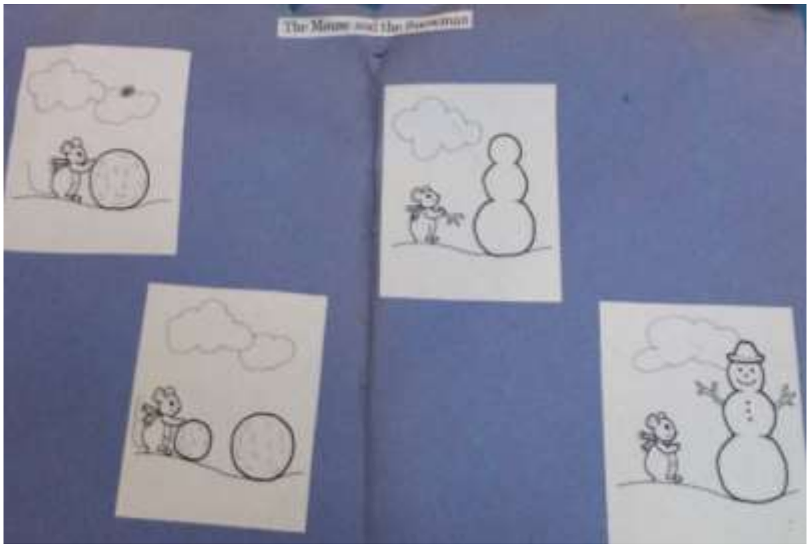
A language sample, observed as he played with objects, showed that he generally used one-to-four-word phrases to express himself. Some words were articulated clearly (chicken, dog), whi

Excerpt from Carter's Initial Speech-Language Evaluation

Textured Flash Cards

Spelling Word Puzzle

Touch and Feel Flashcards



A Sequencing Exercise

A Matching Exercise

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