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One Drug, Two Drugs, Three Drugs, More: A Critical Habilitative Narrative Inquiry into Autism Spectrum Disorder

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A Critical Habilitative Narrative Inquiry into Autism Spectrum Disorder

by

VIRGINIA WILLIAMS

Under the Direction of John Weaver

ABSTRACT

With increasing prevalence of Autism Spectrum Disorder (ASD) being diagnosed since its inception, there is reason for significant concern in regards to the cause, treatment, and prognosis of the disorder. This work investigates some of the political, economic and social factors that impact treatment for persons identified with ASD in the context of public education. Utilizing a grounded theory approach to critically analyze current legislation and practices governing special education services in the public school setting, a disturbing picture is revealed of not only how we educate persons labeled as disordered, but also how we respond to them socially. Future implications to our society, as a result of those perceptions, are also pondered. Through an interview process, the concepts of care, social justice, personal advocacy, and fear are deliberated in respect to those identified as the ASD other.

INDEX WORDS: Autism Spectrum Disorder, ASD, Autism, Grounded theory, Care, Social justice, Fear, Personal advocacy, Critical habilitative narrative, Education, Special education, Curriculum theory

ONE DRUG, TWO DRUGS, THREE DRUGS, MORE:

A CRITICAL HABILITATIVE NARRATIVE INQUIRY INTO AUTISM

SPECTRUM DISORDER

by

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DEDICATION

This work is dedicated to my husband Darrell for his understanding, support and encouragement throughout this process. Thank you for taking this journey along with me.

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PROLOGUE

I would like to begin this work with a general overview of the structure and content that lies ahead for my readers. I find this an important task, in that, it provides content that, hopefully, will help each reader to formulate questions and to make connections in their own mind that will allow them to question and critique this work in a way that makes sense to their own life. This is an important feature of the project because an analysis into the "other" could not be complete without the inclusion of the "self".

In chapter one, we will review previous literature in regards to Autism Spectrum Disorder (ASD). This introduction includes the social construction of ASD as a disorder, the maintenance of the identify of disordered, and then begins to expose the role of public education in the emergence of and maintenance of the label of "disorder". Prior to delving into a review of the literature, I share the story that brought me to this research. It is the story of Drew, a young child labeled as ASD, and his struggle with daily life as he becomes victim of our science. Throughout this text, I seek to answer the question: What roles does public education play in the treatment, diagnosis, social perceptions, and prognosis of ASD?

Chapter two establishes the process that we will undertake to critique the individual stories of Drew, Allison, Kathy and Jessica. Utilizing the technique of triangulation, which checks and cross-checks various artifacts for common themes, a grounded theory is revealed that suggests that public education plays a significant role in the creation and maintenance of the "disordered" label of those identified as ASD.

In this next section, chapter three, the reader is provided with a more in-depth framework of ASD and the current thoughts and conversations that surround the diagnosis. Embarking upon this analysis demonstrates that the conversations surrounding ASD are incomplete and should not be without critique. It is here that I establish the importance of this conversation in hopes of transforming perceptions, thus polices, and practices, surrounding the ASD person.

Chapter four consists of the storied lives of Allison and Kathy, both mothers of children identified as ASD, and Jessica, a teacher of students identified as disordered. Each story is told as a reflection of many hours of conversation between me and these story tellers. While each story is unique because of its setting, personal circumstances, and distinctive characters, all contribute to the themes of fear, otherness, care and activism. Each story reveals a small piece of the central theme, the way we view, talk about, think about, and respond to persons identified as ASD contributes both positively or negatively to their potential outcome.

In chapter five we will embark upon critique of the social, economic, and political structure that impact persons identified as ASD. This critique provides an analysis of structures that influence public education for persons identified as ASD and the stimuli that inhibit change and promote a status quo mentality. The analysis ponders the themes revealed by the storied lives of Allison, Kathy and Jessica. It delves into the economic structure of schools, the science that we produce, and the thoughts that we maintain in regards to persons identified as ASD. Included in this analysis is an inquiry into what it means to be post-human and whether or not persons identified as ASD meet these criteria. It reveals the strengths of the ASD mind and sets forth possibilities for future

critique and change. To those that argue that without science we would not be able to survive and that our current quality of life would be impossible, I say to you that, I agree. I am in no way suggesting that we ought to eliminate science or its benefits. What I am suggesting is that, just because we need and value science and technology, for their positive qualities, we must not forget that science and technology are created by people…living, thinking beings. These beings are not without personal experience and prejudices, thus we have a duty and responsibility, as a species, to critique what we produce. Let us begin with Drew's Story.

Drew's Story

"Check your schedule", says Ms. Burns. On cue, seven children, grades kindergarten to grade two scurry to the wall beside the classroom entrance to obtain the next picture symbol from their multi-colored schedule strip. As each embarks upon their journey, they take time to spin on the whirl-to-spin, jump on the trampoline, and squeeze through the squeeze machine. Once they each reach their destination, they retrieve their picture symbol and maneuver through the equipment maze again, to finally reach their next academic station.

As ten-year-old Drew approaches my speech center, he quickly hits his fist on the table, says "no, no, no" and sits quietly in the chair beside me. With his oversized, blue tee-shirt hanging outside his oversized, baggy khaki shorts, he is out of compliance with the school dress code, but his IEP was written to address his sensory sensitivity to clothes. At least this year, he is able to tolerate his clothes for the entire school day. Drew's light-brown hair hangs over his big blue eyes as he inspects the picture cards that we will be working with today. Flipping quickly through the colored photo pictures,

Drew quickly names each object that he sees and turns to smile at me as if to ask for my approval. I smile back and say, "you did great with those today", Drew quickly slams his fist on the table and says "stupid dog, stupid dog" as he smiles at me again. He begins to stack the picture cards in a neat stack and hands them to me, saying in a familiar tone "are you ready"? As I take the cards from Drew and begin to lay them on the table, he again, slams his fist on the table and says "stupid dog" before he names the category of items that I have laid out for his identification. When I say to him, "I like the way you identified transportation". He hits my arm and says, "stupid dog, stupid dog" all the time smiling at me. We repeat the process many times, Drew providing the correct answer and me providing positive feedback for his correct answer and ignoring the inappropriate behavior, but still, Drew gets louder and louder with his verbal outbursts and his repeated banging on the table. He begins to jerk his head quickly as he produces the verbalizations, but he continues to participate in the day's activities.

Today is good day. It is 10:30 A.M. and Drew continues to work and transition between centers, but the "tics" continue to be more violent as the day progresses. For the past two weeks, each day the tics have appeared to get more significant and more frequent. As a treatment team, Ms. Burns, the classroom teacher, Mr. Cooper, the occupational therapist, and I have discussed what we could do to reduce the occurrences of the tics and hypothesized about what the cause may be. Last week we held a conference with Drew's mother to suggest that she may want to discuss our observations with his current physician. At the conference, Ms. Hamilton, Drew's mother, reviewed Drew's current list of medications with the treatment team. The extensiveness of the list and the dosages were alarming. Since his diagnosis, at age three, Drew has taken

medication for attention and aggression. Each year, his aggression, sensory issues, sleep and communication have become more significant, thus requiring an increase in medication dosage and, at times, an additional medication to offset the side effects of the current treatment regimen. This pattern has been a significant topic of discussion at recent IEP meetings, with all team members questioning the outcome, but what were we to do? Ms. Hamilton often sat in the meetings with tears welling in her eyes. She too, was concerned, frustrated, and at a loss for the answers to breaking the cycle in which she found herself and her child. Drew was becoming larger in size with each day and his tantrums were no longer easily controlled by medication, time-out, or restraint. As a result of our loss for answers, we decided to embark upon an effort to document Drew's behavior, in hope that the data that we collected would provide insight into what we could do to break this vicious cycle.

Because of our decision to document Drew's behavior, we began a system in which we "tallied" each occurrence of a "tic" in ten minute increments. Two days into the process this documentation became alarming. We were able to see quite readily that Drew's tics were occurring more often and with greater intensity. Day one suggested 96 occurrences that were fleeting in their duration. Day two suggested 167 occurrences and no real change in the duration. We were now in day eight and already had documented 127 occurrences by 11:00 A.M. Along with an increase in frequency of the tics came an increase in the duration of the events and a greater intensity of power in vocal productions and pounding. Drew's fist slamming and loud outbursts of "no, no, no" or "stupid dog, stupid dog" were now beginning to interfere with his ability to complete academic tasks, as well as, becoming irritants to his classmates. This pattern of behavior

was observed, once again, when the timer went off and Ms. Burns announced "check your schedule". Each of seven children began their familiar journey through the equipment maze to finally arrive at their schedule. As Drew approached the trampoline to take his turn, he bellowed out "stupid dog, stupid dog" and banged his fist on the back of his classmate Christopher. This interaction was more than Christopher could take, and resulted in Christopher screaming, crying, and hitting Drew in return. After consoling both children, Ms. Burns called to speak with Ms. Hamilton. Another meeting was arranged to discuss a plan of action.

At 3:30 in the afternoon, Ms. Hamilton entered the classroom with tears already in her eyes. The information was more than she could bear. As she sobbed uncontrollably she stated, "I don't know what else to do. When I called the doctor he told me to bring him in, but I can't do that. I haven't been able to take him to the doctor's office in over a year because he won't tolerate the wait in the waiting room. I've asked for more medication, but that doesn't seem to be helping and Drew is punching holes in the walls at home now. I even have to lock him in his room at night, cause he can reach the locks on the doors and I found him in the swimming pool two nights ago at 2:00 in the morning. I just don't know what to do". Once the sobbing had stopped, Ms. Hamilton was finally able to tell us that each time an event occurred in school that resulted in aggressive behavior or lack of attention, she would contact Drew's physician and he would call in a new medication or an increase in dosage of the current medicine. Hearing this, Ms. Burns and I assured Ms. Hamilton that we would accompany her to the physician's office to assist with Drew's behavior. Ms. Burns prompted Ms. Hamilton to "call him now". Ms. Hamilton complied and we were soon on our way to the physician's

office, which was three blocks from the school. Drew was quite cooperative as he sat in the back seat with me. There were only two occurrences of slamming his fist into the side window of the car.

Once we arrived at the physician's office I gave Drew the option to go into the waiting room while his mom waited for the doctor or to stay in the car with me to play a game. He opted for the game in the car. While we waited, Drew often had to stop what he was doing to hit either the car window or the seat. His "stupid dog" screams attracted several onlookers as they passed through the parking lot, but Drew was unaware and I chose not to acknowledge the stares. Finally, after about 50 minutes of waiting, Ms. Hamilton came to the car to tell Drew that it was his turn. Drew eagerly jumped from the car and ran quickly to the front door of the waiting room. As he opened the door, he screamed, "no, no, no, stupid dog" and bolted back into the side street of the doctor's office. I could see the look of horror on Ms. Hamilton's face as well as those of the patients waiting in the waiting room. Luckily, there was no oncoming traffic for Drew to contend with when his mother retrieved him from the middle of the street. After much consoling, Drew was able to enter the side door of the physician's office and be directed into an observation room. The doctor quickly entered and was greeted with a "no, no, no" and a fist to his right shoulder. In an attempt to gain control, Drew was restrained on the floor by four staff members. Twenty minutes later, the physician announced that Drew needed to be "detoxified" quickly, but the medications that he was taking put him "at risk for cardiac failure or stroke if done in an unsupervised environment". Thus, Drew was scheduled for check-in at the regional hospital containing a detoxification unit

the next morning. Ms. Hamilton left the physician's office, again sobbing, "what have I done to my child?"

After a two week hospital stay, Drew was able to return home, taking only two medications. A year and a half later, Drew continues to be exposed to "only the necessary medications" according to his mother, but also still suffers from tics that consist of verbal outbursts and aggressive behavior on a regular basis. Drew is making progress in his academic and social skills, but I often wonder how his progress would have differed had he not experienced the need to be detoxified.

CHAPTER 1

DRUGS, DRUGS, AND MORE DRUGS

Introduction

As a speech-language pathologist, I have had many opportunities to work with children with Autism Spectrum Disorder (ASD). In my work with these children and their families, I have found a great deal of frustration within the family network. This frustration often comes from conflicting views on the cause and treatments for ASD. . It is this frustration that haunts me in my attempt to assist these families in their quest for understanding. As a result of frustration, both my own and that of the families involved, I feel a deep need to investigate the knowledge that we currently have regarding the ASD person, the perception of their personality as disordered, and the impact that current knowledge and societal perception has upon early identification and treatment for ASD. My work with these children and their families has led me to question many of the currently accepted therapeutic techniques and their true value to these persons. While most of the techniques, with which I am familiar, appear to have merit when viewed as an isolated methodology for achieving a given goal, I have come to question whether the various disciplines (cognitive, physiological, social and educational) involved with the diagnosis have ventured to cross in order to achieve a more complete view of the ASD person. This is a quest in which I feel compelled to embark upon for the purpose of self-enlightenment, as well as, to present a challenge to the various members of our society that touch the lives of those with ASD. My challenge is to look beyond the current limited perceptions and ideologies associated with ASD, in order to develop a more complete view of how and why these persons are important to understanding our current

and future society. I feel that they are valuable contributors in spite of the socially constructed label that we impose upon them.

The story that I have shared, Drew's story, is also my story. It is the creation of my frustration with our current understanding of ASD and serves as catalyst in my quest to provide a broader look at ASD. As a curriculum theorist, I feel a need to reflect on the words of William Ayers (2004), "every human life is, by the simple virtue of being human, equal in value to every other" (p. 28).   When I think about how persons with ASD achieve, interact, and live within today's society, I find myself frustrated at the perceptions that I encounter of the ASD person.   As I reflect upon Drew's Story, I cringe at the thoughts of a "throw away" life that was sacrificed for the sake of convenience. As a curriculum theorist, I recognize and sanction the emergence of disability studies as an extension of my field. With the emergence of this area of emphasis as a mode of critique, we have hope of creating what Ayers (2004) referred to as "universal design" (p. 59). Those things in society, although created for those identified as "other," that are beneficial to each of us. Ayers (2004) speaks of "wheelchair-accessible" restrooms that are comfortable and roomy, "gently sloping ramps", and "height-adjustable drinking fountains" all of which have been created for those we have identified as "other", but beneficial to each of us as a member of society (p. 59). I know that this is true, because each time I approach a closed door with both hands full of materials, I become frustrated when the "handicapped button" is not available for my use.   Hopefully, this inquiry, a merger of curriculum studies and disability studies, will provide enlightenment as to how our societal perceptions of ASD (economic, social, and political) have impacted the way

in which we think about and treat persons with ASD and the role that public education plays in this system.

As I walk through the halls of the schools that I serve and meet with teachers, parents and administrators regarding those identified as disordered, I have identified a call to duty that demands that I do more than critique my own pedagogical practices. I find that the call to duty demands that I recognize that those participating in educational politics are identifying the ones that we have identified as "other" as being the reason that we have failing schools. Each time I view a state department report that suggests that a specific district did not meet the achievement criteria for annual yearly progress because of students with disabilities, my blood begins to boil and I find myself thinking that the "disability" label is the key that allows these statements to be presented to the public and that these labels are then used to further segregate and disable those upon which we have bestowed a label. If, instead of suggesting blame, we identified the needs of each child, made a plan to work on those needs, and worked to make each child the best person that they could be, we would have potential to create a caring pedagogy that emphasizes, not those traditionally identified "disabilities" but those "abilities" that create productive, scrutinizing, involved citizens.

Parents want what is best for their child and their family, but often find the frantic search for the "best" therapy and the "best" answer for the causal factors to be elusive. One might suggest that the cause of the disorder is irrelevant and the most practical therapy is the one that is validated by the most scientific research, but this may not be necessarily so. What if the most scientifically validated research is validated only because scientific research has not been focused on methodology that are contradictory to

currently accepted perceptions of the disorder, treatment, cause and prognoses?   It is the

role that public education plays in societal perceptions and their relationship to current

treatment, cause and prognoses upon which this critical habilitative narrative inquiry is

focused. In critical habilitative narrative inquiry the focus of attention is to critically

analyze, through a social, political and economic lens, the life story of those identified as

"disordered" and to identify the strengths that are often overlooked, instead of the

weaknesses, whether they be real or socially constructed. Viewing what we term a

"disorder" with a habilitative lens holds potential for unraveling some of the questions

and concerns that are so prevalent in ASD.

     The American Psychological Association describes Pervasive Developmental

Disorders (the Autism spectrum) in the following manner:

> Pervasive Developmental Disorders are characterized by severe and
>
> pervasive impairment in several areas of development: reciprocal social
>
> interaction skills, communication skills, or the presence of stereotyped
>
> behavior, interests, and activities. The qualitative impairments that define
>
> these conditions are distinctly deviant relative to the individual's
>
> developmental level or mental age. (2000, p. 69)

From this description, it is easy to see that ASD is thought of as a disorder that impacts

total daily functioning of the affected individual. "Before 1980, autism was rare" (Jepson

& Johnson, 2007, p. 24), but today's numbers are quite contradictory to a rare disorder.

The Center for Disease Control and Prevention (CDC) suggest that

> for decades, the best estimate for the prevalence of autism was four to five
>
> per 10,000 children. More recent studies from multiple countries using

current diagnostic criteria [DSM IV-TR] conducted with different methods

have indicated that there is a range of ASD prevalence between 1 in 500

children and 1 in 166 children. The CDC studies provide information on

the occurrence of ASDs in fourteen communities in the United States

(2007, p. 1)

all in relative concurrence with international prevalence numbers. With this knowledge,

the numbers are quite alarming, especially in light of the fact that we have made no real

progress in identifying the cause for the disorder. While there are several speculations

regarding the cause of ADS, such as, genetics, incorrect diagnoses, changes in diagnostic

criteria, a mental disorder, a medical disorder, environmental influences, and even the

possibility of changes that are occurring as a result of the impact of having a

technological society, a conclusive cause has yet to be determined (Jepson and Johnson,

2007).

I would like to suggest that societal perceptions of what we have traditionally

termed a "disorder" may have an impact on how we treat, seek answers for cause, and

give value to the lived experience of persons identified as disordered. The social

construction of ASD is entwined with the APA definition, thus creating a symbiotic

relationship. As society identifies acceptable and non-acceptable behaviors, the APA

identifies many of the non-acceptable behaviors as characteristics of a disorder. This is

evidenced by changes in diagnostic criteria from one DSM edition to another. One

example is the inclusion and exclusion of homosexuality as a disorder. In the early

editions of the DSM, homosexuality was identified as a disorder. As social perceptions

began to change in regards to homosexuality, the label of disordered was eliminated by

the experts, and the "disorder" removed from the DSM. Once removed from the DSM,

social acceptance of the once "disordered" became more likely, thus creating a cyclic,

symbiotic relationship between the creation and maintenance of a given "disorder". In

this example, science interpreted our social values into medical standards and presented

to us our conclusions and reactions to a social perception. McWhorter (2009), in

Foucault and the Government of Disability, suggests that "power-knowledge networks

that produce and regulate disability also produce and regulate ability, ableness, [and]

normality"(p. xv). In this process, science exudes its dominance over social

responsiveness.   This dominance results in oppression over, not only those that we have

socially identified as "other", but also those that are sanctioned "normal" but whom may

become "other" in the future. A critical habilitative narrative analysis of the thoughts that

we currently hold in regards to ASD could provide some enlightenment for persons

identified as disordered, their caregivers, their physicians, their therapists, and educators;

thus producing a grounded theory that could serve to improve societal conditions that

empower those impacted by ASD. In order to critique current societal perceptions of

ASD, we must first begin by attempting to answer the question of how do various

stakeholders perceive ASD, and then, proceed to analyze how those various perceptions

are impacting treatment methodologies, answers to cause, and daily functioning of

persons identified with ASD. It is in answering these questions that we have potential for

habilitating and enriching the lived experience for persons identified with ASD.

What We Currently Know

As I noted earlier, ASD is a rapidly growing phenomenon with few answers as to

why. In an era of science, data, and behavior modification, it is not surprising that there

has been a plethora of literature regarding ASD, its cause, appropriate treatment, and prognosis. There seems to be three main focuses of available literature: pathographies written or co-written by family members or adults with ASD, therapeutic methods and research analyses, and historical accounts of the disorder.

Many of the pathographies have a focus that suggests what it is like to live with the disorder, in other words, they present the lived experience of ASD. These are stories of struggle, frustration and a system that often does not work for persons with ASD, but they almost always offer glimmers of hope into the strengths of ASD (Biklen, 2005; Frank, 1995; Grandin, 1995, 2006) as well as its weaknesses, not unlike Drew's Story. Through these accounts of lived experience we have come to understand that persons identified with ASD have valuable contributions that they can make to the world and that they have a desire to do so (Grandin 1995, 2007; Sacks, 1995). The question then becomes, In what ways can we make this happen? The literature regarding therapeutic methods and research analyses attempt to aid us in this quest.

As in the pathographies, there seems to be a plethora of information regarding what works in the treatment of ASD and where area of weaknesses are in current research (Grandin, 1995, 2006; Nadasan, 2005; Notbohm, 2005; Schumann, et. al., 2004; Levitt, et al., 2003; Kwon, et al., 2004; Klingberg, et al., 2005; Gage, Siegel, & Roberts, 2003; Behrmann, Thomas, & Humphries, 2006 & Barnea-Groraly, et al., 2004). Much of the focus today, appears to be on behavioral and drug treatment and the research appears to be focused on the area of genetics and brain anomalies. "Given this organic orientation, autistic patients today are likely to be treated with a variety of drugs ranging from anti-psychotic to anti-yeast agents" (Nadasan, 2005, p. 22). Nadasan (2005), working in the

area of disability studies and herself a parent of a child identified as Autistic, further

suggests that "the social construction of 'ideas' about the origin and remediation of the

'autistic' patient is imbued with material consequences for parents, researchers, therapists,

and physicians" (p. 23). With this, Nadasan appears to be suggesting that the current

treatment, research for treatment and cause, along with the prognosis for ASD appears to

be highly influenced by the social construction of the disorder, thus suggesting a need for

further investigation into this construction. This is an area that appears to be espousing

gaps in the currently available literature. While much of the literature available does

recognize the social construction of ASD, (Grandin, 1995, 2006; Nadasan, 2005; Sacks,

1995; 1985, 2006; Jepson & Johnson, 2007) there seems to be little conversation

regarding the impact of that construction on treatment and social awareness. As I

suggested earlier in this chapter, social construction of a given "disorder" and the APA

inclusion of the "disorder" with identification of cause, prognosis, and treatment appear

to be symbiotic in their relationships. This reliance creates a cyclic effect on how we

perceive the characteristics of a person we have identified as "other". We utilize the

'scientific" explanation of the DSM to justify "othering" of the person displaying these

characteristics. The fact that they are "other" in society promotes and sustains the idea

that they are disordered. This cyclic relationship carries weight in the creation and

maintenance of what we perceive to be disordered. The relationship allows us to set

"standards" as to what is socially acceptable behavior and what actions will be taken

when there is deviation from the socially accepted behavior. Do we incarcerate them?

Do we hospitalize them? Do we ignore them? Is there really a difference? How do we

reconcile varying views? I would like to suggest that we ought to adjust our perceptions

of what is socially acceptable. Shelly Tremain (2009) reveals that "Foucault urged critical reflections on the current situation and on the historical conditions that led to these formations and how they might be differently perceived" (p. 1). I suggest that we take this leap of faith and explore how we have come to know the persons we have identified as ASD as disordered. The gap in current knowledge regarding the social construction identifies areas of further needed inquiry.

Prior to the 1970's ASD was practically an unknown entity. Through Nadasan (2005) we learn, "autism is a twentieth-century disorder because it is clearly absent from the diagnostic nosologies of nineteenth-century psychiatry. And yet, it seems very likely that the disorder predates its twentieth-century formulations by Kanner (1943) and Asperger (1979)"(p. 29). The lack of acknowledgement of the disorder prior to twentieth-century suggests that prior to that time, the disorder did not exist. Nadasan informs us that this is not an accurate picture, but does suggest that the emergence of surveillance of children has contributed to ASD's identification and its prevalence in today's society.

> Autism could not have emerged in the nineteenth century as a diagnostic category because the pediatric experts-Leo Kanner and Hans Asperger-who produced it were a twentieth-century phenomenon. Moreover, the institutionalization of child psychiatry was indebted to other social institutions that were specific to the early twentieth and late nineteenth centuries, including the formalization of compulsory education and the creation of the child guidance movement. (Nadasan, 2005, p. 53)

With this statement, Nadasan appears to be suggesting that compulsory education (public school education) has contributed to the identification and prevalence of ASD. To my knowledge, at this time, there has been no literature, other than Nadasan's (which only exposed public education's role in the creation of the disorder), that has explored this phenomenon directly, thus exposing a gap in today's literature regarding ASD. With space surrounding the role of public education in current treatment, diagnoses and prognosis of ASD, I formulate a quest for inquiry that will answer the question: What role does public education play in the treatment, diagnosis, social perceptions and prognoses of ASD? By turning once again to Shelly Tremain (2009) we find Nadasan's speculation to be verified.

> During the past two centuries, in particular, a vast apparatus, erected to secure the well-being of the general population, has caused the contemporary disabled subject to emerge into discourse and social existence. Among the items that have comprised this expansive apparatus are asylums, income support programs, quality of life assessments, workers' compensation benefits, special education programs, regimes of rehabilitation, parallel transit systems, prostheses, home care services, telethons, sheltered workshops, poster child campaigns, and prenatal diagnosis." (p. 5)

With this knowledge we can now proceed with our inquiry into the creation of ASD as a disorder, the role that our public education system plays in that creation, and the possibilities for the creation of a paradigm shift regarding our perceptions of disability, but first, let us take a moment to discuss the structure for our exploration.

CHAPTER 2

DESENTIZING OUR NUMBER ADDICTION

Because of my training and work as a speech-language pathologist, it seems

natural for me to begin my work in qualitative inquiry with a foundation in the tradition

of oral history. After all, the role of a speech-language pathologist is to create and foster

a desire to communicate. Oral storytelling is the root of communication for the purpose

of the preservation of social structures and cultural values.

> I believe that the community's duty to education is, therefore, its
>
> paramount moral duty. By law and punishment, by social agitation and
>
> discussion, society can regulate and form itself in a more or less haphazard
>
> and chance way. But through education society can formulate its own
>
> purposes, can organize its own means and resources, and thus shape itself
>
> with definiteness and economy in the direction in which it wishes to move.
>
> (Dworkin, 1967, p. 31)

 But the question remains as to the method of communicating the desired direction. Ruth

Finnegan helps us with this dilemma by reminding us that

> our memories are built up through myth and images, by the conventions
>
> and ideologies around us. In a way our narrative models, draw from the
>
> culture we live in, shape even our own first-hand experience and
>
> expression. To understand who we are and what we have done we 'narrate
>
> our lives' following out those models. (Perks & Thompson, 2006, p.
>
> 180)

   With this reminder, we can begin to see that the sharing of our lived experiences

provides insight into the world in which we live and the values that we hold in esteem

within our culture. Through storytelling we have the opportunity to communicate the

thoughts, ideas, emotions, and injustices experienced by those we know as Other. With a

gentle reminder from Dworkin (1967), we come to understand that "the teacher is not in

the school to impose certain ideas or to form certain habits in the child, but is there as a

member of the community to select the influences which shall affect the child and to

assist him in properly responding to these influences" (p. 24). Through stories, we

possess valuable resources for influence that allow our students to formulate their own

ideas in regards to what ought be acceptable behavior within our society.   Through

stories, we have potential to communicate what it means to be othered in society. In the

world of ASD this means that we hold potential to communicate what it means to be

viewed as "disordered" by those with whom we come into daily contact.

       Because "stories function as arguments in which we learn something essentially

human by understanding an actual life or community as lived" (Short, 1991,   p.136) we

can utilize the life stories of persons identified with ASD, stories from their caregivers,

and stories from their therapists, and teachers to gain a better understanding of what it

means to share the lived experience of ASD. Understanding the lived experience of ASD

allows us to critically analyze the social structures currently in place that may serve as

oppressors to these persons and their families. Through understanding, change has

potential to occur.   Paulo Freire (1993) reminds us that " The teacher talks about reality

as if it were motionless, static, compartmentalized, and predictable [and that] education is

suffering from narration sickness" (p. 71). For this reason, it is important that, as

educators, we listen to, analyze, and act upon the stories that we encounter, so as to ensure praxis as a stimulus for change within our society. Freire (1993) further reminds us of "Lenin's famous statement: 'Without a revolutionary theory there can be no revolutionary movement' [which] means that a revolution is achieved with neither verbalism nor activism, but rather with praxis, that is, with reflection and action directed at the structures to be transformed" (p.125-126). As educators it is not only our challenge to accomplish this task, but it is our duty, our duty to the students we teach and the society in which we live.

The society in which we live today tells us that we have a segment of our population that is special, special persons requiring special education. To emphasize that this is so, we have legislative mandates to view these persons differently and we have mandates to ensure that we provide the special education services they require and are entitled to. When the

> 1990 law was enacted...autism and traumatic brain injury [were included
>
> as areas of disability and in]...1997 and 2004 [the] laws focused on more
>
> inclusive multicultural approaches to provide individualized education
>
> services and alternative education for those who could not be 'normally'
>
> served. (Obiakor, 2007, p. 39)

By telling the lived stories of those touched by ASD, we gain insight into the values that we hold dear and their impact upon our future culture. One such value, one of which I have confessed to have held in high esteem, is that of our science. Because we perceive our science to be of great value (economically and culturally), we often forget that science is controlled by people, people who have ethical and moral values, people who

have prejudices and tolerances, people who have lived experiences that limit their ability to understand those unlike themselves. As a result, we often forget that our science is biased as well. When we look at critical race theory we learn that it "begins with the notion that racism is 'normal, not aberrant, in American society" (Ladson-Billings, 1999, p. 12). This is a similar view to that of special education services. Students are viewed as being defective and societies way of dealing with their differences is to create an atmosphere that suggests that we should expect to treat them differently than others and that doing so is 'normal'. Our science contributes to this ideology, specifically by focusing on differences rather than commonalities, weaknesses rather than strengths and fixes for the "problem" rather than acceptance of differences. This traditionally accepted view can be challenged through the use of lived stories that are critically analyzed through a lens of habilitation.

"It was John Dewey (1927) who wrote that democracy and education are intertwined in their responsibilities to help the public solve its problems. Our work is not merely about data points and effect sizes. It is also about what difference our work can make in the lives of real people" (Ladson-Billings & Tate, 2006, p. 10). Thinking about students labeled as ASD in this manner allows for a lens focused on social equity. The Center for Disease Control and Prevention (CDC) suggest that

> for decades, the best estimate for the prevalence of autism was four to five
>
> per 10,000 children. More recent studies from multiple countries using
>
> current diagnostic criteria [from the Psychological Association's
>
> Diagnostic and Statistical Manual, fourth edition] conducted with different
>
> methods have indicated that there is a range of ASD prevalence between 1

in 500 children and 1 in 166 children. The CDC studies provide

information on the occurrence of ASDs in fourteen communities in the

United States. (2007, p. 1)

With reports such as this, it is easy to see that a public focus that emphasizes only

negative qualities, qualities that must be fixed, of persons labeled with ASD, could prove

detrimental to our long-term social structures, even though, in the short term there may be

large economic rewards for the drug industry. If one accepts the historical role of public

education as one that holds responsibility for solving social issues, then it takes only a

small step to recognize that public education should and will contribute to either a

solution to public awareness and acceptance of ASD or will promote further tension and

inequality for this group of persons upon which we have bestowed this label. The

choices that are made may hinge on public awareness of the lived experience of persons

with ASD. Public awareness and social acceptance of any ideology contribute to political

and economic focuses for our culture at large. Because of this influence, it is important

for educators to relay the message of the lived experience of persons with ASD.

Narrative inquiry holds potential for accomplishing this task. Marshall (2006) tells us

that "narrative analysis values the signs, the symbols, and the expression of feelings in

language, validating how the narrator constructs meaning....[is] useful in developing

feminist and critical theory...[and] is especially useful when exploring issues of social

change, causality, and social identity" (p.118). In other words, narrative accounts hold

potential for demonstrating the values and beliefs of society at large, as well as, creating

change in those values and beliefs.

Multiculturalism names a puzzle or disquiet in social life, and it names a

democratic attitude toward thinking about social life. Narrative, because it

is focused on experience and on life, is a means to explore the democratic

spirit that envelops the notion of multiculturalism.   Multiculturalism

names a way of living, and narrative inquiry is a way to think about living.

(Phillion, He, & Connelly, 2005, p. 254)

Narratives hold the key to a multicultural society, in which, each group of members are

valued for their unique contributions to society and culture.

Phillion, He, & Connelly (2005) write

narrative inquiry is a process of temporarily joining the flow of life for the

sake of inquiry—to understand, make meaning, and enhance the quality of

life (Phillion & He, 2005). Perhaps because of the successes of the

experimental method, it tends to be taken for granted that researchers can

stop life and time, impose controls, and draw new insights. Narrative

inquiry is more complex in its relationship to life and less ambitious about

its possible uses. Its complexity grows out of the demand that inquirers

take life as it comes to them. (p. 255)

In this statement, Phillion, He, & Connelly, seem to be suggesting that qualitative

inquiry, specifically narrative inquiry, provides a more realistic view of life than does

traditional quantitative inquiry methods, in that, it is unrealistic to think that life stops

when inquiry begins and that narrative inquiry demonstrates the interconnections of

researcher, those being studied, and daily life. They further suggest that "inquiry [is]

embedded in life and life [is] embedded in constant change in relation to social, cultural,

and political contexts" (Phillion, He, & Connelly, 2005, p. 1). It is these relationships
that formulate values and thus, change in cultural, political and economic views.

By creating change in cultural, political and economic views we can begin to
question the current curriculum that we hold in esteem. Since

there is no definition of curriculum that will endure for all time and … it is

foolish to search for one, … [perhaps we should recognize that] every

definition serves the interest of the person or group putting it forward, and

that it is always appropriate to ask what the local consequences of

adopting this or that definition might be. (Jackson, 1992, p. 10)

If we understand this relationship, we can begin to critique our curriculum of
unquestioning devotion to our science, thus begin to question the ethics behind our
beliefs and actions for the purpose of formulating questions to ponder for the preservation
of our future society. Pinar et al remind us that "the point of contemporary curriculum
research is to stimulate self-reflection, self-understanding, and social change. Simply
put, practical or theoretical research is intended as much to provoke questions as it is to
answer questions" (Pinar et al, 2004, p. 56-57). This was what I desired to achieve in my
personal inquiry into the lived experience of ASD. This quest required me to embark
upon inquiry that critiques the political, economic and social influences that are
impacting treatment for children identified with ASD. This inquiry was conducted
through a collection of narrative experiences from caregivers of those identified with
ASD and teachers. The narrative experiences were then scrutinized through an analysis
of common themes. It is my desire, to stimulate a conversation in regards to the
treatment of persons labeled ASD, that will provoke further questions in regards to the

ethical considerations of the public education system, the science that we value, and the social perceptions that perpetuate current thoughts regarding this matter. By creating a critical habilitative narrative inquiry, I hope to relay real, lived experiences of those labeled ASD, create passion and connectivity with my readers for the purpose of stimulating individual critique, utilize a method of inquiry that is steeped in tradition, and create a research agenda that is participatory and passionate focused on the creation of changing social perceptions of persons labeled ASD.

While the Commission on Behavioral and Social Science does not directly address pharmacological treatment for children labeled as ASD as a method of intervention, they do acknowledge the use of pharmaceuticals with this population. In my lived experience, I find this treatment to be consistent throughout the group of students with whom I have worked. I have included inquiry into this are in order to help answer the questions: who benefits from the lack of focus on this intervention by the commission? For me, the unspoken, unaddressed issue of pharmaceutical intervention is one to be pondered through open dialogue. This research holds potential to contribute to this segment of the conversation.

Removing the Toxins

Federal legislation in 2004, the Individuals with Disabilities Education Improvement Act (IDEA), mandates that federally funded school districts make attempts to provide a more inclusive environment for persons with disabilities, including those identified with ASD. While this legislation is a step in the right direction for aiding persons with ASD and other "disabilities" in the enrichment of their lived experience, it falls short of accomplishing the task by simply mandating an inclusive environment.

Mandating an inclusive environment means that children identified as having disabilities, covered under IEDA legislation, are being monitored by district, state, and federal overseers to determine if the total amount of time spent in general education classes is appropriate. The goal is to increase not only the amount of time each student participates in general education classes, but also to increase the number of students in every disability category that participate in these classes. Emphasis on analysis of gender, ethnicity and identified areas of eligibility are being monitored due to the disproportionate number of minority students that were identified as having an intellectual disability (mentally retarded) and emotionally behavioral disordered label. Currently, students identified with ASD are increasing rapidly in public schools and teachers are often challenged with the task of "making it work" for these students in their classroom. Because much of the attention focused on persons with ASD by the public news media highlights the negative aspects of the label, teachers find themselves in situations for which they are ill prepared and have little hope in their ability to make real changes in the lives of the students they are charged to mentor. By providing teachers, therapists, and caregivers insight into the strengths, weaknesses and daily functioning of persons identified with ASD this study critiques the traditionally accepted beliefs about persons with this diagnosis, and with a more clear understanding of the societal perceptions behind the diagnosis, it provides an analysis that has potential to act as a stimulus for changing the prognosis for persons with ASD to a more enriched lived experience.

Critical habilitative narrative inquiry can be viewed in three parts: critical inquiry, narrative inquiry, and habilitative inquiry. In this section, I will discuss each

form of inquiry as a separate entity and then re-combine them to complete the analysis of the inquiry method to demonstrate the potential for producing a theory and theoretical implications of the research questions. We will begin first, with an analysis of critical inquiry.

Critical inquiry, as a form of research, has at its basis a commitment to social justice, which allows us to scrutinize the ideas of racism, classism and sexism and other forms of domination as they relate to our social structure. This form of "research tends to be identified with political discourses...although there are links also with racial, gender, and autobiographical discourses" (Pinar et al, 2004, p. 57). Critical inquiry analyzes the social conditions that underlie, accompany and result from various forms of domination and attempts to provide alternative visions with less oppressive conditions. Pinar et al (2004) allow us to understand this research technique as it relates to an educational setting.

> Critical research...attempts to analyze 'false consciousness'
>
> (misunderstanding what is reality, especially political reality) while
>
> indicating strategies for overcoming its effects. [This] research critically
>
> examines those aspects of the dominant social order which block
>
> educators' efforts to pursue authentically educational (rather than political
>
> and economic) goals. (p. 57)

Perhaps Kenneth A. Sirotnik says it best in *Forms of Curriculum Inquiry* when he states that, critical inquiry consistently asks "'is this the way we want things to be?' and 'What are we going to do about it'" (Short,1991, p. 252). By answering these questions, we not

only scrutinize the way we currently think about our social structures and pedagogy, but we also allow potential for improving praxis.

Utilizing this process allows for the current practices associated with treatment, causality, and the quality of daily lived experiences of persons with ASD to be viewed critically, so as to, identify potential oppressive agents that inhibit a more enriched lived experience. "Begin[ing] with the answer 'No!' and continu[ing] with a process of informed reflection and action guided by explicit, normative considerations"(Short, 1991, p. 245) we can begin to filter through the complex structure that we currently have in place for persons identified as "disabled". We can begin to view these practices and thought processes in relation to their impact upon our formulation of structures, perceptions and expectations for those persons which, we as a society, have identified. Because "life's narratives are the context for making meaning of school situations" (Short, 1991, p. 124) we can utilize these stories to critically examine the impact of current practices upon the lives of those we teach.

Marshall & Rossman (2006) describe narrative inquiry as "an interdisciplinary method that views lives holistically and draws from traditions in literary theory, oral history, drama, psychology, folklore, and film philosophy" (p.117). The narrative tradition "may be traced to Aristotle's Poetics and Augustine's Confessions (see Ricoeur's, 1984, use of these two sources to link time and narrative) and may be seen to have various adaptations and applications in a diversity of areas including education" (Short, 1991, p.125). With roots such as these, it is obvious that narrative inquiry has a long history and is valued by society as a means for transferring knowledge from generation to generation. "Narrative and life go together and so the principal attraction of

narrative as method is its capacity to render life experiences, both personal and social, in relevant and meaningful ways" (Short, 1991, p.141). In order to understand the true impact of the narrative experience, one must understand that "our memories are built up through myth and images, by the conventions and ideologies around us. In a way our narrative models, draw from the culture we live in, shape even our own first-hand experience and expression. To understand who we are and what we have done we 'narrate our lives' following out those models" (Perks and Thomas, 1998, p. 180). In other words, in order to understand and seek answers to the enduring questions we seek as a people, we tell the stories of our lives in hopes of answering, Who are we? and Why are we here? Analyzing our lived stories provides us with cues, if not answers, to these enduring questions and aids in our transcendence to a more evolved species.

Because "stories function as arguments in which we learn something essentially human by understanding an actual life or community as lived" (Short, 1991, p.136) we can utilize the life stories of persons identified with ASD, stories from their caregivers, and stories from their therapists, and teachers to gain a better understanding of what it means to share the lived experience of ASD. Understanding the lived experience of ASD allows us to critically analyze the social structures currently in place that serve as oppressors to these persons and their families. Through understanding, change has potential to occur. The concept that I discussed earlier in this chapter, being "normally" served, suggests that students identified with the ASD label are less than normal and suggests that being "normally" served is a goal that they should desire. I contend that this is not necessarily so and would further suggest that this idea ought be challenged. The idea of being "normally" served is specifically the ideology that habilitative inquiry

seeks to engage. Webster defines habilitate as the ability to make fit or capable; to qualify oneself, thus using a habilitative lens to view the needs of students, regardless of the label that society has attached to them, changes the focus from what they can not do, to what they can do. Once the focus of instruction becomes based on the students' strengths, then the definition of "normally" functioning becomes suspect. Because "both special education and multicultural education emerged out of the civil rights era, a time when multicultural students and those with disabilities were denied equal educational opportunities" (Obiakor, 2007, p. 43) we can situate critical habilitative narrative inquiry within the context of multicultural theory.

Situating critical habilitiative narrative inquiry in relation to multiculturalism allows us to understand more thoroughly the ideology behind the former. Remembering that we are beginning with the idea that those we have labeled as "other" are not normal, we find the need for special education services to repair and to protect us against the behaviors that we perceive as different. This thought process is not unlike that of our intolerance of those whose culture deviates from our own. When we view persons of the "other culture" we have a tendency, which is socially reinforced, to identify the differences as weaknesses instead of strengths. Through this process we secretly hope to achieve a world in which we have no discomfort because we all perceive the world through the same lens (In my opinion, this is the same thought process that gave us the Holocaust). There is no cause for conflict or discomfort, therefore no need for effort to be expended in hope of gaining a perspective different from our own. Chow tells us that "more and more pressing is the need to explore the conditions of possibility, the terms on which knowledge itself is produced...knowing is, ever more so, an attempt to know how

knowledge itself comes into being" (2006, p. 3).   With critical habilitative narrative inquiry we are provided with a research method for answering questions regarding current educational programming (treatment), inquiry into causality, and enrichment of the lived experience for persons with ASD. Utilizing this lens to establish grounded characteristics of the daily experiences of persons with ASD has potential to produce a framework that can be used to further investigate and make predictions regarding the cause, treatment, and prognosis of the phenomenon of ASD and for identifying the role that our educational system plays in the creation of our current knowledge.

Creating Variety

"For qualitative studies, context matters" (Marshall & Rossman, 2006, p. 53) and since context matters, it is important that this research was conducted in a context that represents the daily lived experience for persons with ASD. "The cultural world under study should be continuously related to the individual's unfolding life story" (Marshall & Rossman, 2006, p.117). It is also important to note that the inquiry took place in a setting that was comfortable for both the researcher and the participants. Marshall and Rossman remind us that "systematic inquiry in each genre [should] occur in a natural setting, rather than an artificially constrained one, such as the laboratory" (2006, p. 9). We are also informed that

> a realistic site is where (a) entry is possible; (b) there is a high probability
>
> that a rich mix of the processes, people, programs, interactions, and
>
> structures of interest is present; (c) the researcher is likely to be able to
>
> build trusting relations with the participants in the study; (d) the study can

be conducted and reported ethically; and (e) data quality and credibility of

the study are reasonably assured (2006, p. 62).

Since

children with autism can be found in every nation, geographic area, and

ethnic group… [we can be somewhat confident that] autism 'knows no

racial, ethnic, or social boundaries,[therefore] family income, lifestyle,

and educational levels do not affect the chance of autism's occurrence',

[further suggesting]… that [it is] environmental and cultural factors [that]

must be exonerated concerning the etiology of the disorder. (Obiakor,

2007, p.128)

With this knowledge, comes flexibility in identification of research participants. While

economic, geographic area, and social boundaries may not impact etiology, they do have

potential to impact treatment and the quality of the daily lived experience for participants.

For this reason, it was important to take these issues into consideration in the selection of

research participants. In an attempt to satisfy the requirements of high quality qualitative

research, to preserve the integrity of the research participants and the researcher, and to

maintain a reasonable budget and timeline, local family support groups for ASD were

utilized as a source for research participants. In Georgia, there are several family support

groups with significant numbers of participants that represent a variety of ethnic groups,

socio-economic groups, and persons from a variety of geographic locations due to the

presence of military facilities. Within these support groups are representatives of

caregivers, persons with ASD, physicians, therapists, and teachers. This context also

provides a forum for open discussion by participants regarding their experiences,

thoughts, frustrations, and celebrations regarding their contact with ASD, thus resulting in narratives regarding the lived experience of ASD.

Because of the constraints of society and legislative processes that are placed upon teachers, therapists, and physicians to conform to and to utilize a 'traditionally' accepted view of ASD and its therapies, (those verified by quantitative analysis) I feel that it is necessary to proceed through a process of desensitization for our societies' number addiction, thus I utilized a systematic analysis of the collected stories. This stage of analysis serves to console and satisfy the skeptics among us that have difficulty, because of our socially accepted ideas, that good research must quantify its results. Any good 12-step program for addiction utilizes desensitization strategies to slowly withdraw the substance of desire, thus the utilization of a grounded theory analysis satisfies this purpose. The use of grounded theory as a method for data analysis required extensive data collection. A cross-sampling of participants, within and between each representative category (caregivers and teachers), was most effective for obtaining a cross-disciplinary view of ASD. By utilizing a cross-sampling technique, multiple themes and categories were allowed to emerge. This type of analysis is an important component in the development of a grounded theory.

Creating an Album of Sobriety

"Observation is a fundamental and highly important method in all qualitative inquiry" (Marshall & Rossman, 2006, p. 99). Without observations, research participants, become obscure, unknown research participants and the embodied experience becomes at-risk for being lost within the numbers. However, observation alone does not necessarily provide a thoroughly enriched vision of what it means to be

ASD, therefore structured interviews that detail personal experiences, "combined with observation, [were utilized to provide the desired enriched vision.] Interviews allow the researcher to understand the meanings that everyday activities hold for people" (Marshall & Rossman, 2006, p. 102) which are a necessary component in the identification of themes that emerge as the stories are told. Since Creswell (2007) has told us that "qualitative data analysis may be a description of both the story and themes that emerge from it" (p.56), a thorough understanding of emerging themes is an important component of the research, as much so as interpretation of the actual stories told. Marshall and Rossman (2006) remind us that "human actions cannot be understood unless the meaning that humans assign to them is understood. Because thoughts, feelings, beliefs, values, and assumptive worlds are involved, the researcher needs to understand the deeper perspectives that can be captured through face-to-face interaction" (p. 53), therefore observations and structured interviews were determined to be the most effective means for acquiring in-depth knowledge of the lived experiences of persons with ASD, their caregivers, therapists, and teachers.

Twelve over-arching questions were developed to provide a framework for guiding interviews and observations (see appendices A for actual questions), therefore several sessions were necessary to ensure that an in-depth inquiry for each question occured. Marshall & Rossman (2006) suggest that "qualitative studies intrude into settings;;;[that] people may be giving their time to be interviewed…[and that] the researcher should plan to reciprocate…[but] reciprocity should fit within the constraints of [the] research and personal ethics and of maintaining one's role as a researcher" (p. 81). In light of this information and prior affiliation, by this researcher, with some of the

local support groups, it was necessary for the researcher to participate in informal discussions on open topics. While this participation, at times, impacted the overall discussion, it also provided participants with a feeling of reciprocity for their participation in the study and served to provide voice for the researcher that is also a member of one of the targeted populations being surveyed by the research. This process also served to reveal researcher biases in a structured manner throughout the study.

The use of grounded theory methods for data collection and data analysis mandate the use of the "constant comparative approach" which requires that information be analyzed in relation to the information collected and re-analyzed until the "information obtained does not further provide insight into the category" (Creswell, 2007, p. 160). This approach suggests that multiple attempts to collect data may result in multiple site visits, and may also result in the formulation of new questions for inquiry, thus requiring revisions to the initial line of inquiry. This back and forth process is what is identified as "reflexivity" and what Atkinson & Delamont (2008) suggest as capturing the "abductive logic through which analysts explore the social or natural world" (p. 300) thus making it valuable as a tool for the creation of new lines of thought.

Information obtained during observations and interviews was audio recorded, transcribed, stored in computer files and coded based on three open coding categories: treatment, cause and prognosis. Field notes and documents used for the purpose of triangulation were also coded utilizing this process. Once initial coding was completed, resulting in a computerized data base, the process of data analysis began. All audio recordings, transcription and supporting documentation are stored in locked filing cabinets. Digitized computer files are secured through password protection.

Feeding The Number Addiction

A grounded theory analysis suggests utilizing a data analysis process that consists of three separate phases. The first phase is described by Creswell (2007) as one that examines the text for "salient categories" (p. 160) to the point of category saturation. Creswell identifies this phase as the open coding phase. During this phase, the initial categories are divided into sub-categories, or as Creswell (2007) identifies them as "properties," for purpose of "reduc[ing] the database to a small set of themes or categories" (p . 160). In this study, the salient categories were: treatment, cause and prognosis. Once this phase of analysis was complete, the identification of a sub-categories began. Multiple categories emerged from each story. The categories were cross-analyzed to determine common themes. These themes were then analyzed for their impact upon persons with ASD and their ability to function in an educational setting. Themes were further analyzed to determine the presence of the category that would become the central feature of the theory.

The positioning of the identified category as central feature of the theory then allowed analysis of the other categories in relation to the central feature and to the phenomenon under study, thus beginning the next phase of analysis identified by Creswell as the axial coding phase. Creswell (2007) suggests that this phase of coding serve as identification of the 'causal conditions that influence the central phenomenon, the strategies for addressing the phenomenon, the context and intervening conditions that shape the strategies and the consequences of undertaking the strategies" (p. 161). As a result of this analysis a theoretical model emerged, suggesting that, varying views of the cause, legal obligations mandated by government policies and legislation, moral

obligations and perceived responsibilities, along with economic factors are contributing

to the continuation of social perceptions that negatively impact the lived experience for

the person with ASD.

Achieving Sobriety

One reason that ethical concerns have always been evident in research is that it is

extremely difficult, if not impossible, for the researcher to present an unbiased analysis of

the data gathered. Even on occasions in which the researcher is an unbiased observer in

the research, the researcher must then interpret the information that is gathered and that

interpretation is done through the lens of the researcher, which in turn is biased, in the

sense that, it can only be interpreted through knowledge that belongs to the researcher.

Thus, the interpretation is situated in the experiences and background that the researcher

has as a knowledge base. William James (1978) once wrote, "the greatest enemy of any

one of our truths may be the rest of our truths" (p. 43) meaning that we interpret events

that we encounter within what we already believe to be "truth" or we interpret what we

see through the views of what we already know. Because of this bias, that is

unavoidable, we, as researchers, must acknowledge this fact and reveal the lens through

which we view the world and thus, that which we are researching. Short (1991) tells us

that "when both researchers and practitioners tell stories of the research relationship,

they have the possibility of being stories of empowerment" (p. 126) in other words, once

the story is shared and our lens exposed, we have the capability of creating a story that

has potential to give voice to, and authenticates an understanding that reveals a 'truth' in

the view of research participant and researcher. For this reason, it is important that

participants in this research and its readers have an understanding of where this

researcher is situated in regards to persons with ASD, for it is not, and can not be, without bias.

In order to make an attempt to reveal researcher bias, the stories told within this research were discussed and verified with participants. Without this assurance, an accurate theory could not have been achieved, thus invalidating the research. Short reminds us that a "falsehood may be substituted for meaning and narrative truth by using the same criteria that give rise to significance, value, and intention. Not only may one 'fake the data' and write a fiction but one may also use the data to tell a deception as easily as a truth" (Short, 1991, p. 141). It is this error that this researcher wishes to avoid.

Another difficulty that occurs often in the use of grounded theory analysis, is that of determining when a category is saturated. Marshall and Rossman (2006) describe the act of triangulation as "the act of bringing more than one source of data to bear on a single point…[They state that] data from different sources can be used to corroborate, elaborate, or illuminate the research in question" (p. 202). This process serves to provide the reader and the participants with assurance that the derived theory "is an account of which one might say 'I can see that happening'" (Short, 1991, p. 136). Presented in this research are multiple views, multiple sources, and an attempt to verify the told story through various documents.

Finally, another issue that researchers must be aware of is that of providing anonymity for research participants. Providing assurance to research participants that the information they reveal will be presented without identification, in order to protect their privacy, is a most important point. For this reason, research participants within this study

were assured anonymity by providing this assurance, in writing, prior to their agreeing to participate in the research and by allowing them to be released from obligation to participate in the study at any time, up to the point just prior to publication. Participants and their family members were assigned a pseudonym during all phases of the research to protect their identity, thus citations or references to their stories were not included in the bibliography section of this work.

Taking steps to conduct research in an ethical manner is paramount to the quality and equity of research. Failure to expose biases, failure to ensure that the data gathered is representative of the research question that is sought, and failure to protect those who share their experiences leaves future research at risk, at risk for being ignored, at risk for being unbelievable, and at risk for being unexplored. Again, in the words of William James (1978), "I believe that each man is responsible for making the universe better, and that if he does not do this it will be in so far left undone" (p. 134). In order to continue to make the universe better we must rely on our investigative abilities and perform those abilities in an ethical manner to ensure that we have the ability to continue to seek understanding of ourselves and that of the other. We shall now embark upon our quest.

CHAPTER 3

THERAPY, SCIENCE AND THE ROAD AHEAD

In order to begin, let us view through a critical lens, the current treatment and research utilized with children identified with Autism Spectrum Disorder (ASD) in public schools. To embark upon this quest, I will begin first with an analysis of the current recommended treatment for students identified with this label, as recommended by the Commission on Behavioral and Social Sciences and Education, proceed next with an analysis of the science that is being used to support these recommendations, finally I will conclude with recommendations for future research that focuses on social justice for this population that is personal, passionate and participatory.

Let us first begin by establishing that ASD consists of a wide array of variables that are sometimes easily identifiable, but sometimes difficult to pinpoint. "There is no single behavior that is always typical of autism and no behavior that would automatically exclude an individual child from a diagnosis of autism" (Commission on Behavioral and Social Science and Education, 2001, p. 211-212). Because of the variability associated with ASD, many people often find it difficult to accept and understand the diagnosis when it is received and more often find appropriate educational interventions to be elusive. The purpose of the report, complied by the Commission on Behavioral and Social Science and Education, was to formulate a better understanding of the characteristics of ASD, to provide an overview of current research on intervention strategies that assist with acquisition of targeted skills, to make recommendations for future research and to recommend strategies and resources, to be established and maintained by federal and state agencies, that may be beneficial to local school districts,

families and persons with ASD. One reason this report was deemed necessary was because of the significant increase in the prevalence of ASD during the last decade. "Epidemiological studies and service-based reports indicate that the prevalence of autistic spectrum disorders has increased in the last 10 years, in part due to better identification and broader categorization by educators, physicians, and other professionals. There is little doubt that more children are being identified as requiring specific educational interventions for autistic spectrum disorders" (Commission on Behavioral and Social Science and Education, 2001, p. 212). Because of the significant increase in prevalence of ASD, the cost to school districts and families associated with intervention, the variability of the characteristics associated with the diagnosis and the increased numbers of litigation cases being sought by families of children with ASD, a need to formulate guidelines for federal and state educational agencies was identified, thus the Commission on Behavioral and Social Science and Education report was generated to assist with providing a more thorough understanding of our current knowledge and practices associated with ASD.

One of the first concepts presented by the commission was that of identification and eligibility for school-based services. "Regardless of level of severity or function, [a child identified as having characteristics of ASD] should be eligible for special educational services within the category of autistic spectrum disorder" (Commission on Behavioral and Social Science and Education, 2001, p. 213). This was especially important to children diagnosed with high functioning autism and Asperger's disorder. These children often exhibit minimal characteristics of ASD with the exception of deficits in social interactions and higher order language skills. As a result of the minimal

impact, children falling into this diagnostic category were often overlooked for educational interventions. The commission determined that "the most important considerations in programming have to do with the strengths and weaknesses of the individual child, the age of diagnosis, and early intervention" (Commission on Behavioral and Social Science and Education, 2001, p. 212). They also recommended that "identification of autistic spectrum disorders should include a formal multidisciplinary evaluation of social behavior, language and nonverbal communication, adaptive behavior, motor skills, atypical behaviors, and cognitive status by a team of professionals experienced with autism spectrum disorders" (Commission on Behavioral and Social Science and Education, 2001, p. 214). As I read through these recommendations I could not help but ask myself, shouldn't this be done for every child, regardless of the socially imposed label we attach to them? For me, evaluation and assessment of every child's strengths and weaknesses and formulation of a plan to accent strengths and improve weaknesses ought to be the goal of education for every child. Would this not represent social justice in education for everyone? But, I suppose this is an issue that is beyond the scope of this analysis, thus returning to our report, these are areas of findings that I have little argument with in regards to our ASD population.

Another area with which I agree with commission findings is that of the purpose of educational based services. "The appropriate goals for educational services are the same as those for other children: personal independence and social responsibility" (Commission on Behavioral and Social Science and Education, 2001, p. 216). The ideas of personal independence and social responsibility are, what I consider to be, the basis for social justice in our society. A child that is taught personal independence and social

responsibility is taught to formulate ideas that represent ways to improve humanity as a whole. For me, this ought to be the goal of education for our youth regardless of any socially imposed label that we bestow upon them. Michael Apple (2006) suggests that "there is one area that I believe should be at the center of our concerns as educators-providing real answers to real practical problems in education" (p. 41) and I would contend, society at large. In order to accomplish this, we would need to foster personal independence and social responsibility in our children instead of focusing on memorization of multitudes of information. Today, in the age of information and the World Wide Web, ought not the goal of education to be to teach children to access the information that is available to them, and to then, organize that information in a manner in which it becomes a useful tool for improving society, instead of just remembering bits of data? The acquisition of data and information, for the purpose of acquiring an asset is of little value to the individual and to society. It is the use of that information for the purpose of improving society that proves to be of value to our daily lives and the future of our species. Fostering personal independence and social responsibility provide a basis for achieving this goal.

While I agree that the commission identified the appropriate purpose of public education, I find their recommendations regarding appropriate educational objectives to be somewhat disturbing. "Appropriate education objectives…should be observable, measurable behaviors and skills" (2001, p. 218). For me, this statement reduces educational outcomes to a game of numbers. I must admit that some of my concern regarding this statement comes as a direct result of my personal experience with the

Reading First program that was part of the No Child Left Behind initiative. The program

was based on a Congressional mandate

> 'to convene a national panel to assess the status of research-based
>
> knowledge, including the effectiveness of various approaches to teaching
>
> children to read. The panel was charged with providing a report that
>
> 'should present the panel's conclusions, an indication of the readiness for
>
> application in the classroom of the results of this research, and, if
>
> appropriate, a strategy for rapidly disseminating this information to
>
> facilitate effective reading instruction in the school. If found warranted,
>
> the panel should also recommend a plan for additional research regarding
>
> early reading development and instruction.' (Report of the National
>
> Reading Panel, online, Introduction, October, 9, 2008)

As you may be able to detect, the Congressional mandate for this panel was to review the

available scientific research associated with reading development and to make

recommendations as to how to best implement the knowledge we have regarding reading

into practical application for the classroom. This was not necessarily the way in which

the panel's research was interpreted. The resulting federally backed reading program,

Reading First, took information provided by the National Reading Panel and manipulated

that information into a program that was based on assessments that were numerically

based. In order to qualify for Reading First funds state and local school districts were

required to ensure that the

> curricula used in classrooms must reflect scientifically based reading
>
> research that includes the essential components of reading instruction

…[and that the plan] must include procedures for diagnosis and prevention

of early reading difficulties through a) using valid, reliable measures to

screen students; b) using empirically validated intensive interventions to

help struggling students; and c) monitoring the progress of students

experiencing difficulties to ensure that the early interventions are indeed

effective. (Reading First Impact Study: Interim Report, April 2008, p. 1-

2)

In the lived experience of Reading First, this resulted in analysis of numbers on a daily

basis instead of the analysis of children's abilities and needs. For me, the program

became so focused on the analysis of numbers (sometimes accurate and sometimes

inaccurate analysis) that the children and teachers became secondary pawns in the

number game. I contribute this focus on "observable, measurable behavior and skills" to

be the basis of the failure of the program. By maintaining, what some see as an objective

view based on data, and by placing little focus of the lived experience of the program

participants, the program failed to provide accurate reflections of daily classroom

experiences, therefore promoting program failure and failure to achieve what ought be

the goal of education: personal independence and social responsibility. Working as a

literacy coach in this program allowed me to hear daily the concerns of teachers, parents,

and administrators. I can not count the number of times I conversed with teachers to hear

"this is a great idea for some of my children, but this child's progress just isn't reflected

in the data" or "she needs something more. Why can't I use the program that I use to

use? It worked for my students that were having these types of problems in the past." It

was situations such as these that brought much frustration to me when I was directed to

answer, "that program does not meet the criteria for scientific based reading research". It did not matter that the teacher (and sometimes I) believed that the non-scientific approach would better meet the needs of their student. We were mandated to look at the data and scientifically proven methods for meeting the program objectives. The lived experience that resulted from my time spent with Reading First, makes me question and hesitant when I read the recommendations of the commission for appropriate objectives for students diagnosed with ASD to be only those that are objective and measurable. It further disturbs me that the commission notes that "ongoing measurement of educational objectives must be documented in order to determine whether a child is benefiting from a particular intervention" (2001, p. 218). In my experience the idea of "measuring progress" was the driving force behind the failed Reading First program. This need for "measurement" appears to be driving the programs that are being reviewed by the commission, thus limiting the programs that are being presented as alternatives to local school districts, parents, and children identified with ASD. As a result, many of the programs for intervention are designed as behavioral programs and even those that profess to be socially focused, have significant components of behavioral techniques at their roots. It is my hope that the Reading First outcomes will be utilized as a learning experience as to how we interpret commissioned reports regarding our scientific knowledge and that knowledge be utilized to guide future research regarding ASD.

The upfront acknowledgement by the commission that "there does not appear to be a simple relationship between any particular intervention and 'recovery' from autistic spectrum disorders" (2001, p. 217) makes me hopeful that the information contained within the report will be utilized as a guide for local school districts, parents, therapists,

and persons with ASD when they are designing individual programs, as well as, the development of future research. While I am not convinced that "recovery" from ASD is possible or necessary, I find it encouraging that the commission acknowledges that their findings do not represent the promotion of any particular program over another for accomplishing the acquisition of personal independence and social responsibility. When looking at the effectiveness of the intervention programs that were reviewed, the commission critiqued the criteria utilized as outcome measures for judging individual program effectiveness. "The most commonly reported outcome measure in group treatment studies of children with autistic spectrum disorders has been change in IQ scores, which also have many limitations" (Commission on Behavioral and Social Science and Education, 2001, p. 217). Because IQ scores, in most instances, reflect the ability to utilize language to express what is known, they are ultimately a reflection of the child's ability to utilize language rather than a true reflection of their knowledge. Knowledge can be present without the ability to produce language. As a speech-language pathologist, I find it frustrating when I encounter the idea that just because a child does not utilize language to communicate the knowledge they have suggests that they do not posses knowledge. In *The Myth of the Person Alone*, Bliken (2005) was able to demonstrate that persons with ASD, that were considered non-verbal and often identified as having extremely low IQ's were, in fact, persons of intelligence when presented with a mode of communication. One such example was that of Alberto. "As disabled as Alberto appears in body, the content of the text he was producing was perfectly conversational" (p. 23). The fact that Alberto was able to utilize technology to communicate his thoughts proves that he is a thinking, knowledgeable person, that does

not utilize verbal communication to demonstrate the knowledge he possesses, therefore

his performance on IQ tests (the measure we covet), is not reflective of his lived

experience, thus not a reliable measure of effectiveness of a programmatic intervention

utilized to assist him in "recovery" from ASD. My concern regarding the use of IQ as an

outcome measure for program effectiveness in ASD or with any other labeled group of

persons is that outcome measures influence the data reported, thus impacting how the

intervention is perceived by the audience. These do not usually address, in depth, issues

of personal independence and social responsibility which have been identified as the

appropriate goals of educational services, such as in the case of Alberto. I feel the

commission shares this concern, even though they do not specifically address it as such.

Another area of concern presented by the commission, in regards to outcome

measures, was that of participation in the regular classroom environment. "While

successful participation in regular classrooms is an important goal for some children with

autistic spectrum disorders, the usefulness of placement in regular education classes as an

outcome measure is limited" (Commission on Behavioral and Social Science and

Education, 2001, p. 217). I, too, share significant concerns regarding the use of the

placement in regular education classes as an outcome measure for determining the

success of any intervention program. Part of my concern stems from the focus of least

restrictive environment being identified as part of a free and appropriate education.

While I would never suggest that children should be educated in environments that

segregate them unnecessarily from their peers, I do question the criteria set forth in the

Georgia Performance Plan by the Georgia Department of Education. In this plan, special

education services to children are divided into three categories a) those that are "removed

from regular class less than 21% or the day" b) those that are "removed from regular class greater than 60% of the day" and c) those that are "served in public or private separate schools, residential placements, or homebound or hospital placements" (State Performance Plan, February 1, 2008, p. 56). The plan suggests that "a statewide goal was created to increase the percentage of time students with disabilities receive instruction in the general education setting with appropriate supports and accommodations" (February 1, 2008, p. 56). They also report that the "data shows significant statewide improvement" (p. 56) in this area. Again, my concerns are due to the type of data that is collected. The current goal is to change the number of students that are participating in any given setting. There is not evidence that the change of setting is indicated by readiness for instruction in that setting. Instead, this sets the stage for a number game to be played by local school districts, sometimes at the cost of the student's ability to gain personal independence and social responsibility. In my daily work as a speech-language pathologist, I often find students with ASD placed in regular classrooms with a personal aid to shadow them. While this educational plan complies with the state mandated goal of increasing participation in the regular classroom setting with supports, it does not mean that the student is working towards the educational goals set forth by the commission as being the purpose of public education. I often find instead, that students with ASD become dependent upon the personal aid that they have shadowing them and that their instruction is often provided by this aid, which is not generally a certified teacher and often not trained in dealing with students with ASD. Because of my lived experience, I must applaud the commission for their insight as to the lack of effectiveness this criterion has for judging educational effectiveness of any given program. I hope that

the readers of the Commission on Behavioral and Social Science and Education report will be able to discern this element as a significant finding and use this information to critique the findings within the research as it is presented for its usefulness with students identified with ASD. As noted by the commission,

> overall, many of the programs [that were reviewed] are more similar than different in terms of levels of organization, staffing, ongoing monitoring, and the use of certain techniques, such as discrete trials, incidental learning, and structured teaching. However there are real differences in philosophy and practice that provide a range of alternatives for parents and school systems. (Commission on Behavioral and Social Science and Education, 2001, p. 219)

Hopefully, report readers will be able to fill in the blanks that the commission did not address, identify the real differences in the philosophy of the programs that were reviewed, keep in mind the goals for public education, and be able to overcome the number game that is currently part of our society.

> Finally,
> the committee recommends that a variety of steps be taken to ensure that policies are effectively carried out at the state and local levels: 1) At the federal level…appoint a clinical research oversight task force…to review and periodically report on basic and applied research programs…2) States should have regional resource and training centers with expertise in autistic spectrum disorders…3) Families should have access to consultation and legal knowledge…4) State and federal agencies

should…work with and support professional and advocacy groups to

provide up-to-date, practical, scientifically valid information to parents

and practitioners…5) States should have clearly defined minimum

standards for personnel…6)States should develop a systematic strategy to

fund the interventions…so that this cost is not borne primarily by the

parents or local school systems…7) An updated, accurate summary of

case law, consultation services, and mediation mechanisms in autistic

spectrum disorders should be made accessibly by the Office of Special

Education Programs…8) Funding and policy decisions [should include]

persons knowledgeable in the range of needs and interventions associated

with autistic spectrum disorders. (Commission on Behavioral and Social

Science and Education, 2001, p. 222-224).

My concerns regarding these recommendations include questions such as: Will school

staff, faculty and administration interpret these interventions as global areas to be

addressed in a program focused on social justice or will they perceive these to be

validation of the use of the programs that were discussed earlier as being 'research

based'? Even though the panel cautions against pre-packaged interventions will this

caution be adhered to or understood? With the emphasis placed on 'outcome data', will

these programs be seen in the same or a similar manner in which core reading programs,

produced by large corporations, were viewed by school districts during the initiations of

Reading First? Will the state/regional support agencies turn into agencies that promote

specific programs much like the National Reading First Technical Assistance Centers

(NRFTAC) utilized in Reading First? If so, these support agencies will serve as income

producers for promoters of specific materials and programs instead of becoming the

resources that local school districts and parents desperately need for knowledge to assist

them in achieving the recommend outcomes of personal independence and social

responsibility. Will this report become, for the ASD population, the national Reading

Panel report that was used to justify a costly and failed program such as Reading First?

Unfortunately, these are questions that I find difficult to predict answers for, but

questions that I feel could be addressed with appropriate leadership. In order to

determine the steps that educational leaders ought take, we must first begin with an

analysis of the role that our science plays within our society.

Science and Curriculum Studies

When the National Reading Panel was charged with assessing the available

research regarding the knowledge we currently hold about teaching reading, they

"adopted a set of rigorous research methodological standards" (NRP executive summary,

Methodological Overview, p. 3). Those standards were described by the panel: "This

screening process identified a final set of experimental or quasi-experimental research

studies that were then subjected to detailed analysis. The evidence-based methodological

standards adopted by the Panel are essentially those normally used in research studies of

the efficacy of interventions in psychological and medical research." Perhaps this was

the first error made by the NRP. Today and historically, scientific research has been

something that few people question. We have been conditioned to believe that anything

produced by science is above public scrutiny. As a society we have a tendency to accept

this ideology, perhaps because we want to believe that our scientist would never

purposely present to us anything that was harmful to us, partly because we want to

believe that science is the key to our future as a society, and partly because we do not have a thorough understanding of the process that science takes to produce the knowledge that we hold. It is obvious by the statement made by the NRP that their use of the same research standards as in "psychological and medical research" was an attempt to validate their findings at the highest level of scrutiny, but what does this really mean? Exactly how do psychological and medical researchers conduct their studies? To answer this question we will take a quick look at the drug industry.

For most of us, when we are sick, we take a quick trip to the local physician, obtain a prescription for medication that will make us better, fill that prescription at the local drug store and never question how that drug came to be nor do we question any adversities that we may suffer as a result of that drug. If we were to scrutinize drug manufacturing in today's society, we would find that drug manufacturing is an industry. As an industry, drug manufacturing has economic, political, and social agendas that guide its daily work, as does the majority of the science that we encounter. We can see evidence of the value system for science in Kevles and Hood's (1992) work in *The Code of Codes*.

> In the view of the Commission, the genome proposal, which it found consistent with the Community's main objectives for research and development, would enhance the quality of life by decreasing the prevalence of many diseases distressful to families and expensive to European society. Over the long term, it would make Europe more competitive-indirectly, by helping to slow the rate of increase in health expenditures; and directly, by strengthening its scientific and

technological base. (p. 30-31)

While this particular example has its focus in Europe, science works just the same in the United States and even if it did not, our society is becoming so global that the nation-state is becoming obsolete. This is especially so in the field of science, where discoveries are readily opened to international scrutiny and are reviewed in relation to their social contribution to the world. For instance, "the human genetics program included the study of medical disorders-for example, diabetes and epilepsy-not only for their intrinsic interest but because of their social costs" (Kevles and Hood, 1992, p. 5). This focus on social cost is both a blessing and a curse to children with ASD. Because the disorder has been thought to be relatively low incident, especially prior to 1980, there has been little focus on making significant strides in finding cause or treatments. But now, with increased interest, high profile incident numbers and fear of economic impact, governmental agencies are placing emphasis on cause and treatment. In *What is Life*, Schrodinger (1967, 2006) points out that "any possibility of gradually infecting the human race with unwanted latent mutations ought to be a matter of concern to the community" (p. 45). It is this concern that is bringing ASD to the forefront of scientific minds, even if it is an indirect path.

As you may be able to see by the previous examples, economic stability of society at large is playing a role in the science that we pursue. This well-kept secret is exposed by Don Ihde (2002) in his text *Bodies in Technology*. "But, like most science publications today, what gets publicized are the ultimate results, not the processes by which these are attained" (p. 57). The control over what gets published allows the pharmaceutical industry to control the knowledge that is presented to the public. This

form of control serves to perpetuate a secure financial status for the drug companies by allowing current forms of treatment to maintain their market share.

So, how do we do science? We do science in many ways: through observation, chance, hunch, faith, instrument, and accident, to name just a few. Sometimes we do science by beginning with a question and then thinking about ways in which we can answer that question, in doing so, we create talk about our scientific study that holds potential to influence its outcome.

> Scientists usually assume that only their data and theories matter for scientific progress, that how they talk about these data and theories does not matter, that it is irrelevant to their actual work. But in introducing this particular way of talking, the first generation of American geneticists provided a conceptual framework that was critically important for the future course of biological research. (Keller, 1995, p.10)

The way of talking about genetics has influenced the outcome of the science that we pursue. "Ian Hacking has suggested that every scientific discipline has its own 'style of reasoning,' and that this 'style of reasoning' constitutes the epistemological context of that science. In other words, a style creates the very possibility for truth or faslehood and therefore determines what counts as objective (1982)" (Keller, 1995, p. 11-12). This thinking about how to talk about a question and how we talk about the answers to that question serves as a guide to formulating the answers that we need. The talk that we do, as scientists and citizens, guide the thought process into what becomes acceptable and unacceptable solutions to the problems we pose. "Madsen et al. appear to hand-select data to justify vaccine safety-not surprising, given the affiliation of several of the authors

with the Statens Serum Institut, Denmark's premier vaccine manufacturer" (Jepson and Johnson, 2007, p. 127). These incidents offer evidence that the way we talk about our science, even to the detriment of the public, makes a difference in the drugs that are marketed and their use in the society. If this is a reflection of how science is conducted, then should it be surprising that the NRP failed to present to us an accurate picture of our scientific knowledge in regards to the teaching of reading? Should it be surprising to us that the "scientific" knowledge that was presented was used, by Reading First, to promote big textbook companies? I would think not. But, the question from here is how do we overcome this thought process and actually begin to scrutinize the knowledge that is being presented to us. One group of educators has already begun this process; they are our curriculum theorists. We will now begin a journey into the world of curriculum theory to open a conversation in regards to the world of science and medicine.

In order to maintain a focus on what is important to our society, we must continue to use the mechanisms at hand to generate the science that will be beneficial to us and have patients and a critical, open mind regarding what our science reveals to us. John Weaver (2004), tells us in *Curriculum Theorists as Spawns from Hell*, that

the futuristic world of the Gernsback writers was one in which science was king. Where men and, especially, women, created problems because they were cursed with human qualities such as passion, emotion, and subjectivity, the rationality and objectivity of science always created a solution to any problem that developed. (p. 32)

To ensure that we maintain a vision of science in which the problems of our society are addressed because we are "cursed with human qualities" and that we do not allow

"madness…to become the norm" in the science we pursue (Weaver, 2004, p.33) we must scrutinize the information with which we are presented and determine if the only way, and the best way, to view our science is through objective, removed methods of research. With an understanding that as a field of study, curriculum theory is a relative newborn, we can embark upon a journey into the thought process behind the ideas and concepts being placed forth by its members. Weaver, a curriculum theorist, provides insight into the thought process of the field of study when he emphasizes the idea of "human qualities" driving the science that we do. Instead of viewing "human qualities" as a negative, as did the Gerensback writers, Weaver acknowledges the need for "human qualities" to drive our science.

Curriculum theory has deep historical roots in the fields of oral history, psychoanalysis, sociology, political science, mythology, literature and many other fields of study.   The one quality that makes the field of curriculum theory one and of its own, is that, the human aspect of each of the contributory fields is emphasized. The idea behind curriculum theory and its theorists is the idea of taking conversations on topics that appear to be simple and unchallenged to higher levels of thinking. Curriculum theorists create "complicated conversations" and by doing so they seek to answer critical questions regarding social, political, and economic factors that impact the individual and society. They do this by looking through a lens of race, gender, class and oppression. By looking deeper into conversational topics, by complicating them with discussions of individual experiences, by refusing to participate in the number game that is so prevalent today, curriculum theorists seek to find an understanding of the "Other" thus opening the "Self" for understanding. Delores Liston (2001) writes in *Joy As a Metaphor of Convergence,*

that "we do not experience reality directly. Instead, we interpret our experience through a process of knowing that is in turn a reflection of our interpretation of experience, which is a reflection of our relationship to the world as we interpret it" (p. 30). In other words, until we partake of the complicated conversation, in order to learn about the world around us, we have no hope of experiencing the world in a manner different than we currently perceive it. In order to create understanding for ourselves, we must understand the views of those around us; it is through understanding the other that we understand ourselves. To partake of this process means that we must be willing to scrutinize what we currently perceive to be reality and must be willing to alter our perception of that reality for the benefit of true understanding. In order to participate in this process, we are obliged to listen to personal, lived experiences that reflect the reality of our world. We do this through the creation of personal narratives of our lived world, not through an analysis of numbers.

Saundra Murray Nettles, a research psychologist, contributes to the complicated conversation, regarding our science, in the writing of her book, *Crazy Visitation*. This text provides insight into the world of science through the personal, lived experience of a person diagnosed with a brain tumor. Nettles tell this story by relying on personal journals, conversations with friends and family that were part of her life during the experience and the medical records provided to her by her physician, not methods that we traditionally accept as research methods, but methods that provide us with much needed insight.   Nettles (2001)writes, "resilience is more than surviving, more than regaining physical and mental competence. It is also the process of recovering spirit and will, faith, anger, sadness, and above all, joy" (p. 152). Through this description, Nettles provides

her readers with insight into diagnosis, disease and recovery that can not be conveyed through research that is impersonal, controlled, and reported via quantitative methods. By telling her story, Nettles provides us with a personal account of what it is like to be ill in today's society. She connects us to the "human qualities" contained in our science.

　　To continue this theme, we turn to the work of Marla Morris. As a curriculum theorist, Morris has traditionally worked through the lens of oppression by delving into psychoanalysis, philosophy and literature. Much of Morris' work has focused on life in the academy and the Holocaust, both of which are personal and passionate experiences for her. With the publication of her new work, *Teaching Through the Ill Body: A Spiritual and Aesthetic Approach to Pedagogy and Illness*, Morris begins to delve into the conversation of our science and the personal experience of being ill in today's society. Morris (2008) writes, "experiencing chronic illness is living in a constant state of Otherness. Chronically ill people have a sense that those who are well do not understand what it means to live with a chronic condition" (p. 2). In other words, no amount of clinical trials, impersonal data collection, or controlled environments can provide us with the insight into what it is like to be inside an ill body. If we accept curriculum as a learning experience then we must acknowledge that,

> curriculum is meant here in the sense of curriculum vita, or life story.
> The telling of a life story is both psychic and political—this is Pinar's
> point. Critics of autobiography—especially those of the Marxist bent—
> argue that autobiography is narcissistic. But isn't narcissism necessary in
> order to understand the other within the self as well as the self within the

> Other? How else do you understand Others if not through understanding
>
> yourself? (Morris, 2008, p. 3)

Morris, like Nettles, provides us insight into the world of illness and acknowledges that the view that she is presenting is biased and filled with "human qualities", but it is through the biases and human qualities that we come to understand ourselves and others. "Making the best of illness means making meaning out of it. Making the best of illness means writing about it so that others might learn about what it means to be sick. Everybody gets sick at some time. Reading about sickness helps one get through it. Reading about sickness is a way of having company" (Morris, 2008, p. 5). For me, "making meaning" out of any given life experience is a major contributor to the goal of education: personal independence and social responsibility. Without "making meaning" out of the situations that we encounter we are trapped by our pre-conceived notions of what ought be therefore making personal independence illusive. Without meaning, we can not take on the goal of social responsibility because we have a skewed understanding of what ought be occurring in our society. Morris' suggestion of making the best of illness by writing about it, conveys social responsibility, the responsibility of sharing a personal experience with others so that their suffering may be reduced. When we understand that we are not alone in our experiences, we are more likely to recover.

> As I began studying the pathography literature I felt a bit of relief
>
> psychologically. I also studied illness from the narrative perspective of
>
> the physician. The literatures—especially if they turned on narrative—
>
> were all fascinating to me. I became engrossed with my studies and I

think that it was this that helped me get through those early days. (Morris,

2008, p. 15)

Morris recognizes a need for and the benefit of personal narrative in research, she was brought to this realization through a colleague, Delese Wear.

Wear has worked significantly in the field of science through analysis of the American medical school. She views medicine through the lens of the feminist and appears to be comfortable critiquing not only the observable curriculum of medicine, but also the hidden curriculum that exists. Wear (1996) states that "humanities inquiry-literature in particular-can confront, critique, and unsettle learners" (p. 104). She suggests using this type of inquiry in the medical school setting for the purpose of deep thought and self-reflection regarding medical ethics.

One way to move literary inquiry in medical education in this direction is

to ground it theoretically in feminist criticism, which views any

knowledge as inadequate that censures or ignores the experiences,

perspectives, and persons of most of the human race (Messer-Davidow,

1989). Feminist criticism, is, of course, tied to the larger sociopolitical

movement of feminism, which resists not only the subjugation of women

but is also committed to countering oppression of all people. (Wear, 1996,

p. 104)

Wear not only situates herself among curriculum theorists through use of a feminist lens, she also directly challenges the pedagogy of medical school curriculum. "Feminist criticism is a 'mode of praxis…its point is to change the world' (Schweickart, 1986, 38). Confronting morally unacceptable medical practices, then, would be one reflection of a

feminist presence in literature and medicine" (Wear, 1996, p. 105). By acknowledging that oppression exists in medical school curriculum and the medical field in general, Wear challenges her readers to become personally independent in their thoughts and socially responsible for the choices they make during their daily lives.

> Not living in a vacuum, Wear realizes that
>
> change destabilizes society and organizations and, especially when
>
> resources are tight, may produce a we/they adversarial mindset. But from
>
> a global leadership perspective, diversity is a fact, not a problem.
>
> Certainly one of the primary challenges facing leaders now is to increase
>
> collaborations among diverse groups and to see difference as a strength
>
> and a resource. (Bickel, 1996, p. 19)

This is not an isolated problem to the medical school environment. It is instead, a problem of society, one that families and persons with ASD are all too familiar with. In spite of the many strengths that are associated with ASD, society has chosen to label them disabled. With this label comes pre-conceived ideas about what persons carrying the ASD label can and can not do. If you recall the case of Alberto, you may remember that he was identified as having low intelligence because of his inability to verbally communicate, when in fact, he was highly intelligent given the opportunity to express himself through written words. Alberto was only disabled by the idea that he was not capable of communicating. When presented with an opportunity to express his thoughts through a written medium, he was found to be quite intelligent. Had the persons around Alberto not broken the pre-conceived notions they had about him, Alberto may have been destined to a life of silence. Alberto's perceived weakness has become a strength, in that,

he is now able to exhibit personal independence through the written word. Through his writing, he is now able to demonstrate social responsibility by sharing his lived-experience with the rest of the world.

Reiser (2000) shares his thoughts regarding the ethics put forth in the medical school setting by speaking of the hidden curriculum that exists.

> Teachers also influence students by caring about and respecting them. All teaching involves the simultaneous transmission of two lessons: one is a lesson about theory or technique—why nature or artifact is what it is, or how to do something; the second is a lesson about ethics—the teacher's response to the student's efforts to learn and grow. The first lesson teaches students about intellectual constructs and technological reach and limits; the second instructs them about the exercise of power and authority and the meaning of human dignity. Too often teachers focus on the first lesson, either unaware of or unsympathetic to the second. But diminishing the significance of concern and respect in human relationships may be by far the most powerful lesson that teachers leave behind. (p. 4)

But how do we provide teachers with the background to assist them in the development of fostering these skills? After all, ethics is an area that is diminishing in today's curriculum. Reiser (2000) helps us to find clues to these questions when he states that

> the opportunity to teach is not restricted to the instruction of students in a classroom or clinic. I would point out to the administrator that when he creates and oversees budgets, policies, and educational initiatives, and

influences by these actions the communities within and outside of the

school, he teachers powerful lessons. (p. 7)

These are issues that are taught not only by the classroom teacher or professor, but also

by each and every person that comes into contact with the student. This means that

parents, peers, school administrators, government officials, custodians, school staff, the

media, and all other members of the community hold responsibility for presenting

socially just practices in all that they do. Having established ethical, just, practices as the

knowledge that needs to be transmitted to our students today, we now have a less muted

picture of what school leaders need to focus upon for children with ASD. Leaders ought

promote an environment that is conducive to open discussions regarding lived

experiences of all persons, they ought promote individual strengths and minimize

individual weaknesses, they ought fight for socially just practices within their institutions,

and they ought make decisions that foster personal independence and social responsibility

in each and every person they mentor. The Commission on Behavioral and Social

Science and Education made several suggestions regarding the responsibilities of school

leaders in regards to children labeled ASD, however these recommendations were

focused on staff training and providing parents with training and information regarding

diagnosis and treatment of ASD. While professional development for teachers and staff

and parent training are important components in educating children with the ASD

diagnosis, alone, they fall short of creating the leadership necessary to provide students

with the skills that they need to be successful in life, the skills of independence and

caring. To foster the development of these skills in our children labeled as ASD, leaders

in education must first develop the qualities of independence and caring in their own

lives. This development begins with the type and quality of studies that we undertake as analysis of our pedagogical practices.

We are reminded by Hafferty (2000) that "the values of an organization are reflected in its organizational structure and its system of rewards" (p. 23). When educational leaders place high rewards upon research and reflective practices that are steeped in "data" and "objective" analysis, we fail to bring forth the qualities of care and independent thought. Through this structure, we eliminate the human qualities that exist in the lived experience of the other. Without an understanding of the human qualities that are part of our daily existence, we have little hope in understanding the other, and thus the self. Pursuing reflection of our practice that is personal, passionate, and participatory is one way of creating an understanding that holds potential to bring, not only changes in our behavior, but also changes in our understanding of what we do as educators.

An Alternate Way of Analysis

As I stated at the beginning of this paper, I would like to turn now to recommendations for future research into the lives of those labeled ASD. To embark upon this journey, I must first reveal to you my position as a researcher into this topic. During the past eleven years I have worked as a speech-language pathologist serving students labeled ASD. As I think about many of the children and families with which I have worked, I find myself reflecting on what I have affectionately labeled Drew's Story. This is a story of a young child diagnosed with ASD that became a victim of our social views and our political and economic structures. Because Drew was viewed as defective, we utilized medicine to "fix" his defective qualities. Instead, we created a child that became a victim of our economic and political structures. We created a "Frankenstein"

with our medical knowledge and our desire for economic wealth and we utilized our

political structure to justify the decisions that we made. Drew's story quickly became,

for me, a measure of my pedagogical practices, some of which I am not proud to have

participated in.

The field of speech-language pathology has close ties to behavioral psychology.

As a result of this relationship, my view of quantitative research has been one of comfort

and esteem; I fully embraced the scientific method of research. It was not until I became

a participant in the Reading First research project that I began to question my dedication

to this method of research. My experience with the Reading First project brought to light

the flaws in using numerical data to interpret and project pedagogical practice. The

strategies utilized in the Reading First program were validated by the numbers and

scientific methods, but failed to produce change in student knowledge when placed into

practice. Observing this phenomenon first hand, allowed me to engage in a thought

process that revealed the weaknesses associated with quantitative research: the lack of

lived experience. With this revelation, I began to inquire into the world of qualitative

research. During my inquiry into qualitative research I have come to understand that

while my training in behavioral methods taught me to analyze the numerical data, it was

the qualitative data that I relied upon to provide me with the knowledge that I needed to

improve my pedagogical practices when working with children labeled as ASD. It was

my clinical notes, the scribbles that I made when observing students reactions to different

actions and techniques that I was using, not the percentages that I recorded, that helped

me improve my practices. Enlightened, I came to a new way of thinking about research,

thus I come to qualitative research as a new researcher.

And finally, as a concerned member of society, I often find myself reflecting on the morality that exists in our social structure and the consequences of that morality for current and future humanity. Realizing that moral and ethical values are what set us apart from other species within our world, I find that my role as an educational leader mandates that I pass along ethical and moral practices, not only in word, but also in deed. I embark upon this quest, not only as an educator, but also as a student, to seek truths hidden in the world of the other. As a student, I seek to become; as an educator, I seek to guide my students in the art of becoming.   Now that we have explored the foundational structure that appear to be supporting the idea of the ASD person as disordered, let us begin next with a look at the lived experiences of those caregivers other than myself in order to triangulate these perceptions between sources. We will now venture into the lives of Allison, Kathy and Jessica.

CHAPTER 4

STORIED LIVES

The Rollercoaster Ride

Allison, a young working mother of three, shares a story filled with struggle, fear, rejection, love, caring, and determination when she recalls the events surrounding her middle child, Billy. From the very beginning, Allison knew that life would be a challenge for Billy. "Let's see, his first diagnosis was, he had failure to thrive, that was from his feeding disorder and he also had, I can't think of the name of it, its like lethargicness, like um low muscle tone" (personal communication, August 21, 2009). Feeding issues and muscle coordination were to be the start of the struggles that were to be a daily occurrence for Allison and her family. Specialized formula and attention to balance and coordination, resulted in repeated trips to the family physician, contributing significantly to the financial cost of an additional child to the family. While parental hearts were filled with joy at the birth of their second son, the family struggled with the additional demands for care and financial resources, but the significance of the situation was yet to be understood by the young family. It was with Allison's return to work that the awakening began to unfold. With the mounting cost of the continuous visits with the feeding team at the local hospital, the additional demands on the family budget for occupational and physical therapies, above and beyond what the insurance company would pay, and the planned costs of a second child, Allison had little choice but to return to the workforce. "The route that I have chosen ends up costing us money for [Billy] and um as a matter of fact it is quite expensive and most people probably can't afford to do what we do and its not just because of me working its because of my mom, my parents

put in. My husband's parents help out some too" (personal communication, August 21, 2009). Seeking day care services was to be the challenge that began the unraveling of the cloak of denial of their new arrival's situation.

Infant care can be a challenge for any family with a new child, but it was to be even more pronounced for Allison and her husband James. "A lot of schools, they just don't want any kids with special needs in their school. At the school that he was in, they didn't want any kids with special needs" (personal communication, August 21, 2009). Billy's feeding issues were more than many caregivers were willing to deal with. His care was significantly more than a typical child of his age, at least that is what Allison began to hear as she struggled to find a safe, nurturing place for Billy during his time away from his family. Allison, a determined loving mother, thought that she had finally found a solution. She would place Billy in a class for children younger than his chronological age; this would lessen the perception of his needs being so significantly different from his peers. Since Billy was small for his age and since he did not have the motor skills of an older child, he would not stand out as being of higher needs than his peers, at least this was Allison's logic. Even though the change in class resulted in a higher day care cost to Allison and her family, the school was not happy with this decision. Although Billy did not appear significantly different from the younger children, the school staff was aware that he was older and the expectation for his performance was different from the younger children. These expectations established an atmosphere of intolerance. Billy was going to require extra effort from the staff. "And they just didn't have time to care for him with the feeding. Um and I guess he was extra work, to me he wasn't, I didn't see that there was anything anything majorly different from him as

opposed to the other kids that he was in the classroom with" (personal communication, August 21, 2009). Knowing that he was not able to perform the tasks assumed to be of typical development for his age aided school staff in their endeavor to bestow upon Billy a label. This was the beginning of Billy's identity of "different".

As Billy grew, his lack of speech and his awkwardness in motor abilities made Allison uncomfortable. She loved her child, but knew deep down that something was different about him. His developmental milestones were not what she expected when she compared Billy to his older brother Wyatt. Her concerns resulted in late night internet searches that led her to wonder if Billy was a child that fell somewhere on the Autism Spectrum. The internet searches, her need to know as a mother, and her determination to find help for her young son, led her to return visits with the pediatrician. "Whenever I went to the pediatrician at 9 months old and told him that I thought that [Billy] had autism, he was like, [Allison] you are worrying too much about this…he is only nine months old" (personal communication, August 21, 2009). Concerns shared with the pediatrician just seemed to be dismissed, but Allison was determined and persistent. She continued her research and continued voicing concerns to the pediatrician, until finally she received a referral to a neurologist. "I went to the neurologist and um I, he kinda said the same thing, but he didn't discount…the pediatrician discounted what I said but neurologist just said, let's see how he develops" (personal communication, August 21, 2009). Allison knew that this would be the visit that confirmed her nightmare, but again, she was told, "let's wait and see". By this time, Billy was two-years-old. His speech was not developing, his motor coordination continued to be a concern, his feeding issues were still prevalent and Allison was more convinced than ever that Billy was demonstrating

characteristics of a child with Autism. She could not bring herself to discuss her

concerns with her family. "Let's see It started out that I knew that, I felt like, he had

autism and I didn't want to tell [James]" (personal communication, August 21, 2009).

Her husband appeared to be totally unaware and her mother, a nurse, had not spoke of

any concerns, but deep inside, Allison knew. "My mom, at the same time, was staying

up crying, because she thought she knew, but she didn't know how to tell me" (personal

communication, August 21, 2009). The next office visit to the pediatrician would confirm

Allison's fears. A nonchalant conversation with the attending nurse resulted in

confirmation of a diagnosis. Allison obtained copies of Billy's medical records and

found that at least two visits prior, a diagnosis of Autism had been bestowed upon her

child without her having been told. "It said in all those records that, cause I got a copy of

his records. From, I think two visits before that, they had already put down that he had a

diagnosis of Autism" (personal communication, August 21, 2009). Emotions were mixed

for Allison, but the sense of urgency to do something for her child was overwhelming.

Allison began the next phase of her journey. She boarded the rollercoaster of

intervention for those identified as "different".

Allison's research had proven beneficial, in that, she had found information

regarding early intervention services that were available in Georgia. She knew that Billy

would meet the criteria for assistance and felt that this was just what he needed to get

back on track. The fact that the services were free was a plus to the family that had

incurred financial strain as a result of Billy's need for services. By the time that Allison

had drugged through the paperwork and assessment process, Billy was turning three.

Thus, Allison found herself at the doorstep of the public school system, desperately

hoping for services that would meet her Billy's needs. Little did she know what awaited her and her family around the next loop on the rollercoaster of intervention.

Just a few weeks later, Allison found herself sitting in an IEP meeting (individual education plan as she was informed by the staff) that included all those that possibly may be involved in creating this plan. As Allison wandered through the alphabet soup of disability (IEP, OT, ST, PT, FSP, BIP, FUBA and many, many more), she began to worry that her hope for a satisfactory plan for Billy was quickly becoming a fantasy in the wind of her rollercoaster ride. A plan was proposed by the school staff that included the needed occupational, physical and speech therapies along with instruction for school readiness skills that was to be at no cost to the family; there was even transportation to and from home. Friends and family often hesitated to assist with Billy. They seemed afraid that he would be more than they could handle. This added emotional and physical stress to the already difficult situation. The transportation would be an added relief, but Allison's fears had become reality. "None of us want our kids pulled out and put them into some kind of a special environment. I didn't want to pull [Billy] out and put him in some kind of special environment. I wanted him to be in there with the other kids and try to learn to do what the other kids were doing. Which I've always had a problem with schools" (personal communication, August 21, 2009). The plan that was proposed was for Billy to be placed in a class with several children that were non-verbal and "disabled". This was just the type of situation that Allison's research had warned about. She found herself rejecting the offer for services. This rejection left Allison with the need to find private services that would better meet Billy's needs. The family would incur the cost, both financially and emotionally.

As Allison continued her diligent search for services, she felt the need to become the expert on her son's condition and accepted the responsibility for providing the needed intervention. Her search led her to Applied Behavioral Analysis therapy (ABA). Searching for a local therapist proved to be another loop on her proverbial rollercoaster ride. South Georgia just did not have the skilled persons available. She soon found herself attempting to act as mother and therapist. This was one loop on the rollercoaster that Allison knew that she would be unable to survive. She would not be able to be mother and therapist to her Billy. She had to find a therapist. "I actually tried to work with [Billy] and tried to help him learn and develop skills and I was no good—no good" (personal communication, August 21, 2009). Finally, Allison was able to find someone to provide the therapy that Billy needed (a minimum of 25 hours per week of one-to-one instruction across a variety of setting that included home, school and social situations), but this therapist was not trained in the ABA techniques that Billy so desperately required. Allison's search continued until she was able to find a consultant to train her therapist. This would be an additional financial cost to the family, but well worth it in the end. Vicki, Billy's therapist, would be well worth the financial cost to the family as she proved to be caring, concerned, diligent, and supportive, just what Billy needed. She focused the therapy on Billy's interests and over time, Billy grew, his communication improved and he began to develop social skills that were appropriate for a school setting. While Billy's ability to attend to task remained a concern, several trials of medication had proven ineffective in changing the behavior and had only shown benefit in improving Billy's feeding issues. Vicki and Allison agreed that these were issues that could be addressed in a classroom setting with the appropriate support. Allison's next loop was to

find a school that would allow her Billy to participate in class activities with typically

developing peers, another emotional ride.

Private school after private school, Allison searched diligently, aggressively, to no

avail. She finally found herself returning to public school as a last resort. Again, she sat

through a long, difficult IEP meeting to develop a plan that she considered only

minimally satisfactory. Telling herself that she had done her best and that public school

was her only option at this point, Allison struggled with the thoughts of the plan that she

had developed. Flashbacks of all of the negative correspondence that she received

regarding Billy's feeding issues, early in his development, began to overwhelm her mind.

"Public school. I think that didn't work out very well for me, because I knew how hard it

was to teach [Billy] and um I felt like I personally, I needed to know that something was

happening. And with public school, I couldn't really know because well I did figure out

ways, but I didn't know what was going on and I wasn't—I really wasn't accepted"

(personal communication, August 21, 2009). She was dedicated to continuing her search

for an alternative. By this time, the family had grown. Allison had added a third child, a

daughter, Susan. Susan was now attending a day care at the local church. As Allison

chatted with Susan's teacher, she began to wonder if she could possibly find a place in

the church's elementary school for Billy. "She already went to school there and when I

was up there I talked to somebody and they said yea I don't think it will be a problem at

all" (personal communication, August 21, 2009). She approached the first grade teacher

with the idea, giving her all the information that she would need about Billy, assuring her

that Billy would be attending with support from Vicki and that the purpose was for social

interactions, not academic instruction. The teacher surprised Allison when she rejected

the idea without due consideration. "That teacher said no—she didn't want him"

(personal communication, August 21, 2009). She wanted no part in dealing with a child

that was "different". She assured Allison that she did not have the expertise for the

situation and that the placement would not be in Billy's best interest. Devastated, Allison

did not know what to do. How could this teacher, without even meeting Billy, reject him

because he was "different". Allison knew that he was a loving, considerate child. She

did know that there were "differences", but nothing that could not be overcome with care

and consideration. "I was very clear that in kindergarten I did not want anything except

for him to be in the classroom you know doing some of the things that the other kids were

doing that he was capable of doing" (personal communication, August 21, 2009). The

rollercoaster ride was beginning again and the emotions were overwhelming. As Allison

began to contemplate her next steps, she happened to meet with the principal at Susan's

school. She talked with her about Billy and was told that the teacher that was to teach

first grade the next year, was moved to another grade and that the new teacher would be

open to Billy participating in her class. Finally, something was happening right. Allison

had a plan and it was a good plan. She was happy.

The following school year proved to be difficult for Billy, Vicki, Allison and the

rest of the family. The academic skills that were presented were difficult for Billy,

especially the language and reading tasks. He did do well with math activities. The areas

of difficulty required many hours of pre-teaching and re-teaching so that Billy could

participate in the class activities without appearing "different". This left little time to

work on Billy's communication and social skills, which were becoming more noticeable

to his peers. Allison hoped that she would be able to retain Billy in first grade the

following school year, so that the academic tasks would be less demanding, therefore providing extra time to work on communication and social skills, but alas, Billy had made good grades. A's and B's on his report card and the school staff were resistant to a retention. "Some parts he made A's and B's and some he made C's and D's but was always able to pull out—he might not have understood one thing and couldn't pass that but you know made an A or a B and it all washes out" (personal communication, August 21, 2009). Allison attempted to explain her concerns to school staff. "I don't think that he got a good grasp—um to me the early foundation skills are so important and I know that you can keep moving them along… but at that same time I don't want to move him… the foundation skills are so important—how is he ever going to do well when he gets into the fourth or fifth grade if he still didn't have a good foundation" (personal communication, August 21, 2009). As a result of the pre-teaching and re-teaching of academic skills during the home program with Vicky, Billy was successful in completing daily academic activities in the classroom, thus, the A's and B's, but he lacked the needed social and communication skills. He lacked the foundation. Even with Allison's pleas, the conversation seemed to fall on deaf ears, after all, school curriculum was focused on reading, writing, math, science, and social studies skills, not social interactions that were not behavioral concerns. Once again, Allison found herself researching on Billy's behalf. She found that she had little recourse to fall back on. "Because this is not public school and I don't have IEP and all that good stuff um we also have to go with the director and talk with her" (personal communication, August 21, 2009). She had no IEP, they are not required in a private school setting, she had no support for the deficits in language skills that were impacting Billy's education, she had no failing grades to support her request.

Again, she was left without help in providing the education that her child needed. Allison took her pleas to the teacher again. She discovered that the class that Billy would attend next year, would be a split class, one that contained both first and second grade students. Would the teacher allow Billy to participate in first grade language arts and reading activities while participating in second grade math instruction? She would have to wait until August to find out.

In Between Parent and Advocate

In between parent and political advocate, that is where Kathy's story takes place. Kathy a mother of two, talks with great candor about the journey of her first child's diagnosis of Autism. She shares details that suggest that she was totally unaware at first, details of the family's struggle to find and maintain an appropriate treatment, the family's role and responsibility to, her son, Ricky's future, and finally, the political advocate that she has become as a result of her family's experiences.

The family journey began with a visit to Ricky's pediatrician.

Well, I wouldn't have known that I need to do anything but I had a doctor
that said to take him to the speech therapist—but yea the behaviors were
horrible but I didn't know—it was just normal to me—I would have never
known—I just didn't know that there was a problem—I don't know how
in the world it got past me, you know I had just never heard of it—never
seen it—never had a friend that had dealt with it—never read about of it.
(personal communication, August 24, 2009)

The visit revealed the physician's concern regarding Ricky's lack of communication; this concern resulted in a referral to a speech-language pathologist. Unfamiliar with child

developmental norms, Kathy suggests that she would never have known there was

anything wrong with Ricky's development had it not been for this visit. Although, she

notes, reflecting back, there were behaviors that were evident, but not enough for a new

mother to identify. Just three months prior to his third birthday, the family received the

news. Ricky was diagnosed as Autistic. What did all of this mean? Kathy began a

journey filled with inquiry, hope, fear, frustration, anger, and enlightenment. The first

fears and realizations came when Kathy's research suggested that Autism had a genetic

basis. It was scary enough that her son had already been diagnosed, but the realization

that the child that she currently carried was also at risk, added to the devastating event.

"He was three months from being three when he was diagnosed—July 24, 2002—I'll

never forget and being pregnant—it was terrifying" (personal communication, September

5, 2009).   Somewhat relieved by the news that the child that she carried was female, not

male, Kathy continued her research into the cause and treatment for Autism. As Kathy

read more and more on the subject of Autism, she resigned herself to a diet free of wheat

and dairy when nursing the newborn child. "when I started reading about treatments and

causes and I was pregnant I didn't know what to do with her—I didn't eat wheat and

dairy when I nursed her—I was just grasping at straws" (personal communication,

August 24, 2009). She wasn't sure if this was the answer, but the research that she had

done, suggested that the risk could be reduced for her second child if she changed her

lifestyle. Being a responsible parent, she had no choice other than to try. As for Ricky,

he was already at the point of diagnosis. The research was not clear as to how significant

the benefits of diet could be on eliminating the label, but Kathy was destined to try. "the

first thing I did that next day after I researched that night was to take him off of wheat

and dairy " (personal communication, August 24, 2009). She, at once, withdrew wheat and dairy from Ricky's diet, to find a child that was displaying withdrawal symptoms much like those of a heroin addict. "He had a ten hour withdrawal—like a heroin addict" (personal communication, August 24, 2009). After ten hours of watching her child wander the house with dry heaves, Kathy almost gave in. About three days into the diet, an awakening occurred in Ricky. He sat in his highchair starring into space, when suddenly, the realization came that the woman that he was starring at was his mother. He recognized her again. "About two or three days into the diet that he did this and then it stopped and he looked at me like he had never seen me before" (personal communication, August 24, 2009). While the behaviors were still evident, Ricky had returned. From this point forward, Kathy resigned to never look back. She had rescued her son from the opiate effects of his environment. While the journey was to be a long one ahead, with many trials to come, Ricky would at least have the opportunity to take the journey instead of becoming absorbed into a lost world. The next step was to begin preparation for the journey ahead, the journey of education.

Beginning with preschool intervention services in the public school system, Kathy knew that Ricky was not ready to learn from his peers. "I did not want him to be in a classroom with children that were severe or as severe as him—I knew he needed good peer examples but at that age he didn't know what was going around him anyway so nobody was having any effect on what he learned" (personal communication, August 24, 2009). He did not attend to interactions within his environment and he certainly did not imitate those interactions, positive or negative, thus the focus for Ricky's intervention was to learn the routines of being in a school environment. He learned to take care of his

backpack, how to sit in circle time, and how to be responsible for things, all before academic achievement really mattered. Ricky learned how to be in school. Kathy learned how to be in an IEP meeting. While Ricky learned to control his behaviors and to interact appropriately, Kathy learned to pitch fits and learned how to go crazy when she did not get what she knew that her child needed. "I had to learn to pitch a fit and go crazy in his IEP meetings a few times—but I learned how to do that and then I went with other parents to help them" (personal communication, August 24, 2009). With an air of intimidation, Kathy also learned that the meetings did not always reveal the totality of the services that were available. This further compounded the problem of knowing what was right for her son. "They don't tell you what is available—they don't tell you what you can ask for and it seems to be very vague and different every where you go" (personal communication, August 24, 2009).   If the professionals that dealt with children with this diagnosis would not be forthcoming with possible interventions, then how was a parent of a newly diagnosed child to sort through the legal and therapeutic issues that surrounded the event. Could it be that the professionals were hiding a secret from her? Why would they want to keep the answers secret?   Could it be that the professionals were just as lost as Kathy regarding educating her child? It was these thoughts, along with Kathy's personal research that suggested that Autism was not only linked with genetics, but also the environment, that propelled Kathy upon the voyage of political advocacy.

Availability of services, the cost of services, the types of treatment that are available, general knowledge of the disorder, its cause, community supports that are available, and the prognosis for those diagnosed on the spectrum are just a few of the conversation topics that surround Kathy's daily existence. "We have no savings, we have

spent all of our savings …[and] insurance doesn't pay for anything" (personal communication, August 24, 2009). Her background as a journalist, and her part-time work with a local pediatrician that supports the ideology of environmental factors, as well as, genetics as being contributors to the occurrence of Autism, allow Kathy to not only share her personal story with many parents, but also allows her to have a broader perspective of the difficulties that parents and children face today, once the diagnosis of ASD has been bestowed upon them. The first step in understanding ASD is to understand the wide range of the spectrum. "The whole thing is that there is 11 or 12 percent of autism that is actually mentally retarded—its just not MR" (personal communication, August 24, 2009). Kathy knows that no two children are the same, regardless of their diagnosis, but she also recognizes that many times parents and families experience very similar emotions and family difficulties as a result of the diagnosis. One fact that Kathy often shares with parents of the newly diagnosed is the availability of services in their area. This often becomes a difficult undertaking for many parents because adequate services are often available only with the commitment to significant time and cost for travel expenses. "There's nobody providing this stuff… And so this is a lost generation—there is a huge gap in services available—and people" (personal communication, August 24, 2009). As the demand grows for treatment, the availability of qualified therapist and physicians decreases, this in turn increases the cost of an already expensive venture, resulting in many families having to make the difficult decision of good treatment or adequate treatment or perhaps even, treatment or no treatment. "The minute one state passes that and insurance has to pay—there's still going to be just as many kids getting ABA as there are right now cause there's no providers—

there is not going to be anybody trained to take your kid to even if your insurance would pay for it" (personal communication, August 24, 2009). With rising health care cost, the reluctance of the insurance industry to recognize and support some of the available treatments, and the lack of trained professionals, Kathy finds this job more difficult with each passing day. "To do this correctly you have to spend from 10-40 thousand dollars per year—alright—there's a government grant that can represent 20 grand but that is for a very very slim amount of people—we don't qualify—we've never gotten it" (personal communication, August 24, 2009). However, the cost and availability of treatment are just the beginning.

Occupational therapy, speech therapy, physical therapy, Applied Behavioral Analysis, Relationship Development Intervention , Floor Time, social skills training, diets, Chelation (the process of eliminating heavy metals from the body), B-12 injections, sensory training, Picture Exchange Communication System, American Sign Language, and pharmaceutical drugs, are just a few of the treatment options that are commonly used with children bearing the Autism label. "ABA is a program for people that are lower on the scale of performance of the spectrum—high functioning people don't belong in ABA—they need the RDI's of the world or the social therapies" (personal communication, August 24, 2009). Kathy often struggles to give an overview of available treatment and for which children each one may be effective. Knowing that each child is different, that each family situation is different, and that each child's response to treatment will be different, Kathy attempts to summarize her years of personal and professional experience with the diagnosis. She often relies on the stories that she has collected to serve as conversation catalysts for each type of treatment. Many

times, relaying these stories requires a commitment to social support organizations that

are designed to help parents and professionals gain a better understanding of the

diagnosis and its treatment options. Disseminating this knowledge has become more than

a job for Kathy, it has become an obsession, an obsession that she did not willingly

choose, but one that she chooses not to set aside for it is through knowledge and

acceptance that change occurs, the change that Kathy desires for not only her Ricky, but

for every Ricky that has been stricken with the ASD label. "I'm looking to help the

movement to make this stop—we've marched on Washington—I write letters to media

outlets and text my congressman everyday—cause it's gotta stop" (personal

communication, August 24, 2009).   Knowing that her contribution has potential for

creating change makes the time that she steals from her family and willingly gives to

others worthwhile.

Because of her belief that ASD is a result of multiple environmental insults that

compound a genetic predisposition to the diagnosis, Kathy holds hope for a positive

prognosis in the future.

> The kind of Autism that our son has is a genetic predisposition to
>
> autoimmune problems with an environmental insults unnamed—
>
> combination—combination of many environmental insults we're sure but
>
> vaccines certainly did pull the trigger—um my mother has Lupus, [Stan's]
>
> mother has Lupus. [Shaun's] mother also has epilepsy so we feel like—
>
> when born [Ricky] has a screwed up enough immune system to when they
>
> went on day one with the hepatitis B shot and his were filled with the full
>
> amount of thermasol um—that his already compromised immune system

couldn't handle something that was trying trick his immune system and it

went haywire from there—you know he wasn't an aggressor—he did say

some words that disappeared but not like he was completely normal at 18

months old and then got the MMR and it was gone—we really didn't have

that story he was always—something was always up. (personal

communication, August 24, 2009)

It is because of this belief system that she continues to participate in political activism

that includes marching on Washington, writing or texting to challenge Senators and

Congressmen, and continuing to share the knowledge and stories that she has with each

family that she encounters. The thoughts that her son will one day attend college, hold a

good paying job in the workforce, live on his own, and perhaps gain the social skills that

are appropriate to enable him to sustain a relationship with a significant other, are not

enough to curtail the re-occurring thoughts that she has not done the right thing, that she

has failed her son, her family and future generations. For this assurance, Kathy must rely

upon the stories that she hears on a daily basis. Stories that tell of a families' decision to

choose one treatment over another, stories that mirror her decision making process, with

choices that were different from her own. The following is but one example of a story

that is motivator to Kathy's activism and her ability to make the correct decision for her

child and family.

You know that I've seen about two hundred patients at the doctor's office

to this point, and I do two hours of intake and some of them are new to the

diagnosis. Some of them don't even have a diagnosis yet, they're two,

three, or four year olds. Sometimes we get some nine or ten year olds in

there as severely, physically, violent and delayed as [Ricky] was. I

sometimes wonder, have we really improved him by doing all the

biomedical stuff we've done or would he be like this anyway? You have

to ask, right? We have to ask ourselves are these naysayer's right and

have we just wasted our money? Some studies say that kids get better

over time anyway. One day, this mom came in and her child was three or

four months older than [Ricky], so basically the same age. We started at

the beginning and she tells the story of the child, and everything is just

clicking. It sounds exactly like [Ricky], the behavior, the things he did

right, the things he did wrong, the violence, anyway the story goes on and

she tells me what he is like today. She tells about what kind of treatments

they had done. They stuck with the neurologist, and they put him on

Risperdol, and Ambilify. They put him on Chlonodine. They put him on

Adderall, Ritalin, whatever else you name it, they put him on one and then

piled on another and another and piled on another. If one is not working

they don't back the child out of it and start another, they just add it on top

of it. A ten-year-old or eleven-year-old can be up to four or five drugs that

I see. None of these drugs are approved in children, most of the time, and

certainly not approved in combination with each other in anyone. They're

not approved, so again a little science project is going on with the

psychologist or neurologist or whoever. This child sounds just like

[Ricky] up until about four years old, when Ricky started doing better and

was able to mainstream. [Ricky's] language was coming, behaviors were

better and all that. This child at four had to be pulled out of school

because he was so violent, no teacher could handle him. Ever since then

he had been at home. [Ricky's] normal weight, appears as a normal child,

he was mainstreamed in second grade last year, he talks, he is potty

trained. This child, who went the drug route instead of the biomedical

route, weighed twice as much as [Ricky], 150 pounds at nine years old

where Ricky weighs 75. He was not potty trained, was still taking his

feces and smearing it all over the house, and was so violent, they didn't

know what to do. That is why they were feeling like we were the last

straw. They wanted to come and see what we had to say, to see if we

could help him. Grandmother was the caretaker and was getting older. He

was getting stronger and more violent and she could no longer keep him at

home. So, where this child and [Ricky] were exactly the same up until

three or four-year-old, I mean it was uncanny the story that she was

telling, it could have been me. I went one way, she went another, this is

what her kid is like, and this is what my kid is like. I think that from that

day on, I knew that we had done the right thing. [Ricky's] never been on a

drug, at least not on a behavioral drug. He's been on yeast killers,

Oxytocin, nasal spray, B12 shots things that are prescription, but not a

behavioral drug. The children that I see that have been on drugs are so, so

sad. They pull their hair out, they get tics, and they hit themselves. They

suffer and so do the parents. (August 24, 2009)

As Kathy recollects the stories of her personal and professional life, it is easy to see that there is a problem with the way we perceive, interact with, and teach children identified as ASD. When children "pull their hair out", "get tics" and "hit themselves", as a result of the drugs that they are given, and we continue to administer those drugs, ought we not re-evaluate our thought process.

Jessica's Class

It was a brisk fall morning as Jessica and her staff stood waiting for the arrival of the busses. Today was going to be a day just as many others for Jessica's class. The class consisted of eight students, all identified with disabilities that impacted their ability to achieve academically. Each had an individual education plan that guided Jessica's daily activities. These plans, developed by school staff in conjunction with parents and private service providers, were not only to guide the daily activities of the school, but were developed to assist with life beyond school. Jessica knew very well that what she does in her classroom, on a daily basis, formed the foundation skills that her students would take into life. If she failed to teach them to read or to solve math problems, then they would most likely, be destined to life without those skills which would be important in their contribution to society and to their future. Jessica acknowledged that she and her staff, paraprofessionals, Wendy and Judy, were charged with the important task of promoting academic success in students that had been identified as having weaknesses in those skills. They were children that not just everyone knew how to teach. But, teaching students with significant challenges was Jessica's specialty. She had been prepared in her formal studies at the university to teach children with learning disabilities and low cognitive abilities. She was even prepared to some extent to deal with behaviors in the classroom, but what Jessica faced today was more than her time at the university had prepared her to do. Today, she was faced with an ever growing number of students identified as Autistic. "I have worked with Autistic children for seven years now—I have had the opportunity to see a wide range—varying from what I

would consider mildly Autistic to quite severely Autistic—between academic and behavior intertwined and I've seen a lot of difference in the students" (personal communication, September 5, 2009). In the public school system in Georgia, state guidelines categorizes all students on the Autism Spectrum as Autistic, in spite of the varying ability levels of these students to be academically successful in the general education classroom (Georgia Special Education State Rules, July 1, 2007). With assurances from her special education director and her school principal, of support from various experts within the district, Jessica was ready for the day. She knew that she would be able to deal with Justin's aggressive, self injurious behaviors, be able to deal with Nicholas' echolalic speech, deal with Taquan's seizure disorder, deal with Samantha's special dietary needs, deal with Julia's attention issues, deal with Samantha's lack of home support, deal with Jeremiah's medication needs, all while providing grade level academic instruction for Jeffery and Shannon. As Jessica's mind wandered through the plan for the day, she heard the busses with their distinctive bounce in the distance. It was time to begin.

As the busses approached the ramp, Jessica, Wendy, and Judy were waiting for their arrivals with a smile and helping hands. Everyone except for Justin staggered from the bus. Some with smiles, some with blank stares, but all were eager to begin another day in Jessica's class. This eagerness was in part because of the level of attention and care that the children felt while in Jessica's room, but also in part because of the rigidity of the classroom routine that Jessica had established as part of her day. The time that Jessica, Wendy, and Judy had spent with the school district's behavior analyst, reviewing the data from class observations, had been beneficial in developing a routine that made both staff and students comfortable with the multitude of activities that had to occur each day in order to meet the needs of the students in Jessica's class. As the book bags began to fly through the air, across shoulders, and into their neighbor's private space Jessica, Wendy, and Judy began their day. First came unpacking and

morning greetings. Each student, familiar with the routine, began to unpack and find their way to their desk for breakfast. Breakfast was both a struggle and an opportunity. "I have seen how changing diets and different diets have affected different students—and also some different therapies" (personal communication, September 5, 2009). It was a struggle because many of the students in Jessica's class had dietary restrictions because of the medical regimen that was being used to treat their behavioral issues or allergies that restricted certain foods. Parental support was generally quite good for Jessica's students. "His parents were real good about—he could still have snacks at school but they sent in stuff for him to have and a lot of it we shared it with everybody so he wasn't left out by himself" (personal communication, September 5, 2009). Most of the children brought food from home for meals and snacks throughout the day. This was a great relief for Jessica, as dealing with special dietary needs through the school lunch program was a difficult task, even for a simple peanut allergy. "For me it was not as bad cause the parents sent stuff in um—now had he not had his own lunch—I think it would have been very difficult to try to find things—on the average day when you look at a lunch tray—there is a lot of things that have different colors in them" (personal communication, September 5, 2009). All meals must be balanced, but that was a real problem for some of Jessica's students. Some only ate white foods, some ate only crunchy foods, and some ate foods without dye, wheat, and dairy. Balanced meals from the school lunchroom meant that there may only be one or two items on the tray that the students would eat. This was a real problem because for some of Jessica's students, weight gain was an issue. Just as everyone had settled for breakfast, the classroom door swings open with a slam against the wall, Justin had arrived.

Both Justin and his mother enter the classroom. Mom was carrying Justin's book bag. He had thrown it on the ground as he entered the outside door of the school. Justin

was just beginning to transition back to half days at school. Two years ago, Justin had

been one of Jessica's more academic students. He was able to calculate math problems,

decode text on a first grade level, even though he was third grade, and even answer some

comprehension questions from the stories that he had read. Jessica was quite pleased

with his progress at the time. He held great potential. As he was becoming more

successful with academic tasks, Justin was becoming more willing to take risks on tasks

that he perceived as difficult. But last year, something happened. No one is really sure

what it was, but something just snapped. He was having stomach issues, more than in the

past, and he started throwing up everything that he was eating. Sometimes he would start

coughing and cough until he threw up, whether he was eating or not. When this started

happening his doctor recommended a diet restricted to protein, but some of the stuff that

he was required to eat, just was not what he wanted so he would just spit it out. As a

result of the stomach issues and the diet, Justin began to loose a lot of weight. Behavior

issues began to be significant. He wasn't always harmful to others, but he was extremely

harmful to himself. He would hit himself in the nose until his nose would bleed.

Everyone was extremely fearful for his safety. After all, what would happen if he hit

himself the wrong way? It was possible for him to kill himself by accident. No one

really knew what was causing the problem, we thought it could be hormone related, but

we weren't sure and Justin couldn't say. "he was very bright but you could not get it out

of him—he had a lot of the echolalia and he just—or if he heard something that morning

he would repeat the same thing over, and over, and over again" (personal

communication, September 5, 2009). He was basically non-verbal except when he was

reading. Listening to Jessica's reflection here made me recall Douglas Bilken's

interviews with non-verbal persons, in which, he tells the story of Richard. Richard was

a young many that was able to record complex thoughts in writing and was then able to

read them aloud to an audience, even though he was unable to say the words aloud

without a written script. "Richard was among the first people with the autism label who I

had heard could read aloud what they wrote or typed, even though extemporaneous

conversation was still very difficult. When he read aloud, he could say things of great

complexity" (Bilken, 2005, p. 58). So, most of the last school year, Justin was taught at

home. "some kids start out with not so many problems—just like my child that I had to

IEP at home—with minor issues two years ago—compared to last year and that was just

like—he did an instant flip—and is still struggling—he's no where near where he was

two years ago—and he may—he may grow these next two years and grow out of it"

(personal communication, September 5, 2009). Jessica went to his house after school

three days a week to work on academic instruction. It was frustrating because the child

that she had worked with the previous year was gone. The two of them were beginning

again. "he did not realize that he was hurting himself—that was just his response to any

change in routine or being told no… But academically two years ago he was able to read

to me—he was able to follow comprehension—he could add, subtract, work with money"

(personal communication, September 5, 2009). Justin could no longer calculate math

problems, even simple ones, he could not decode and he simply had no idea when it came

to comprehension of something that had been read to him. Justin had regressed. He was

starting over. The health issues had improved and the self-injurious behaviors had been

reduced, so Justin was transitioning back to the school setting. He was not quite ready

for the bus ride to school, therefore his mom had decided to transport him until he could

settle in. This was a decision that she made with great apprehension, since it required her to take a reduction in work hours, which the family really needed for financial support. There were medical bills that the insurance did not cover and the special therapies required extensive travel. "I know that she tried to find somebody local but wasn't able to at that time—so I believe they were going back and forth—he went every Friday and had the therapy done" (personal communication, September 5, 2009). Justin was back and he had just arrived.

Justin flopped at his desk and began to unpack his lunch box with assistance from Judy. He smiled at her when she opened the container that held his breakfast. As everyone ate, Jessica prepared the academic centers for the day. Eight different levels of academic achievement required eight different levels of instruction. Jessica was ready. In the midst of bags rumbling and containers popping, the transition to the first activity was beginning. Some students were preparing for PE class, some computer, some work tasks that were designed to improve fine motor skills and develop assembly skills that could be used for future jobs. Everyone checked their schedule to ensure that they were going to the right location. While the schedule differed from day to day, the posted schedule ensured that everyone adhered to the appropriate routine. For some, deviation from the posted schedule would result in tantrum and aggressive behaviors. Ensuring that the schedule was properly adjusted prior to the student's arrival was a large part of Jessica, Wendy, and Judy's after school activities. Things as simple as picture day could prove to be a nightmare without the appropriate planning.

Planning time was something that was precious and greatly lacking in Jessica's schedule. Writing IEP's, conferencing with parents and general education teachers,

participating in professional development activities to improve severely needed specialty skills for working with special populations, designing instructional activities and analyzing data were all supposed to occur during Jessica's planning time. Forty-five minutes, first thing in the morning, from 8:00 to 8:45 and one hour in the afternoon from 2:30 to 3:30, that is when Jessica was supposed to complete her to-do list. From an onlooker's perspective it seemed possible, but Jessica knew from experience that it was not enough. The many evenings that she spent with schedules and textbooks sprawled across her kitchen table were enough to convince her that while her administrators and her parents were sympathetic, they really did not understand what it was like to survive one of her days. Jessica's lack of planning time is just one example of the difficulty that teachers face daily in regards to educating children identified with ASD. Eventhough data analysis is identified as a key to interventions with children labeled ASD, teachers still are not given appropriate time to review and reflect upon the efficacy of their instruction. This, at least in part, is a result of tightly controlled government regulations that designate the number of students funded per segment of each day. Federal and state funding is linked to the number of students and the area of identified disability that are served by each teacher for the designated time blocks during the school day. These regulations control state and federal funds allotted to each school district for services of identified students. Because of the stipulations for a minimum number of students (five students fund a segment of special education services in a general education classroom), Jessica is forced to constantly move from lesson to lesson, without the benefit of deep reflection or analysis of student response, in order to fund her existence as an educator for children with special needs, thus instruction becomes routine and non-evolving (Georgia

Special Education State Rules, July 1, 2007). But Jessica, a dedicated teacher, was willing to do whatever it takes to make her students successful, even if it meant sacrificing some of her personal time with her own family. At least this year, the responsibility of extended instructional time for homebound services was not an issue. At times, Jessica has felt as if her general education peers think that special education is not as demanding as the general education curriculum, but what they do not understand is that once a child is identified as a person with a disability the responsibilities for their academic instruction becomes compounded. The school is no longer able to say that a student is not learning, they must ensure that they are learning, by whatever means is necessary to ensure that a free and appropriate public education is evident (Georgia Special Education State Rules, July 1, 2007). In today's society, Jessica knows that many more students are now receiving educational services in their home environment due to medical issues and behavioral problems. This not only extends the instructional day for many special educators and further contributes to the lack of planning, analysis and reflection, but it also isolates children from social interactions with their peers.

Opportunities for social interactions are something that Jessica is becoming more aware of with each day that she teaches. The training that she receives as part of her school district's support and the conversations that she has had with parents of the children in her classroom have served to increase her awareness. Several of Jessica's students participate in extra curricular activities that are available for students with special needs, but there are not many of those activities that occur on a regular basis. "this is not so much a resource to help them at school but it is a nice outside resource— um there is a group that works with horses and they do therapy and its open free –they

don't charge parents" (personal communication, September 5, 2009). At first, Jessica

assumed that cost was a primary factor for many of her parents. While her school resides

in a middle class neighborhood, her school district does have several pockets of poverty.

Because Jessica's program is specialized, many of her students are not from the school's

attendance area, many are from those pockets of poverty, thus her assumption of cost

being a primary factor in social opportunities. By being open to learning and listening to

the needs of her students, Jessica was able to identify that the problem ran deeper than

cost. "I don't have the availability to find the time to be able to do it myself but if I knew

where to go to—I would be willing to work with someone—I would love for there to be

more stuff for them to do outside of school" (personal communication, September 5,

2009). The problem was that there were not enough people trained or willing to develop

programs such as the hippotherapy program that many of her students benefited from.

This program was developed to provide children with special needs the opportunity to

interact with horses, to ride, communicate with, and care for horses. Through the

program, the children not only developed their sensory systems, but also developed skills

of trust, responsibility, and empathy, skills that are lacking and difficult to teach to

children identified on the Autism Spectrum. "Whether it be that they worked on

interaction with the animals um and in working with other adults and by interacting with

other kids that were there the same time they were there—it was not necessarily the same

kids from their classroom—so I definitely saw them become more social" (personal

communication, September 5, 2009). So, as Jessica learns more about the possibilities

for extra curricular activities in her neighborhood, she is beginning to understand that

awareness and understanding is not enough. She is learning that in order to see the

needed changes, someone will need to step up to actively engage the public at large in regards to the cause. Jessica is beginning to understand that part of her role, as an educator, is becoming an advocate and voice for those she represents.

As Jessica, Wendy and Judy prepare the children for the bus ride home, Jessica is already planning for the after school faculty meeting that occurs every other week. She is planning her presentation to the faculty to ask for ideas on ways to begin an after school program that focuses, not on academic skills, but those skills that are necessary in life, the skills that will allow her students to become part of their community and contribute to its future. The task will not be an easy one. Jessica will need a plan of action that will include the type of activities that will engage her target population, provide the skills that they need to be successful, recruit staff to operate the program, provide funding for the program and a plan that will ensure the continuation of the program that she develops long after her departure.

CHAPTER 5

A CALL FOR ADVOCACY

So, you may be sitting there thinking what does all of this mean? Those are really nice stories but what real relevance do they have to education? A significant amount I would reply. As a curriculum theorist, I find myself frustrated as I read and re-read these stories. As I recall the words in my head, I become enraged that we say that we know what to do to assist the children that we so willingly label as ASD, but yet, we allow structures and policies to prevent us from applying what we profess to know. These are structures and policies that we create and maintain, as a society, as part of our system of education. I find that teachers are frustrated, parents are frustrated, students are frustrated, and society at large is frustrated with the process that we now hold dear and call "education". It is through this frustration that I find my own call for advocacy. As a result of my call to action, I feel the need to provide, what some would say was a less biased analysis of the stories that have been told, in hopes of creating a space through which our social structures and policies may begin to evolve into supportive structures that assist our children identified as ASD instead of roadblocks that hinder the efforts of caring parents and teachers.

Through the process of axial coding, which identifies and compares categories that emerge within text, we will venture next in our quest. During the process of axial coding, several common themes emerged within and across the collective stories. Themes of activism, fear, cost, educational purpose and otherness were all evident. It is in the analysis of how these themes were presented by each storyteller that provides to us

a grounded theory that is based in social justice. Kathy Charmaz (2008) tells us that "a social justice researcher can use grounded theory to anchor agendas for future action, practice, and policies in the analysis by making explicit connections between the theorized antecedents, current conditions, and consequences of major processes"(p. 210). This is the quest upon which we will embark in our next analysis.

The Cost

We shall begin our quest with an analysis of cost within the collective stories. In Allison's story, she tells about having to incur additional cost due to the significant feeding needs that her child had. "He was still the same size as the 9 month olds and he was still doing the same doing the same stuff, and I paid the fee for the younger class, because as they get older the fee gets less, so I always paid the extra fee even though his age was going up. I still had to pay the more expensive fee to keep him in the younger classroom" (personal communication, August 21, 2009). Kathy shares her experience of incurring the cost of multiple meals for her family in order to satisfy the dietary needs of her diagnosed child. "It's not easy. Its time consuming and its expensive. I end up cooking three to four different meals in an evening, and in a family of four, if he has a special meal for three meals a day, I make 12 different things in a day" (personal communication, August 24, 2009). While Jessica does not share the financial burden of special meals, special services or medical treatment for her children, as a teacher she recognizes the cost that the parents incur in their quest to seek treatment and she understands what can be achieved through community based services. "This is not so much a resource to help them at school but it is a nice outside resource, um there is a group that works with horses and they do therapy and its open free. They don't charge

parents, they do donations and they don't center just on Autistic kids. They actually open

it to all special needs kids but I've had several students go there" (personal

communication, September 5, 2009). It is easy to see that cost is recognized, by all who

shared stories, as a significant contributor to the overall perception of disorder. By being

disordered, a need is created that requires additional financial contributions by those that

surround the disordered, including its institutions, one of which is education.

Children in Weighting

One role that curriculum theorists play in the process of education is to critique

situations, rules, policies, and actions for the purpose of determining who benefits and for

whom the area of critique is troublesome or even oppressive. Let us begin by looking at

the social and economic purposes of public education. Joel Spring (2007) writes

"education was the key to social control and improvement of society" (p. 22). This is

true historically and currently. Values of society are both, sustained and created through

public education. Spring (2007) suggests that public education works in two ways to

propagate social beliefs: "one method is to use education to control a population after it

has been conquered…the other method, based on a fear of the liberating possibilities of

education, is to deny a population an education or to try to limit their educational

opportunities" (p. 42). We can see evidence of the second method in today's public

schools by looking at the process of special education and the methods of "intervention"

that are utilized with the persons identified as ASD and others with special education

categorical labels. When a student is identified as a student with a disability, the process

of creating an individual education plan (IEP) begins. The IEP process is mandated by

IDEA and is supposed to be for the benefit of the student. Its purpose is to create a

specialized program of instruction that meets the specific needs of each student. Instead, what many parents and teachers encounter is a process that attempts to place a student in the environment that provides the most economic support for the school district.

If you will recall our discussion in chapter three in regards to inclusion, you will remember that school districts are held accountable, through state and federal mandates, for being disproportionate in areas of the various disabilities and in their service settings. Each of the various disability categories and service settings generate a different amount of funding for the school districts. These funding formulas require that a certain number of children be present in a given setting, in order to obtain the full amount of funding necessary for earning a teacher. These funding formulas, known as full time equivalency formulas (FTE's), inhibit at least as much as they support education for students identified as disabled.

While each student, regardless of the identification label they hold, general education student, gifted student, student with a disability, student with limited English proficiency or any other that might be bestowed, generates a FTE, either weighted or unweighted. For students with special needs, their contribution is a weighted contribution, which means that, depending on the area of disability and the setting in which the services are provided, the FTE formula is weighted at more than one FTE. For example, if a student is identified as having a label of Hearing Impaired and served in a Level III setting (1-3 segments per day), then the FTE formula is calculated at 3.5897000 x (designated $ amount for one FTE). If the same student was served in a Level IV setting (4-6 segments per day) then the formula would be calculated using 5.8227000. The difference in the two decisions can become a financial decision when teacher

positions are linked to the process (Georgia Department of Education, FTE Data Collection Program Codes and Weights, June 4, 2009, p. 4-6).

It is easy to see that economic decisions could easily become the determining factor in services for a student identified as disabled. This is especially so, in a time of economic hardship such as the situation that we face today. As an educator, I would like to think that all decisions are made in the best interest of the student, and I think that most times this is the case, but knowing that making a decision to serve a student for reading, math, science, and social studies, rather than reading and math alone, could potentially result in the school earning the salary for an additional teacher, makes this process an ethical dilemma for school personnel, one in which there is no "right" choice. In this sense, our economic policies and structures hold potential for impacting students negatively, as much as they do positively. As curriculum theorists, it is our job to continue to delve deeply into these types of structures to expose their oppressive qualities and to set forth alternative possibilities.

In addition to the financial cost of treatment, Kathy and Allison also identified social costs that were evident with the label. "A couple of years ago Alzheimer's research tripled Autism research and when somebody gets diagnosed with Alzheimer's you have a life expectancy of 9-13 years to live… but when you are diagnosed with Autism, you've got a whole lifespan ahead of you" (personal communication, August 24, 2009). "I have visions that um that he will be home with us and that he will um have a little job, a little job that he can go, um, and do during the day…I have a vision that I don't want him at home. I don't mean to sound selfish or anything but that—Oh I'm gonna cry—that's not what I had planned out for life and I want to get him to a point that

he can go and live somewhere and do his own thing and be more independent and not be

coming back and forth into my house" (personal communication, August 21, 2009). The

struggle for these children and families is quite obvious when tantrums are observed and

conversations turn to long-term care. But, long-term care will continue to be of grave

concern to these families as long as structures such as standardized testing continue to be

the focus of our educational practices.

Validating Our Addiction

Standardized testing has long been a part of our public education system. It has

served to identify those we call disabled, those we call slow learners, gifted and normal.

We have come to depend upon our system of numbers to tell us where and how students

will fit into our society. This has never been more so than today. During a time of

economic instability and uncertain futures, we appear to be grasping for ways to show

that we can "validate" our educational practices. Our political leaders are searching

desperately for ways to determine who will and who will not receive the latest funding

and we find ourselves, as educators, in a position in which we are have no choice other

than to try to compete on the field that is placed before us. While the era of No Child

Left Behind appears to be coming to a close there appears to be a new line of thought in

the era of accountability emerging. This new era is that of, Common Core State Standards

(CCSS). In other words, we are taking another step in the creation of a national standard

and national control of public education. The CCSS is described as an initiative that "is

a state-led effort coordinated by the National Governors Association Center for Best

Practices and the Council of Chief State School Officers…[that is] committed to

developing a common core of state standards in English-language arts and mathematics

for grades K-12" (www.corestandards.org, February 27, 2010). According to this source, the standards will "define the knowledge and skills students should have to succeed in entry-level, credit-bearing, academic college courses and in workforce training programs" (www.corestandards.org, February 27, 2010).   At a recent meeting with the Department of Curriculum and Instruction at Georgia Department of Education, it was announced, with great pride, that the Georgia Performance Standards were being viewed as a possible model in the development of the CCSS (personal communication, February 25, 2010). This announcement was made during the introduction of "Formative Assessment" training for school improvement staff. The training was developed to be a model for school improvement specialists in their training of teachers and school administrators, especially in their work with "Needs Improvement" schools identified by AYP scores. The focus of this training was to teach teachers how to create multiple choice question tests and to use them to guide classroom instruction. While on the surface this sounds like a reasonable expectation, a closer look at multiple-choice assessments may reveal a contradictory picture.

One might think that developing assessment questions is a relatively simple task, but that would be an incorrect assumption. Because developing assessment questions is a task that requires thought and planning, there has been an industry that has emerged to satisfy this need. Assessment, especially those standardized assessments that are used for summative data and tied to teacher and school proficiency, has become an industry of experts. Experts study and scrutinize test questions for racial, gender, and cultural biases, because society has come to recognize that tests are only as good as their validity data. If a test is created to measure reading comprehension in children of a given age, and that

test includes vocabulary words that are not used in the child's culture then the test is not measuring reading comprehension, it is instead measuring a child's knowledge of a different culture. Testing companies therefore train their test makers to recognize cultural, racial, and gender differences. They are beginning to utilize brain research to look at how visual layout of various questions impact student responses (personal communication, Karen Bailey, February 26, 2010). Yet, scrutiny does not always eliminate unfair or inappropriate assessment questions such as the one below:

School Bus Item

A teacher is planning a field trip and will need school buses to transport students. A school bus hold 36 students. If 1,128 students will be transported, how many buses are needed?

A. 31
B. 31.33
C. 32
D. 36

Bailey pointed out in her presentation, that the child that was able to arrive at the correct answer, through the use of division and rounding, was still faced with the logic of how to answer the question. For example, if the child used prior knowledge and life experience, then the child might reason that 31 buses were needed, because the remaining 12 children would be able to "squeeze" in. This happens on a daily basis in schools, possibly to the chagrin of school transportation directors. In order to get the answer correct, the student must forgo what life experience tells him to be accurate and rational and instead answer with 32, a devastating thought in a time of economic struggle. Who would possibly consider expending the cost for a bus that would be two-thirds empty when there was an alternative? This type of test question is frustrating to students who attempt to use

critical thinking skills and attempt to apply the test situation to life situations, because they are set up for failure instead of success. It is even more frustrating to children identified as ASD, because their logic tells them that what they experience in life is not reliable information. It further promotes "rote memorization" to ensure that the answer is correct. Even more disturbing was the story that Bailey told of another faulty assessment question. If the first example of unjust assessment were not enough, this example should caused great alarm for educators.

Bailey's story of a faulty test question, that was reviewed post exam, suggested that tests truly do inflict harm to children, and might I add, to teachers and school administrators that struggle to comply with the game of making AYP. Bailey relayed the story of working for a testing company that reviewed a specific test question, post exam, because of the number of students that failed the specific question. One question was reviewed for its validity and accuracy and was found to be significantly flawed. As a result of its flaw, many children failed to arrive at the correct answer. You might think that this could not have possibly had a significant impact on any given student; after all, they missed one test question. But Bailey told of multiple children that missed the flawed question and as a result of one incorrect answer, failed the test, preventing them from progressing on with their education. What Bailey did not discuss, was when and how this error was resolved and the final consequence for students, teachers and school administrators. I cannot answer for my readers, but for me, as an educator, this is unspeakable. There is no manner in which I can resolve this error as a socially just curriculum; this instead, is a curriculum of addictive thoughts, an addiction to numbers

and assessments. This is a curriculum filled with social costs for its citizens that holds

potential to stimulate anger and fear.

Anger rears its ugly head with the realization that children identified as ASD will

potentially contribute minimally or not at all to society, but instead become a burden to

the remaining members. They require special classes, specially trained instructors, special

diets, expensive medications, and multiple therapies just to function from day to day.

With many of these costs falling upon the community taxpayer (approximately $22,300

per person in Georgia with approximately 8,479 persons receiving Medicaid wavers in

2003 for a diagnosis of Autism without mental retardation), anger becomes a realistic and

understandable emotion (Spigel, 2007, p.1). While financial cost worry me, and I suspect

anyone that is still reading this analysis, I think that my fear of the social cost of the

disordered has become a more significant concern. What impact will the disordered label

of ASD have upon our ability to function as a society? By labeling and treating these

children as being less that "normal" members of society, we create a need for "space" for

those that are labeled.   Instead of recognizing and utilizing the strengths that the children

possess, today we focus on the weaknesses. We create a system that acknowledges what

they can't do, what their limitations are, instead of identifying what they can do, many

times with superb skills, skills that hold interest and have value to individuals and

society. John Dewey (2001) addresses this issue by saying "here individualism and

socialism are at one. Only by being true to the full growth of all the individuals who

make it up, can society by any chance be true to itself" (p. 5). By acknowledging that it

takes all members of society to maintain its effectiveness, then we acknowledge that we,

as society, have an obligation, both financial and social, to ensure that all members make

a contribution to the best of their ability. We can not do this without acknowledging that our label of "disabled" interferes with this activity and creates unnecessary fear in its citizens. Fear serves two purposes; it identifies a target that needs to be addressed and it serves as an accelerator for change of the identified target. Without fear, we may never be motivated to change the injustices we find in society today. As William (A.) Bram(ham) Stoker reminds us in *Dracula*, "but a stranger in a strange land, he is no one; men know him not-and to know not is to care not for. I am content if I am like the rest, so that no man stops if he see me, or pause in his speaking if he hear my words, to say, 'Ha, ha! a stranger!'(2003, p. 25). Fear of the unknown, those unlike us, fear of the Other, serves as a stimulant to seek answers to the questions and concerns that we have. In the case of ASD, we find that the economic impact of the disorder is cause for us to take a close look at how we stimulate scientific research and how we resolve the financial burden that is placed upon society.

The Fear

Fear was an area of concern for all story participants. For Allison, she not only feared what would happen to her child after her death, but she also feared the repercussions of the label. "Billy was so young that I didn't want to say it…that was a really difficult time. I didn't know how to say it" (personal communication, August 21, 2009). Allison somehow knew that labeling her child would have consequences. While she desperately wanted an answer to the difficulties and struggles that she was observing in her young child, she also knew that the answer held potential for a devastating label that would impact Billy's life forever. "There's always so many roadblocks and so much trouble that you run into and a lot of misunderstanding of his diagnosis that other people

have. It is kind of weird, I run into some people and they are completely open and they want to figure out how they can help me and other people are standoffish" (personal communication, August 21, 2009).   Allison's concerns are not unlike Kathy's in regards to her child's diagnosis. Kathy, too, feared the label, but not only for her son, but for the child that she was carrying. "He was three months from being three when he was diagnosed, July 24, 2002, I'll never forget and being pregnant. It was terrifying, cause there is so much of a higher chance and we did not know whether we were having a boy or girl, so it was very exciting that it was going to be a girl since the rates were lower" (personal communication August 24, 2009). Both mothers recognize that identification of "disability" is a double edge sword, one that has potential for sacrificing future possibilities, at least in the minds of some, and the relief of knowing why your young child is struggling. Both mothers feared the label as well as the possibilities for the future.

The evidence of fear was also prevalent in Jessica's story. She feared the possibility of injury to her student. "His response was to hurt himself and when he hurt himself he would be crying and saying ouch, hurt, but he didn't know how to handle the hurt so he would do it again…it was just stacking up to where he would bust his nose almost everyday" (personal communication, September 5, 2009).   The idea of one of her students injuring themselves was traumatic for Jessica. She struggled with handling the situation. She asked for help from parents, school support staff and anyone else that would listen. Jessica recognized that she was not equipped to handle the situation. She realized that she could not focus her attention on the duty of academic instruction. She knew that her first responsibility was to ensure the safety of the student that she was

caring for. While Jessica's concern was one of physical injury, Allison also feared the

school environment for a much different reason.   "The communication between school

and home and his development was so important to me that um it was necessary for me

to know what all was going on and that he was you know, getting what he needed. And

for me as a parent there was no way that I was going to um not know" (personal

communication, August 21, 2009). Allison's concern related to the reluctance of the

school to provide her with information regarding her son's daily activities. Without

communication to enlighten her of the activities, her mind wandered and thoughts of ill

happenings emerged. "If there is not an open door policy then parents think that there is

something wrong" (personal communication, August 21, 2009).

Allison's open door policy broaches the topic of communication and

miscommunication. It identifies the catalyst for relieving the fear surrounding ASD.

Garrison (1997) reminds us that "Dewey thought that reality is infinitely complex but

that mortals can only gather a finite number of perspectives. Thus finite creatures can

grow wiser only if they share perspectives, for seeing things from the standpoint of others

also allows us to multiply perspectives. That is why Dewey thought dialogues across

differences were essential for those who desire to grow" (p. 15). By acknowledging that

as communicators, regardless of which perspective we come, parent, teacher, those

identified as "disabled", politician or caring member of society, we fail each other when

we withhold knowledge of self and perspective.

Recognizing and Communicating Our Fears

Stoddard Holmes (2001) writes that "the meaning of our bodies is produced in

continuous, lifelong negotiations between how we see ourselves and how our culture sees

us" (p. 27). In other words, the laws and social norms that we adhere to, work to define how we view ourselves as part of the world in which we live. The American with Disabilities Act (ADA) was fashioned to provide an equalization for those that our society identifies as disabled. It provides protection for those that are viewed as having a difference that society has determined to be a deficit. It has served and still serves, to bring awareness and legal clout to those who need its protection. Working much as the Brown v BOE case law (1954), for persons identified by our society with minority racial status, the ADA serves to ensure that persons identified as disabled have equal access to the workforce and social services within our society. Social views that suggest that "differences" is equivalent to "abnormal" have deep historical roots and significant consequences, both in and outside of the United States. Joel Springs (2007) writes "for Romans, those who lived by Roman law and within the limits of the Roman Empire were human. Those who lived outside Roman rule were less than human. The word 'civil meant a form of law and the verb 'to civilize' meant to being a people under the control of law" (p. 2-3). From this view, anyone not living within the Roman Empire were considered to be "abnormal" in their culture. We also see this with the English's perception of the Irish. "The English considered the Irish inferior savages who could only be redeemed by adopting English culture" (Spring, 2007, p. 5). Not all differences were contributed to culture alone. "The concept of skin color as a bar to citizenship was made explicit in 1923 when a group of Asian Indians claimed they were eligible for citizenship because they were Caucasian" (Spring, 2007, p. 74). Just as the concept of skin color identified those that were "different" and "abnormal," persons with a medical "difference" are considered to be "abnormal" "powerful discourses in medicine and

other regulatory domains work to represent, construct and position some people as 'impaired' or 'disabled' and others as 'normal'" (Thomas, 2002, p. 51). In order to change long held perceptions about those with "disabilities" Wilson and Lewiecki-Wilson (2001) suggest that

> transforming disability will require transforming economic, social, ethical, and educational practices, reimagining social spaces, and rethinking ordinary habits. It will also require an understanding of embodiment as difference and the transformation of the category ab/normal and all such thinking that reads 'difference' as defect and deficit and thereby lays the foundation for the many walls of exclusion. (p. 18).

But, you may ask, why do we need to change this perception? After all, "disability" is a scientifically proven "fact".

The social perception that difference equals defect and deficit provides a medium in which fear of those "defective" persons is allowed to prosper and grow. Through fear of the person identified as ASD, the characteristics seen as unique to these persons also become feared. Susan Sontag (1990) writes that "any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious" (p.6). With increasing frequencies of occurrence, increasing media focus, increasing costs associated with the "disorder", and increasing scientific research into the cause and treatment for ASD that appear to be making few strides, the fear factor mounts and spreads. To gather a better understanding of why the identified ASD person would be considered a threat to our society, let us begin by delving into the characteristics that identify the ASD person as "different".   Perhaps then, we stand a chance of transforming

social perceptions that drive economic and political practices that currently hinder the advancement of ASD person into society without bias or fear.

Autism Spectrum Disorder: The Posthuman?

As I discussed earlier in chapter three, there are many speculated causes of Autism Spectrum Disorder (ASD), including environmental causes which are predominately focused on medication, foods and toxins, and the use of technology. It is the connection to technology that I would like to explore in this section. Brian Jepson and Jane Johnson (2007) address these concerns in their text, *Changing the Course of Autism*, in reference to an increase in cases of the disorder in California.

> Since California was the high-tech capital of the world and since people with autism were particularly adept at computers, the previously undiagnosed adults were now marrying each other and their children were more severely affected. Or better yet, autistic males now had a place in the world because of their computer skills and were able to make a lot of money and were, therefore, more attractive to the opposite sex. They were now given the opportunity to procreate when previously they would have been shunned, or relegated to monasteries to spend their days making copies of the Bible. (p. 27-28)

They however, do not expound upon this hypothesis within the text, only identifying it as a hypothesis that had been generated by concerned persons. While these scenarios offer, as the cause, a change in culture as a result of the emergence of technology, they fall short in their possibilities because they do not address what I see as the real questions in regards to technology: are persons with ASD cyborg? Are they post-human as a result of

a merger with technology? If so, what does this mean for our changing society and the way we perceive the person identified as ASD? In order to address these questions we must first define the terms cyborg and posthuman and then analyze what they mean in terms of today's society. We can then look at the characteristics of ASD and their relationship with the "posthuman/cyborg" body.

Cyborg or Posthuman: What Does This Mean?

Let us begin this quest by looking at Katherine Hayles' (1999) definition of the cyborg in How We Became Posthuman.

> Central to the construction of the cyborg are informational pathways connecting the organic body to its prosthetic extensions. This presumes a conception of information as a (disembodied) entity that can flow between carbon-based organic components and silicone-based electronic components to make protein and silicone operate as a single system. When information loses its body, equating humans and computers is especially easy, for the materiality in which the thinking mind is instantiated appears incidental to its essential nature. (p. 2)

In other words, for Hayles (1999), cyborg is the physical merger of man and machine.

> Fusing cybernetic device and biological organism, the cyborg violates the human/machine distinction; replacing cognition with neural feedback, it challenges the human-animal differences; explaining the behavior of thermostats and people through theories of feedback, hierarchical structures, and control, it erases the animate/inanimate distinction. (p. 84)

But what does this physical merger look like? Does this mean that we must replace or

enhance human parts with mechanical parts? Does this mean that we take on thought

processes similar to machines? Hayles (1999) helps us by providing a vision of her

cyborg in her agreement with Donna Haraway, in that,

> "cyborgs actually exist. About 10 percent of the current U.S. population
>
> are estimated to be cyborgs in the technical sense, including people with
>
> electronic pacemakers, artificial joints, drug-implant systems, implanted
>
> corneal lenses, and artificial skin. A much higher percentage participates
>
> in occupations that make them into metaphoric cyborgs, including the
>
> computer keyboarder joined in a cybernetic circuit with the screen, the
>
> neurosurgeon guided by fiber-optic microscopy during an operation, and
>
> the adolescent game player in the local video-game arcade. 'Terminal
>
> identify' Scott Bukatman has named this condition, calling it an
>
> 'unmistakably doubled articulation' that signals the end of traditional
>
> concepts of identity even as it points toward the cybernetic loop that
>
> generates a new kind of subjectivity. (p. 115)

Hayles helps us by making a distinction between what she calls the "technical" sense and

the "metaphoric" sense. With this description we are allowed to understand that the

physical connection between human and machine is not only that of replaced or enhanced

parts, but also the dependence we have upon technology to perform our daily routines.

This metaphoric merger can be seen in daily life through the connections we have with

cell phones, palm pilots and blackberries. The implant is not physically connected to the

brain, but is instead, connected through our constant use and preoccupation with these

devices. (If you question the existence of this preoccupation, then simply recall recent

media attention given to the use of cell phone "texting" while driving. Many states, already have or are currently considering, laws prohibiting this activity due to its potential danger to the public). Hayles (1999) further expounds that "once the correlation is made, cybernetics can be used not only to correct dysfunction but also to improve normal functioning. As a result, the cyborg signifies something more than a retrofitted human. It points toward an improved hybrid species that has the capacity to be humanity's evolutionary successor" (p. 119). It is the possibility of this hybrid species that captures my attention in regards to ASD, but we will address that more in depth later. Hayles (1999) further challenges us to think about the fact that

> humans have been without peer in their ability to store, transmit, and
>
> manipulate information. Now they share that ability with intelligent
>
> machines. To foresee the future of this evolutionary path, we have only to
>
> ask which of these organisms, competing in many ways for the same
>
> evolutionary niche, has the information-processing capability to evolve
>
> more quickly.(p. 243)

These are questions that, for me, must be addressed through cultural norms and must include our standards and expectations for our science. Now that we have a definition for cyborg, we can attempt to understand what it means to be posthuman.

Again, to begin this quest for understanding, we can turn to Katherine Hayles (1999), "becoming a posthuman means much more than having prosthetic devices grafted onto one's body. It means envisioning humans as information-processing machines with fundamental similarities to other kinds of information-processing machines, especially intelligent computers" (p. 246). Through this definition we can begin to understand that,

for Hayles, the definition of posthuman encompasses the cyborg, but is much more. To

be posthuman, we must envision our species as information-processors. This is not a

difficult task to accomplish when we envision the curriculum in today's schools. It is a

curriculum of information, that is to be imparted upon our students and that is to be

regurgitated back to us at the appropriate time and place. Hayles (1999) further expounds

her definition of posthuman by saying that "whether or not interventions have been made

on the body, new models of subjectivity emerging from such fields as cognitive science

and artificial life imply that even a biologically unaltered Homo Sapiens counts as

posthuman. The defining characteristics involve the construction of subjectivity, not the

presence of nonbiological components" (p. 4). To Hayles, the construction of

subjectivity, involves minimizing or erasing embodied features of the species, including

those of gender, race, sex, and ethnicity. These characteristics can be found in today's

society with the emergence of multiple personalities, for each individual, when

"connected" to the information highway of the World Wide Web. This has been

demonstrated to us in *The War of Desire and Technology* by Allucquere Stone (1995),

when she recounts the story of Stanford Lewin and his on-line creation, Julie.

> What had happened instead was that he'd found himself deeply engaged in
>
> developing a whole new part of himself that he'd never known existed.
>
> His responses had long since ceased to be a masquerade; with the help of
>
> the on-line mode and a certain amount of textual prosthetics, he was in the
>
> process of becoming Julie. She no longer simply carried out his wishes at
>
> the keyboard she had her own emergent personality, her own ideas, her
>
> own directions, Not that he was losing his own identity, but he was

certainly developing a parallel one, one of considerable puissance. Jekyll

and Julie. (p. 76)

With this recounting, Stone presents to us the emergence, and acceptance, of multiple

personalities within the culture of technology that exists today. She highlights for us the

disembodiment that can occur within our world of technology. In Stone's world, we no

longer are bound by bodily constraints. Since we now have a working definition of what

it means to be cyborg and posthuman, we can venture further upon our path in

questioning the cyborgness and posthumanness of persons with ASD.

The Posthuman ASD Brain

We shall first begin by looking at the definition of ASD. The American

Psychological Association describes Pervasive Developmental Disorders (the Autism

spectrum) in the following manner:

Pervasive Developmental Disorders are characterized by severe and

pervasive impairment in several areas of development: reciprocal social

interaction skills, communication skills, or the presence of stereotyped

behavior, interests, and activities. The qualitative impairments that define

these conditions are distinctly deviant relative to the individual's

developmental level or mental age. (2000, p. 69)

In order to determine the presence or absence of cyborgness or posthumanness in this

population we may benefit by investigating the way in which the characteristics, which

are described by the DSM IV as being disordered, are evidenced in this population. If we

compare these areas of impairment to that of the cyborg and the posthuman, we should be

able to accept or reject the hypothesis that ASD persons are either cyborg or posthuman

in their existence.

Let us first look at communication in regards to the ASD person and that of technology. Hayles (1999) tells us that

> if what is exactly stated can be done by a machine, the residue of the uniquely human becomes coextensive with the linguistic qualities that interfere with precise specification-ambiguity, metaphoric play, multiple encoding, and allusive exchanges between one symbol system and another. The uniqueness of human behavior thus becomes assimilated to the ineffability of language, and the common ground that humans and machines share is identified with the univocality of an instrumental language that has banished ambiguity from its lexicon. (p. 67)

In this description Hayles seem to be saying that when ambiguity, metaphors, and multiple meaning terms are removed from the human conversation the conversation then becomes replicable by machine. This description is relevant to many ASD persons, in that, they are often black and white in their interpretations of social interactions, including language; they do not understand, and are not able to process ambiguity, not unlike a machine. This represents a merging of man and machine. The ASD population struggle with speech and written words. They generally excel with technological code, not unlike the computer. "If we were to ask about the parallel characteristic that leaps to mind to distinguish code from speech and writing, an obvious contender would be the fact that code is addressed both to humans and intelligent machines"(Hayles, 2005, p. 40-41). Code, therefore becomes the preferred form of communication for the ASD person and serves not only in a functional manner for daily activities, but also in a social manner

with the inclusion of games, chat rooms (whether the ASD person interacts or merely listens in), and the creative arts. Many children identified with ASD interface with computers better than with people. They are effectively and efficiently posthuman in this respect. They have no need for the human connection---they use language to convey information not to have a conversation.

When we look at social interaction skills evident in the ASD population, it could be beneficial to, again, look through the eyes of Katherine Hayles in *How We Became Post Human*. Hayles (1999) delves into

> *Mindblindness: An Essay on Autism and theory of Mind*, [by] Simon
> Baron-Cohen, [in the essay, he] argues this is what happens with autistic
> children. Somehow the shaping mechanism fail to direct neural
> development, and as a result the child is unable to create an internal
> scenario that would explain why others act as they do. For such children,
> Baron-Cohen argues, the world of social interactions is chaotic and
> unpredictable because they suffer from 'mindblindness,' an inability to
> imagine for others the emotions and feelings they themselves have.
> autopoietic theory, in its zeal to construct an autonomous sphere of action
> for self-enclosing entities, formulates a description that ironically
> describes autistic individuals more accurately than it does normally
> responsive people. For the autistic person, the environment is indeed
> merely a trigger for processes that closes on themselves and leave the
> world outside. (p. 148)

Emotions for the ASD person are often exaggerated or lacking. Again, Katherine Hayles

(1999) offers us insight into the ASD mind by looking at how Antonio Damasio describes the function of emotions in relation to the body.

> Drawing on his detailed knowledge of neurophysiology and his [Antonio Damasio] years of experience working with patients who have suffered neural damage, he argues that feelings constitute a window through which the mind looks into the body. Feelings are how the body communicates to the mind information about its structure and continuously varying states. If feelings and emotions are the body murmuring to the mind, then feelings are 'just as cognitive as other precepts,' part of thought and indeed part of what makes us rational creatures. (p. 245)

Does the breakdown in communication between mind and body in persons with ASD reflect a disordered mind or a mind that is attempting to function much like a machine? Is this the mind of the posthuman? Hayles (1999) again provides us with a possible answer when she delves into the fiction of Philip K. Dick .

> In Dick's fiction, the schizoid functions as if autistic. Typically gendered female, she is often represented as a bright, cold, emotionally distant woman. She is characterized by a flattening of affect and an inability to feel empathy, incapable of understanding others as people like herself. Whether such creatures deserve to be called human or are 'things' most appropriately classified as androids is a question that resonates throughout Dick's fictions and essays. In one of its guises, then, the schizoid android represents the coming together of a person who acts like a machine with a literal interpretation of that person as a machine. (p. 161-162)

From this perspective, we can directly infer that, in Hayles mind, the ASD person is functionally posthuman and that the emotional aspect of the ASD personality is paramount in the unfolding of the posthuman characteristics. "Repetition was built into the machinery. Each patron's deposit of a coin formed a single transaction among an implied infinitude of transactions that were exactly and automatically the same, although the earliest slot machines were easy to fool" (Gitelman, 2006, p. 46). The ASD person is also capable of repetition, if fact, repetition of motor movements and vocalizations is one of the qualities that we find "disordered" about them. As we have seen thus far, there is evidence of malfunction (or may I suggest, differences, as compared to what is considered the norm) in the interactions of the ASD person with the world in which they reside, but are there also malfunctions (or differences) that can be interpreted as positive in today's society?

Sadie Plant (1997) provides us insight into the perception of the ASD person in her text *Zeros and Ones* when she discusses the change in our culture from an industry based, assembly line mentality to that of a society focused on information.

> In the West, the decline of heavy industry, the automation of manufacturing, the emergence of the service sector, and the rise of a vast range of new manufacturing and information-processing industries have combined to reduce the importance of the muscular strength and hormonal energies which were once given such high economic rewards. In their place come demands for speed, intelligence, and transferable, interpersonal, and communications skills. (p. 38)

ASD persons have whole perception; they see the final product and then are able to

assemble the parts. For them, this whole-to-part perception is not hysteria, it is reality and it allows them to create rapidly and efficiently. ASD persons communicate in the language of technology; they understand the zeros and ones. The change in society/culture from the assembly line mentality, where we see and are concerned with only parts, to the age of technology and information, in which we must place those parts together effectively, is a reflection of the ASD personality. Plant (1997) goes further to enlighten us regarding the use of technology and its link to the interactions and processing of the ASD person as she describes the chaos we seek to eliminate with the use of technology.

> Technology itself was supposed to be a vital means of exerting this explanatory and organizational power. But the revolutions in telecommunications, media, intelligence gathering, and information processing they unleashed have coincided with an unprecedented sense of disorder and unease, not only in societies, states, economies, families, sexes, but also in species, bodies, brains weather patterns, ecological systems. There is turbulence at so many scales that reality itself seems suddenly on edge. Centers are subsumed by peripheries, mainstreams overwhelmed by their backwaters, cores eroded by the skins which were once supposed to be protecting them. Organizers have found themselves eaten up by whatever they were trying to organize. Master copies lose their mastery, and everything valued for its size and strength finds itself overrun by microprocessing once supposed too small and insignificant to count. (p. 45)

In the ASD mind, this chaos, is turned into order and serves functional uses as it allows the ASD mind to act as a filter to find the useful pieces of information and place them together, many times, resulting in a creative aesthetic work. It is the aspect of creativity that allows for a positive perspective for this seemingly disordered type of thinking. But, how does this chaos turn into order and creativity?   Hayles suggests that this could occur through the perceptual vision system when she relays the story of the paper *What the Frog's Eye Tells the Frog's Brain*, created by players from the Macy Conferences, Katherine Hayles (1999) provides us with a look at the perceptional system of the ASD person.

> From wired-up brain, the researchers discovered that small objects in fast, erratic motion elicited maximum response, whereas large, slow-moving objects evoked little or no response. It is easy to see how such perceptual equipment is adaptive from the frog's point of view, because it allows the frog to perceive flies while ignoring other phenomena irrelevant to its interests. The results implied that the frog's perceptual system does not so much register reality as construct it. (p. 135)

This verifies the ideology that the human brain acts as a filter, identifying only the information that is currently relevant, within the environment. The relevance may be due to curiosity or a desire to learn, eminent danger, other social purposes such as creativity as Hayles (1999) reminds us. "Each living system thus constructs its environment through the 'domain of interactions' made possible by its autopoietic organization. What lies outside that domain does not exist for that system"(p. 137). For verification of this perception we can turn to Mark B. N. Hansen (2004) in *New Philosophy for New Media.*

It stems not simply from the embodied nature of vision (i.e., the fact that

the eye is an organ), but more fundamentally from the fact that the body is

the site where all sensory information is processed and where information

from distinct senses can be interchanged, exchanged, fused, and (in the

case of true synthesis) cross mapped. The body is the precondition not

just for vision, but for sensation as such. It is why there is sensation at all.

(p. 27)

In Hansen's description of the nature of vision and the processing of information, we find

that it takes an embodied brain to make sense of the sensory input provided us during

daily interactions. Through the embodied brain, we filter the environment, process the

filtered information, and organize it in a manner useful to our interactions with the

environment. This information allows us to view the ASD brain as one that has potential

for "interfacing" with the technology that we use today while remaining embodied. With

knowledge of how the ASD brain reacts to its environment, we can now pursue our

investigation into what meaning this has for our changing society.

Evolving the Posthuman

If we critically analyze the changes that are occurring within our technological

society today, we find a need for speed and multi-tasking, changing social interactions, a

global society, and a blurred line between work and leisure. Let us first take a look at the

speed at which we function in today's society and what we can expect for the future. To

do this, we can depend upon Sadie Plant (1997) for our vision.

'On the human scale, anything that lasts less than about a tenth of a second

passes by too quickly for the brain to form a visual image and is thus

invisible; if the duration is less than a thousandth of a second or so, the

event becomes too fast even for subliminal perception and is completely

outside the human sphere.' Such speeds are simply too much to take.

'There is no way for humans, in our pokey world of seconds, minutes,

hours, to conceive of a time period like 1/100,000 second, much less the

microsecond (1/1,000,000 second), the nanosecond (1/1,000,000,000

second), the picosecond (1/1,000,000,000,000 second), or the femtosecond

(1/1,000,000,000,000,000 second).' for those 'reconciled to the

nanosecond...computer operations are conceptually fairly simple.' The

boundaries of perception might well be imposing, but they are also far

from fixed. The so-called 'history of technology ' is also a process of

microengineering which continually changes perception itself. And

regardless of the rumors of disembodied lives, cryogenic havens, and

bodiless zones which have accompanied these speeding machines, the

digital revolution has spawned a vast swathe of debate about cyborgs,

replicants, and other posthuman, inhuman, extrahuman entities which are

complicating orthodox Western notions of what it is to be a human being.

(p. 176-177)

If we look at what Plant is saying in this example, we can come to an understanding that

currently the human brain is not capable of processing information as rapidly as the

mechanical brain (the computer). But if we recall therapeutic interventions originally

utilized with persons with ASD, we find that the original thought behind the ASD brain

was to slow down information presented to these persons in order to provide additional

processing time for the information they were receiving. This therapeutic ideology has since been rejected, by most, because of its relative ineffectiveness over long-term treatment. Instead, today most clinicians working with ASD persons will verify that a more rapid processing speed has yielded much greater results. This change in methodology has served to enlighten clinicians, parents, educators, ASD persons, and the general public, that the original hypothesis of processing speed being extremely slow for this population has been for the most part incorrect. If we ask ourselves about the connection between processing speed and environment we can, again, turn to Plant (1997) to assist us in our understanding. "All new media, as Marshall McLuhan pointed out in the 1960's, have an extraordinary ability to rewire the people who are using them and the cultures in which they circulate" (p. 144). It is this re-wiring that has relevance in today's society of technology.

> While the notion that technologies are prostheses, expanding existing
>
> organs and fulfilling desires, continues to legitimize vast swathes of
>
> technical development, the digital machines of the late twentieth century
>
> are not add-on parts which serve to augment an existing human form.
>
> Quite beyond their own perceptions and control, bodies are continually
>
> engineered by the processes in which they are engaged. (Plant, 1997, p.
>
> 182)

In other words, the post-human is not necessarily a literal merging of human mind, body and machine, but instead can be described as the changes that occur in the human body, mind as a result of their interaction with technology. If we again take a look at Hayles (1999) description of the posthuman view we may be able to better structure our look into

the posthuman society.

> The posthuman view privileges informational pattern over material instantiation, so that embodiment in a biological substrate is seen as an accident of history rather than an inevitability of life. Second, the posthuman view considers consciousness, regarded as the seat of human identify in the Western tradition long before Descartes thought he was a mind thinking, as an epiphenomenon, as an evolutionary upstart trying to claim that it is the whole show when in actuality it is only a minor sideshow. Third, the posthuman view thinks of the body as the original prosthesis we all learn to manipulate, so that extending or replacing the body with other prostheses becomes a continuation of a process that began before we were born. Forth, and most important, by these and other means, the posthuman view configures human being so that it can be seamlessly articulated with intelligent machines. In the posthuman, there are no essential differences or absolute demarcations between bodily existence and computer simulation, cybernetic mechanism and biological organism, robot teleology and human goals. (p. 2-3)

This blur between technology and humans becomes better clarified if we view the potentiality for our technology to take on human characteristics as well as for humans to take on technological characterisits. We can accomplish this with the assistance of Gerd Gigerenzer (2007) in his text *Gut Feelings: The Intelligence of the Unconscious*.

> The gaze heuristic exemplifies how a complex problem that no robot could match a human in solving-catching a ball in real time-can be easily

mastered. It ignores all causal information relevant to computing the ball's

trajectory and only attends to one piece of information, the angle of gaze.

Its rationale is myopic relying on incremental changes, rather than on the

ideal of first computing the best solution and thereafter acting on it. (p.

13)

In this example, Gigerenzer presents to us the idea that the human thought process

consists of more than just rational problem solving techniques. He further states that,

"the cerebral cortex in which the flame of consciousness resides is packed with

unconscious processes, as are the older parts of our brain. It would be erroneous to

assume that intelligence is necessarily conscious and deliberate"(2007, p. 16). For

Gigerenzer, these unconscious processes are the processes that have yet to be imitated by

technology, because they exist based on evolutionary changes in our environment that

machines have no reference for. "Intuition is more than impulse and caprice; it has its

own rational...[intuition is] simple rules of thumb, which take advantage of evolved

capacities of the brain"(2007p. 17-18). What Gigerenzer is attempting to explain is that,

unlike technological machines, our brain stores information gathered throughout our

existence, both our own and our ancestors, and utilizes that information in making

decisions when speed is of importance. Included in this process is the quality of emotion.

Evolved capacities, including language, recognition memory, object

tracking, imitation, and emotions such as love, are acquired through

natural selection, cultural transmission, or other mechanisms...they

evolved in tandem with the environment in which our ancestors lived and

are shaped by the environment in which a child grows up. The human

ability to imitate the behavior of others, for instance, is a precondition for

the evolution of culture. (2007, p. 58-59)

This is reason that we can not explain why, in some situations, we react the way that we

do when our reactions are contradictory to "rational" thinking or problem solving.

Currently, machines have been programmed to 'think' rationally and utilize problem

solving strategies to find solutions to complex issues, but they have yet to be

programmed to mimic the "intuition" that the human mind relies upon. "Nature gives

humans a capability, and extended practice turns it into a capacity. Without evolved

capacities, the simple rule could not do the job; without the rule, the capacities alone

could not solve the problem either"(Gigerenzer, 2007, p. 18). In other words, we obtain

information from the environment, process it as it is likely to occur in future situations,

and practice using that rule within the environment in which we exist until it becomes

intuitive to us. For Gigerenzer, this intuitive process is lacking in machines and can not

be imitated by them, but that does not mean that we will not continue to try.

Allucquere Stone (1995) demonstrates to us the acknowledged need to replicate

this intuitive process when she explains the differences in bandwidth in *The War of*

Desire and Technology.

'Reality' is wide[bandwidth, because people who communicate face to

face in real time use multiple modes simultaneously-speech, gestures,

facial expression, the entire gamut of semiotics...Computer conferencing is

narrow bandwidth, because communication is restricted to lines of text on

a screen...The cultural history of electronic communication is in part a

history of exponentially increasing bandwidth, the effect of narrowing

bandwidth is to engage more of the participants' interpretive faculties. This increase engagement has the effect of making communication more difficult when the information needs to be conveyed precisely. On the other hand, for symbolic exchange originating at and relating to the surface of the body, narrowing the bandwidth has startling effects. A deep need is revealed to create extremely detailed images of the absent and invisible body, of human interaction, and the symbol-generating artifacts which are part of that interaction. (p. 93)

Stone defines for us the characteristics necessary for a conversation. With this, Stone explains why there is a need to attempt to include pragmatic language into the conversation. The need for pragmatic interaction fills the space that is evident when the disembodied form attempts communicative interactions. Once defined, science can seek the answers as to how computers will be able to achieve the status of conversation partner. How will this be accomplished in our future society? A beginning may be through virtual reality technology.

In its fantasy form, though certainly not in reality, virtual reality works-or rather would work-like an externalization of neuroscientist Antonio Damasio's analogy for consciousness: if consciousness can be likened to a 'movie-in-the-brain' with no external spectator, then virtual reality would comprise something like a movie outside-the-brain, again, importantly, with no external spectator. The mixed reality paradigm differs most saliently from this fantasy in its deployment of the functional homology between virtual reality technologies and perception: rather than

conceiving he virtual as a total technical simulacrum and as the opening of

a fully immersive, self-contained fantasy world, the mixed reality

paradigm treats it as simply one more realm among others that can be

accessed through embodied perception or inaction (Varela). In this way,

emphasis falls less on the content of the virtual than on the means of

access to it, less on what is perceived in the world than on how it comes to

be perceived in the first place. (Hansen, 2006, p. 4-5)

This "movie-in-the-brain" mentality is often found in persons with ASD. They appear to

be able to experience the actual world in much the same way that we experience the

virtual world. Hansen (2006) further reminds us that

as a technology that lays bare the enabling constraints of the body (that is,

the body's necessity), virtual reality comprises our culture's privileged

pathway for laying bare mixed reality as a technical-transcendental

structure, which is equally to say, for exposing the technical element that

lies at the heart of embodiment. (p. 15)

For Hansen, technology is becoming embodied and with this embodiment will come

changes in humans.

Insofar as it yields a doubling of perception, this tactile dimension serves

to confer a bodily-that is sensory-reality on external perceptual

experiences (whether it is 'physical' or 'virtual'). It generates a felt

correlate of perception that is part of the functionalist understanding of

embodied agency. Together, these two corollaries-the primacy of the

body as ontological access to the world and the role of tactility in the

actualization of such access-effect a passage from the axiom that has been

my focus thus far (all virtual reality is mixed reality) to the more general

axiom that all reality is mixed reality. (2006, p. 5)

In other words, for Hansen, the virtual world and the real world are experienced in the

same way; there is no distinction, nor does there need to be.

As we are reminded,

within a short time, the number of hours that a broad segment of children

will spend playing computer-based games will exceed the number of hours

that they spend watching television. It is entirely possible that computer-

based games will turn out to be the major unacknowledged source of

socialization and education in industrialized societies before the 1990's

have run their course. (Stone, 1995, p. 27)

If this be the case then we must remember

the communication between the larger social world and software use and

design is a two-way process. As we work with software and use the

operations embedded in it, these operations become part of how we

understand ourselves, others, and the world. Strategies of working with

computer data become our general cognitive strategies. at the same time,

the design of software and the human-computer interface reflects a larger

social logic, ideology, and imaginary of the contemporary society.

(Manovich, 2001, p. 118)

If this is so, then the more we interact with software during our course of daily activities,

then the more likely we are to begin to think in the same manner as the software. Our

cognitive processes will begin to mimic that of our technology. We will become functionally posthuman and the ASD thought process could be the norm rather than the exception to future generations. We must remember the words of Lisa Gitelman (2006) in *Always Already New,* "media and their publics coevolve" (p. 13). This co-evolvement holds potential for a further blurring of the lines between human and machine which is something that, at least for me, should be monitored and critiqued for its usefulness and harm to humanity. Without monitoring and critique we may find ourselves in a similar situation as Dr. Frankenstein when he began his monstrous creation. "So much has been done, exclaimed the soul of Frankenstein-more, far more, will I achieve; treading in the steps already marked, I will pioneer a new way, explore unknown powers, and unfold to the world the deepest mysteries of creation"(Shelley, 1963, p. 33). In a time when we find ourselves questioning whether we can and should design our offspring should we not begin to question what technology we should allow to become embodied? As Franklin and Roberts point out, "'we cannot deny the powerful drive within us to invest our very best in our children, and apply the benefits of discovery.' (30). For this reason, he [Gosden] suggests, the designer baby option is not only inevitable-it is completely ordinary, predictable, and understandable"(2006, p. 31). Perhaps the steps that we have already taken in the creation of Virtual Reality (VR) and Artificial Intelligence (AI) have set the stage for us to continue to explore unknown powers. Hopefully, the mysteries of the creation that we have yet to reveal will be unlike those of Frankenstein's monster.

If we keep in mind Heidegger's (1977) warning in regards to technology, perhaps we shall be safe.

But this much remains correct: modern technology too is a means to an

end. That is why the instrumental conception of technology conditions

every attempt to bring man into the right relation to technology.

Everything depends on our manipulating technology in the proper manner

as a means. We will, as we say, 'get' technology 'spiritually in hand.' We

will master it. The will to mastery becomes all the more urgent the more

technology threatens to slip from human control. (p. 5)

 Remembering also that

the essence of technology is the matter of an ongoing change or movement

that Heidegger refers to as Enthbergung, a term that is usually translated

as 'revealing' or 'disclosure.' Yet, as Weber argues, Enthbergung might

also be translated as 'unsecuring,' because it also carries the implication of

'a dismantling, an unleashing or releasing of an ambiguous, indeed highly

conflictual dynamic.' As a form of enthbergung, then, "technology has

always been an ambiguous movement or process, It involves a 'setting up'

or 'setting forth' that brings things into representation, sets them in place,

in order, Yet, this setting in place or into representation can only 'take

place' inasmuch as technology is, at the same time, an unsettling

movement or change (as in 'setting forth' on a journey): an unsecuring that

breaks things free and brings them forth, into representation, into play.

(Rutsky, 1999, p. 6-7)

I must ask myself, is it through the mind and sensory body of the ASD person that

technology will find its freedom and begin its journey of setting forth the next generation

of humans? Is this why we fear those identified as ASD? Perhaps this is our destination,

perhaps not, but at least today, it seems to be the direction in which we are headed.   In
Science Fiction Curriculum, John Weaver (2004) writes,

> What concerns me here is whether curriculum theorists and educators are
> prepared to deal with the post-human generation and, as of this writing I
> would have to say we are not prepared to educate the post-human
> generation. Curriculum theorists too often erase techno-cultures from their
> discourses, and schools are still enamored with the factory model where
> students are not computer hackers but empty vessels waiting to be
> enlightened. In a post-human generation classroom, the only empty vessel
> is the teacher who is not wired and the curriculum theorists who still
> envision technology as a deterrent to learning and creativity. (p. 31)

With this statement, Weaver begins to lay the groundwork for curriculum theorist in a
post-human era. Will we begin our acceptance of the persons labeled ASD and recognize
their potential contributions to society, or will we continue to deny that these
characteristics are strengths that hold potential to propel us into the future?

Elimination of the Other

Wilson and Lewiecki-Wilson (2001) tell us that, as with technology, we must also
question our scientific abilities related to genetic testing.

> Genetic testing, the mapping and patenting of human DNA, and its
> manipulation are contemporary practices demonstrating that the material
> body is sociopolitical. What level of genetic research and what kinds of
> tests and procedures will be allowed are sociopolitical, ethical, economic,

and scientific questions, as are related ones, such as which genes will be

allowed to remain in the human gene pool and which will not.   (p. 17)

Will we allow fear of those we label the ASD other to lead us to justify the elimination of

the genetic characteristics associated with ASD? If we allow this to happen, then what

components of our future potential have we sacrificed? Perhaps we would be better

served to understand the purpose of "othering" as a feature of our social makeup. To

begin this analysis, let us first turn to Mark Taylor.

"No matter how hard I think or how much I analyze, I can never know myself by

myself but must always come to myself in and through an other" (Taylor, 2009, p. 1). In

this statement, Taylor seems to be saying to us that the only way to understand ourselves

is through a reflection of those we call other. Is this the reason that we react the way that

we do to those that are "different" from us? By identifying the qualities that we find

distasteful in others are we really identifying the qualities in our selves that we find to be

unspeakable? By rejecting the post human qualities of the persons we have identified as

ASD are we rejecting the idea that, we, ourselves possess those qualities? To what

benefit would this serve our purpose? As a society, we often want to reject what we do

not understand. If we do not understand certain qualities that we see in the other, we

deny that those qualities exist in ourselves. We can then protect ourselves from those

qualities that appear to be a threat to our livelihood and our existence. I would like to

suggest that in order to justify or reject eliminating a quality from our gene pool, (which

can be accomplished through modern technology and science or through social isolation

which we have practiced throughout history) we must resolve the dissonance that exists

between perceptions of ourselves and the other.   One way that we do this is by

identifying those qualities that we find questionable in the other, critiquing them, coming to terms with them, and finally accepting that they are qualities that provide benefit to our society, thus qualities that can be recognized and accepted in ourselves. Taylor (2009) suggests that "what is available, accessible, exposed does not seduce. Reticence arouses desire, by implying what is not there and suggesting what is not known" (p. 27). In other words, by identifying and speaking out about the qualities that we find offensive in the ASD other, we open an opportunity to critique those qualities and bring resolution to the qualities that we find offensive in ourselves without the need to jeopardize our self-perception. Taylor (1984) writes, "the struggle in which the subject attempts to assert itself by negating other and tries to secure identity by excluding difference inverts itself and becomes an act of identification with and incorporation of the other"(p. 24). We use the other to justify ourselves. By focusing on "differences" in the other, we are able to identify the value of those differences and the value of their existence to our current and future society. Through understanding the ASD other, we are able to identify, understand, and accept human qualities that are valuable to our social existence whether those qualities serve to provide economic gain, as in graphic design, or social rituals, such as the emergence of electronic social networks. In order for this transformation to take place, educational institutions must begin the work of acceptance of the ASD person, because it is through the educational institutions that social, political and economic customs are sustained.

The mere act of sharing information becomes the catalyst for understanding of those we choose to call "other", which in turn acts as a stimulus for change. Remember that Susan Sontag (1990) stated, "any disease that is treated as a mystery and acutely

enough feared will be felt to be morally, if not literally, contagious" (p. 6). The thought

of being contagious is a stimulus for fear. As educators, this means that we no longer

withhold information from parents, students or our fellow educators, but instead we act to

enlighten those with the knowledge that we hold. "In one important sense, school

curriculum is what older generations choose to tell younger generations" (Pinar, 2004, p.

185). This call for a sharing of knowledge becomes a paradigm shift in our thinking about

education. Pinar et al (2004), describe the phenomenon of paradigm as " a general

'mind-set' or perspective which dictates, for example, in which directions research might

go, what constitutes legitimate knowledge, and who is a legitimate speaker for the field"

(p. 12). A shift that helps to call to action those that possess knowledge of the one we

call "disabled" and "othered". In order to transition us to the paradigm that we seek, let

us begin by looking at the perceptions of what public education should focus upon. Let

us look at what it means to have a socially just curriculum. But before we move on, I

would like to address the elephant in the room that you may have noticed, the lack of

therapist input, other than my own, in this analysis. When beginning this quest, it was

my intention to include parents, teachers, and physicians or therapist working with the

ASD population. The exclusion of therapists and physician was not purposeful; it was

due to lack of agreement to participate on their part. While conducting the research, I

must admit, there was little interaction with therapists or physicians, but when

participation was evident within the support group, this group of participants rejected an

opportunity to be heard. They chose not to participate in the study. I include this

information here, because I feel that, at least to some extent, these professionals were

unwilling to voice their opinion due to fear. I can not verify that assumption with hard

facts, but the opportunity to speak out was proposed and rejected without explanation other than "I don't think that would be a good idea for me right now considering my position" (personal communication, anonymous, September, 10, 2009).   Having said that, we are ready to move to our inquiry into what it means to have a socially just curriculum.

The Advocacy

As an educator, Jessica readily acknowledges her call to duty when it comes to academic achievement. "At times it was very hard to get any type of academic instruction in because we were having to physically restrain, or work on you can't hit yourself or you can't bite that person whereas we couldn't work on learning how to read or learning how to write" (personal communication, September 5, 2009). She also acknowledges the frustration that comes as a result of not being able to focus on the task with which she is charged. "For many practicing teachers, 'curriculum' is understood as what the district office requires them to teach, what the state education department publishes in scope and sequence guides" (Pinar, 2004, p. 185). In today's educational system, making annual yearly progress (AYP) is of a great concern to teachers and school administrators. The consequence of not having a focus on academic skills that are covered on the mandated tests is identification of the school or district as being in a "needs improvement" status. Teachers and administrators are being held "accountable" for the designated outcome during their annual performance review. While I in no way would condone allowing apathy towards reading or math instruction, I do find it difficult to accept that teaching reading and math to students that are having significant issues,

such as self-injurious behaviors, is the socially just response to instruction. Allison made it very clear that she shares this analysis.

> I was very clear that in kindergarten I did not want anything except for
> him to be in the classroom you know doing some of the things that the
> other kids were doing that he was capable of doing. …[I told her that] I
> was not expecting her to teach him and that we would pull him out and
> teach him anything that he needed to be taught as far as academics go and
> that we would also pre-teach him any academic skills before he got to the
> classroom so that he could be successful when he was in the classroom.
> (personal communication, August 21, 2009)

It is obvious from this statement that Allison was more than willing to accept the responsibility of teaching her child the academic content areas of reading and math, but that she, and her child, needed the school setting to teach socialization skills that would be necessary for success in life. Interpersonal interactions with peers was not something that Allison was able to provide to her child in the home setting. It was what she needed the institution to do for her. Teach her child to interact with peers in a socially acceptable manner, a manner in which he could contribute to his future. Kathy would agree.

> Yes he's high functioning. He understands. Yes, he is doing great. He'll
> fall in line. He gets it. When he gets into the routine of school he does get
> into it and do a lot of stuff right… but for our own goals personally, we're
> still not where we need to be and its not awesome… There is a huge gap
> between him and a neurotypical child… Where is the agenda or the action

plan for people that are at the top of that scale, to break through?"

(personal communication, August 24, 2009)

Kathy's thoughts stimulate the idea that public school should be more, more than a focus

on gaining academic knowledge. Pinar et al (2004) suggest that

we must also take responsibility for the problem of anti-intellectualism

ourselves, including its expression in popular misunderstandings of our

field's mission [the field of curriculum studies], namely, that we are to find

out 'what works' and then 'apply it' in the schools.   This misunderstanding

seems to assume that education is some how like a complex automobile

engine, that if only we will get it humming smoothly, and that it will

transport us to our destination, the promised land of high test scores. (p.

170)

 Kathy suggests that education should include all of the skills that the child will need in

order to be successful in society, not just those bits of knowledge that we now deem to be

education. Martin Buber (1947, 2006) agrees.

For the genuine educator does not merely consider individual functions of

his pupil, as one intending to teach him only to know or be capable of

certain definite things; but his concerns is always the person as a whole,

both in the actuality in which he lives before you now and in his

possibilities, what he can become. (p.123)

Jonathan Kozol (2005) reminds us that "the efficiency agenda and the notion that

our public schools exist primarily to give the business sector what it asks for, or believes

it needs, are anything but new" (p. 214). Those ideas may not be new, but they are with

us today and serve as mandates to the focus on the memorization of skills and facts that can be tested and measured, at the expense of the social issues that may be prevalent. In order to move from this realm of thinking, in order to create the desired paradigm shift, educators and concerned citizens must receive their call to action. They must be willing to go forth and call for educational reform.   In the words of Che Guevara (2006), "we have to be more revolutionary and strive to set an example" (p. 209). In other words, we must take action. Kozol (2005) further suggests that "political movements aren't so hard to start' … he tells his listeners. 'There are people right here in this room who could begin a movement in this city if they have the will and the resolve'" (p. 222). But will knowledge of ability and means be enough to ignite the fires of change? To help us answer this question, let us turn to our storytellers' thoughts on activism.

Allison begins to reveal her thoughts and experiences as an advocate for her son when she tells us

> I don't accept no as an answer, unless, I mean I shouldn't say I don't accept no, it depends on the situation. When it comes to Billy I don't accept no because I have learned that that is the only way to be, quite frankly. Every door would be shut for him if I didn't—if when somebody said no, I said okay that's fine. You know if the answer is no-well the answer is not no. (personal communication, August 21, 2009)

She quickly realizes that she must step up to her personal call for action, in order to ensure that her son will have the opportunities that he deserves. Allison begins to live the words of William Ayers. "Moral thought and virtuous action in school begin with being cared for and accepted—teachers should demonstrate a fundamental belief in the unique

value of each human being, and a recognition of our shared predicament" (2004, p. 23).
Allison strives to demonstrate to Billy's teachers that he has "unique value" and a need
for being "accepted".

Kathy also reports a similar experience with her son when she reflects on what it
was like to attend an IEP meeting. "I had to learn to pitch a fit and go crazy in his IEP
meetings a few times—but I learned how to do that and then I went with other parents to
help them" (personal communication, August 24, 2009). Jessica recognized a need for
advocacy when she found that, after school therapies, which focused on social
interactions, were lacking in her neighborhood. "I don't have the availability to find the
time to be able to do it myself but if I knew where to go to—I would be willing to work
with someone—I would love for there to be more stuff for them to do outside of school"
(personal communication, September 5, 2009). The recognition that not only a lack of
availability of services existed, but that in order to obtain these services, someone would
have to initiate the process, was a huge undertaking for Jessica. It was the beginning of
her recognition and acceptance that she was being called to serve. Jessica is brought to
reality when she comprehends that "teaching becomes ethical action, the practice of
freedom, when it is guided by an unshakable commitment to working with particular
human beings to reach the full measure of their humanity, a willingness to reach toward a
future fit for all" (Ayers, 2004, p. xi). Jessica understands and accepts this commitment,
but continues to seek guidance as to possibilities for accomplishing her duty. While each
of these women recognize a need and accept their responsibility in satisfying that need
for the lives that they touch daily, Kathy takes one step further.

Perhaps because of her background in journalism or perhaps because of her work in the medical field, which exposes her to many children and families that suffer the consequences of a diagnosis of "disability", Kathy has chosen, or perhaps has been chosen, to represent collectively those identified with ASD. She shares one of those experiences when she reflects upon her thoughts. "If I get another 3 year old in [the doctor's] office—I'm just gonna kill somebody—I think everyday of things I could do to make a national splash enough for people to pay attention—stop and pay attention—I just can't think of things" (personal communication, August 24, 2009).   Having these types of thoughts may seem detrimental to the cause, but the thoughts and commitment stimulated Kathy's next recollection.

 When we were marching on Washington we were on this …big atrium to

go into a senate building and …I had taken Ricky into go tee tee and [our

daughter] was a baby so she was in a stroller and I was looking down at

the street and here comes this big gaggle of people and one of them was

Hillary Clinton and I said "Hey Senator Clinton", and everybody jumped

and they were like screaming and I said "Hey we're just across the street,

protesting the use of mercury in medicine you should come over there"

and she was like oh yea, oh yea—I said my son has Autism and it was

caused by vaccines and she just [shrugged] and kept walking. That was

that. She was real nice at first until I said what I said. It's real hard—but I

was proud of myself—I was real proud of myself but I wish that I could

have said more. (personal communication, August 24, 2009)

It is obvious from Kathy's words that she has accepted the responsibility that she had identified, or perhaps that has been identified for her, as a call to action for all those that she believes has been impacted by environmental factors that contribute to the ASD diagnosis. In the words of William Ayers (2004),

> Each of us is planted in the mud and the muck of daily existence, thrust into a world not of our choosing, and tethered then to hard-rock reality; each of us is also endowed with a mind able to reflect on that reality, to choose who to be in light of the cold facts and the merely given. We each have a spirit capable of joining that mind and soaring overhead, poised to transgress boundaries, destroy obstacles, and transform ourselves and our world. (p. xiv)

 Kathy has accepted this call to duty without regards to the cost that she may incur.

Becoming Othered

The cost that Kathy incurs from her activism is that of becoming "othered". She is set aside. She is demonized for her thoughts and practices. She is ridiculed and criticized by her peers. She is rejected for advocating for not only her child, but all children bestowed with the ASD label. Not only are the children that have been identified as ASD, been "othered", identified and labeled as different, but their advocates have also been bestowed with the label. Kathy shares her experiences of her othering in her recollection of personal relationships gone awry. "I've lost a lot of friends. We loose close friends and people make their living off this and we're not trying to get their income but—much of the dollars in a pediatrician's office comes in through vaccinations" (personal communication, August 24, 2009). Kathy has been identified as

a critic of ASD and its manufactures. She has been identified as trouble for an industry that contributes great financial gain to the U.S. economy. She has become "othered" as a result. You may ask yourself why Kathy's friends and acquaintances so readily set her aside when all she is attempting to do is to protect her child, do what she believes to be best for him, and to communicate her experience to those that find themselves in a similar position. If we take a quick look at the drug industry, the answer may become clear. Jepson and Johnson (2007) theorize the cause of ASD and offers some insight as to why the treatment for the disorder continues in the manner that it does today.

> I want to make it clear that I do not believe that mercury is the cause of autism. I don't believe there is a single cause. I believe that autism comes about in children who are born with a genetically vulnerable immune system that sustains damage from multiple environmental exposures acting cumulatively and synergistically. The environmental exposures are likely to be different in different children, which could explain the range of symptoms and the differing ages of onset. (p. 112)

While Jepson and Johnson (2007) suggest that mercury, in and of itself is not the primary cause of ASD, they do not rule out mercury as a contributor. Jepson and Johnson state that "as environmental toxins accumulate, a critical point is reached when the struggling immune system can no longer deal with them appropriately, and damage occurs" (p. 46). If this be the case, and this is a plausible explanation for the onset of ASD, then why do we continue to treat the disorder with additional drugs? This question may be answered when we take a look at the types of drugs that are recommended for use with persons with ASD and their contributions to the pharmaceutical industry.

Medication is considered one of the most important treatments for [Attention Deficit Hyperactivity Disorder] ADHD [which is often co-diagnosed along with ASD]. In fact, its use with this disorder has been studied more extensively than any other application of psychopharmacology in children. One recent large study in children with ADHD and without other disorders completed in New York and Montreal demonstrated that, compared to intensive multimodal treatment including medications and psychotherapy, properly prescribed stimulants alone had the greatest positive effect after 2 years. Another very important study, funded by the National Institute of Mental Health, produced similar results, showing that medications were superior to behavioral treatments alone for the core symptoms of ADHD. The study also found that behavioral treatment along with medication management was the most effective treatment to address some of the noncore symptoms (self-esteem, peer relationships, family functioning, and social skills). (Wilens, 2003, p. 146)

As Wilens (2003) points out, medication is often used with these children and not only for the symptoms of ADHD but for other symptoms as well.

Two classes of medications, the antihypertensives and the atypical antipsychotics, also can be helpful for certain behaviors associated with the developmental disorders [ASD]...beta blockers such as Propranolol at generally high doses (up to 240 mg per day) and Clonidine (typically dosed 0.1 mg three to four times daily) are increasingly reported to be

useful in controlling the aggression of developmentally disordered

patients. (p. 157)

If one accepts Jepson and Johnson's theory of the causation of ASD to be environmental

as well as genetic, then these drug treatments seem to be extreme. Questioning the use of

such large doses of medication and such large quantities of different medications may be

the path upon which we should embark. Why do we use mind altering medications for

treatment of ASD symptoms when there are side-effects to the drugs and drug treatment

is only addressing the symptoms not the cause, at least according to Jepson and Johnson?

Perhaps there is not an alternative.

Pharmaceutical companies develop medications that manipulate our

body's biochemistry, and they market their products very aggressively to

physicians...Of course, there are other ways to manipulate biochemistry.

There's an entire industry marketing vitamins and herbs to consumers,

claiming to modulate disease processes. We physicians tend to discount

the importance of nutriceuticals in the treatment of illness. No vitamin

reps come to our office to give us all of the details, and we don't have time

to research the studies on our own. We consider the doctors who look

outside the pharmaceutical box to be 'quacks' or 'alternative'. (Jepson and

Johnson, 2007, p. 4-5)

If this be the case, then why do we persist in accepting the use of outdated, ineffective

treatments?

Very often, the understanding of a disease that has been passed down

through generations in the medical community and accepted as truth or

'standard of care' is later proven wrong, or is modified as further research

is done. Often this dogma is based on nothing more than the opinions of a

few individuals. (Jepson and Johnson, 2007, p. 6)

In other words, we allow ineffective treatments to continue because of the way we do

science and the ability of large pharmaceutical companies to hold us captive in order to

maintain market share. When Kathy challenges the use of these medications, when she

vocalizes the stories that she has heard as well as her own experiences, she exhibits

pressure on the medical industry to accept responsibility for their actions and to recognize

that financial contributions to the pharmaceutical industry in the form of prescription

medications has social and moral consequences. It is not surprising that she is "othered"

within her social circle.

Allison, too, has shared events of othering. In her attempts to communicate with

the school system, Allison reports a feeling of being labeled a trouble maker. " All I

wanted was as much information as I possibly could get and then what I felt like

happened was because of that, all of a sudden, I was a problem" (personal

communication, August 21, 2009). A simple request for open communication resulted in

Allison becoming an outsider, someone that wanted trouble, someone that was going to

cause the status quo to go away. Advocacy for Allison and Kathy had become personal.

For Jessica, her attempt to share information that, she felt, would help to meet the needs

of students that needed a "push", but were not identified with a label of "disabled"

resulted in rejection and frustration of her attempts by a parent. "For the parents who

think there is just absolutely nothing wrong—um and I've had two of them—then it is

just like beating my head against the wall because they shoot down everything that I try

to do for their child because they don't want their child to have anything different"

(personal communication, August 21, 2009). As a result, Jessica is often not a welcomed

part of the support team for these students. She, too, has become labeled. Advocacy has

its cost and each of these women has demonstrated that creating change in a system that

is resistant to change, is difficult, both professionally and personally.

Implications for the Future of Education

So, what does all of this mean? It means that as a society we have historically

sought to identify and label those that are different from us. Instead of a quest to seek

understanding and enlightenment in regards to those that we "other" we choose to cast

them aside, make them forgotten members of our society, devalue their lives, reject and

punish any attempt that is made on their behalf. We seek to create and maintain the

status quo of our social make up. Prendergast (2001) tells us that

> the presence of a diagnosis would be the very thing that would 'identify'
>
> the mentally ill, the thrust of identity politics--to end discrimination--
>
> effectively recasts the mentally ill not as 'ill,' not as being in need of
>
> treatment, but as being in need of social empowerment and liberation,
>
> much like other historically excluded groups (e.g. Native Americans,
>
> African Americans). (p. 49-50)

Perhaps we ought heed this warning, identify the ones we call "disabled" and use this

label as a call for empowerment. In other words, heed this label as a call for social

justice. Perhaps we all need to join with Kathy, Allison and Jessica in their quest to be

come advocates for empowerment of those identified with ASD. James A. Banks (2006)

suggests that an "equity pedagogy exists when teachers modify teaching in ways that will

facilitate the academic achievement of students from diverse groups" (p. 148). In other words, when teachers begin to teach a socially just curriculum, one in which all persons are able to participate, have representation, and be considered reflective members of society, we may say that we have achieved a paradigm shift towards inclusion instead of exclusion of the "other" Perhaps we ought strive to change our curriculum to include those life skills that are necessary for social acceptance, but not testable with a standardized assessment that renders numbers and percentages. After all, this is what Allison and Kathy identified as the area that sets their children apart from what we have determined to be the "norm" for society. This is what they are unable to provide to their children that we have labeled ASD. This is what society has determined they need in order to be accepted as a contributing member of the culture. Why do we resist this notion in the era of the 21st century? This is not a new concept to the American education system. Joel Spring (2007) tells us that "many public officials wanted Mexican children in school so that they could be 'Americanized'" (p. 95). While I must cringe at the idea that as a society we desire to "Americanize" our citizenship, I would be amiss if I did not point out that throughout American history, we have used the educational institutions to "socialize" our immigrant citizenship for the purpose of political and social control and economic gain. Why would teaching social skills to a population of children that we have labeled as "othered" be so offensive to us now? I would suggest that it is perhaps correlated with our number addiction of which I spoke earlier. Social interactions are not conducive to quantification; they are qualitative in nature and do not fit into our accepted pattern of analysis of numerical data. They are difficult to quantify, control and analyze. As school administrators strive to "hold teachers accountable" they desire easily

recognized patterns of compliance. Teaching social interactions is difficult to critique, is

often long term in its outcome and most definitely subjective. Teaching appropriate

social interactions is not easily justifiable to those that fund our educational system.

Perhaps as, at least part of our obligation, as curriculum theorists we need to accept the

task of identifying the positive aspects of the person labeled ASD and how those positive

qualities can be fostered with a habilitative curriculum.   Bilken (2005) writes "from a

phenomenological perspective, the explanation is not that people labeled autistic are

defective or lacking a key 'mechanism' but that they may experience the world differently

than do so-called neurotypicals" (p. 40). Perhaps we ought advocate for reform to a

system that provides therapy and treatment at outrageous costs to families. Perhaps we

ought seek reform of a drug industry that uses children as experiments for drugs that

produce great financial profits to the industry. With new prevalence numbers just

released from the CDC (December 18, 2009 / 58(SS10);1-20) that suggest that "in 2006,

on average, approximately 1% or one child in every 110, 1.1% of US children" were

reported to have currently diagnosed ASD it is easy to see that our status quo, will no

longer be possible in regards to this label. Perhaps we ought call for a system of social

justice in which we desire to know the one we call "other". Pinar et. al.(2004), write that

> central to a postmodern critical pedagogy is an elaboration of the
>
> relationship between the self and other. A pedagogy of 'difference' is one
>
> in which the 'Other' is neither exoticized nor demonized, 'but rather seeks
>
> to locate difference in both its specificity and ability to provide position
>
> for critically engaging social relations and cultural practices'". (p. 305)

Perhaps as curriculum theorists, teachers, parents and concerned citizens we ought strive to seek knowledge of the one we call "other" to aid us in our becoming.

Paulo Freire (1993) writes that "it is absolutely essential that the oppressed participate in the revolutionary process with an increasingly critical awareness of their role as Subjects of the transformation" (p. 127). In other words, those that are "othered" must be aware that they are "othered" and acknowledge when they have truly achieved power. Today many have identified supporters, mostly parents, of those with ASD as a powerful lobby group, but, according to Freire, to be truly powerful, those persons must understand that while their voice is beginning to be heard, the achievement of power and recognition has yet to be reached. The day that students with ASD are able to step inside the doors of educational institutions without the need for someone to "go crazy" in order for them to have access to the curriculum that they need and deserve in order to be successful, participating, contributing members of society, then we will know that they and their supporters no longer carry the status of "other" but instead they are bestowed with the label of 'citizen'. Freire (2005) again reminds us that "revolutionary praxis is a unity and the leaders cannot treat the oppressed as their possession" (p. 126). This is a call to educational leaders to recognize that they ought remember that persons with ASD and their supporters, ought not be treated as possessions that we house inside classrooms, but instead they are persons with which unity is desired. Leaders ought remember that through unity the unreachable can be obtained.

Jim Garrison (1997) tells us that "perception is crucial for an ethics of caring. It allows us to perceive the needs, desires, interests, wishes, and hopes of others under our care. It involves sympathy. Perception provides the 'data' for creative moral responses"

(p. 66). In other words, perception, that qualitative undertaking that comes with being human, that which is not quantifiable data, that which is often unable to be easily defined, are the elements that define what it means to "care" for our students, not only for those with ASD, but also for those without ASD. As educators it is our moral responsibility to view and responsibly critique that which we have chosen to identify as our obligation and contribution to future societies, with scrutiny and openness to revision, for without this critique of praxis we are destined to continue a system which strives to "other" those what we do not know or wish to know. We will continue to foster discord. "The flames of passionate teaching die when not fueled by reciprocal care and creative opportunity" (Garrison, 1997, p. 41). In a system that "others" those educators that speak out for oppressed individuals, those that dare to express displeasure and offer suggestions for change, is creating a "death" so to speak for, not only those that educate, but of education itself. What educational administrators ought remember is that "people are participants in, and not spectators of, the world" (Garrison, 1997, p. 39). This holds true of those that call education their profession, as well as, those that are educated. Education ought stimulate a desire to critique and questions, not squelch that desire.

Reflections for Change

When reflecting on the experience and frustrations of Kathy, Jessica, and Allison, it is easy to understand why they have experienced the situations that they have. Social, political, and economic factors influence educational curriculum and school decisions on a daily basis. Without the call to action that each of these ladies have recognized, we would have little hope of bringing about change to a system filled with oppressive agents. When we recognize that "people with the problems are also the people with the

solutions"(Ayers, 1998, p. 153), we will have hope for resolutions to the issues that we face as educators. Recognizing that parents of children identified as ASD and those that are labeled ASD, have positive productive things to contribute to our society and our educational system will be a step in the right direction for resolving some of our most oppressive systems today. For curriculum theorists, this is the work that is to be done. Ayers writes, "change in small places can gesture toward larger transformations, and that changing a single mind can unleash a universe of possibilities. We must be willing, then, to act on small changes rather than waiting for some monumental movement when everything will fall into place" (Ayers, 2004, p. 119). The work that Jessica, Allison and Kathy have taken upon themselves serves in this manner. They are working to make small changes that will create monumental change rather than waiting for our politicians, economists, and other various government officials to discover and make the change that is needed. As educators, "we are in search of a pedagogy of experience and participation, a pedagogy capable of questioning, rethinking, re-imagining. We are looking for teaching that is alive and dynamic, teaching that helps students grapple with the question 'Where is my place in the world'? (Ayers, 2004, p. 84) When teachers are able to make decisions regarding what children need in order to achieve an education, when class placements are based on what children need, when teachers are funded based on the number and skill of teachers that are needed to teach what the children need, and when school curriculum is based on what children want and need to learn, in order to think and participate critically, in the social and political world, then we can say that we have a socially just curriculum and the work of the curriculum theorist will be complete.

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Appendix A
Interview Questions
Caregivers

1. Tell me about your experience when you found out that your child was diagnosed with ASD.
    a. How did you feel when you originally received the diagnosis?
    b. What led you to seek a diagnosis?
    c. When was your child diagnosed?
    d. By whom was your child diagnosed?

2. Tell me about how this impacted your life as a family.

3. Tell me how you feel about this diagnosis.

4. Tell me how others feel about the ASD diagnosis?

5. Tell me about your child.
   a. strengths
   b. weaknesses

6. Tell me about your vision for your child.
    a. during the next year
    b. during the next 5 years
    c. during the next 10 years
    d. during the next 15 years

7. Tell me about the types of treatments/therapies your child has/does received.
    a. medical
    b. drug
    c. educational
    d. behavioral

8. Tell me how you feel about the treatments/therapies your child has received.

9. Tell me how others feel about these treatments (spouse, teachers, physicians, therapists, child)

10. Tell me about the supports that you have for yourself/your child and your family.
    a. social organizations
    b. support groups
    c. religious organizations
    d. friends
    e. family members

11. Tell me about your perceptions of the cause of ASD.

12. Tell me about the changes you would like to see in relation to ASD.

Appendix B
Interview/Observation Questions
Teachers/Therapists/Physicians

1. Tell me about your experience when your clients found out they or their child was diagnosed with ASD.
   a. How do you think most people feel when they originally received the diagnosis?
   b. Why do most people seek a diagnosis?
   c. When are most people diagnosed?
   d. By whom are most persons diagnosed?

2. . What impact do you see occurring in the lives of families?

3. Tell me how you feel about this diagnosis.

4. Tell me how others feel about the ASD diagnosis?

5. Tell me about some of the children that you have worked with having this diagnosis
   a. strengths
   b. weaknesses

6. Tell me about your vision for these children.
   a. during the next year
   b. during the next 5 years
   c. during the next 10 years
   d. during the next 15 years

7. Tell me about the types of treatments that are available for ASD.
   a. medical
   b. drug
   c. educational
   d. behavioral

8. Tell me how you feel about the treatments/therapies your patients/students have received.

9. Tell me how others feel about these treatments (individuals with ASD, caregivers, teachers, physicians, therapists)

10. Tell me about the supports that are available for persons with ASD diagnosis and their family.
    a. social organizations
    b. support groups
    c. religious organizations
    d. friends

    e. family members

11. Tell me about your perceptions of the cause of ASD.

12. Tell me about the changes you would like to see in relation to ASD.