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How do We Understand and Make Sense of the Needs of Individuals with Autism: An Interpretive Inquiry.

By

Kevin Grant Hatch ©

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Abstract

How Do We Understand and Make Sense of the Needs of Individuals with Autism: An Interpretive Inquiry

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This study is an interpretive inquiry into how we come to understand and make sense of the needs of individuals with autism. A particular focus in placed in the individual perspective which seeks to understand the individual from their perspective as opposed to viewing the individual with autism in relation to their deficits in functioning.

This study uses qualitative research methods to organize data gathered through narrative interviews with individuals who work with, care for and teach individuals with autism. The interviews were a collaborative venture in which we sought to gain a richer understanding of how we understand and make sense of the needs of the individual with autism.

Findings are presented as themes that emerged from the narrative accounts. These themes emerged following a process known as thematic analysis. The themes are presented with exemplars from the narrative accounts to help capture the meaning of the presented theme. The themes that emerged are represented by the following headings: Adjusting to fit society's expectations; It takes time to understand autism; Social needs: Guardians; Trauma: A basis for behavior and lastly; Expression of needs. Each theme is followed in the text by implications identified by the author.

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CHAPTER ONE

Introduction

James, a fourteen year old boy was awoken at 6:00am with the abruptness of his bedroom light being turned on and the loud but cheery sound of Susan's voice telling him to get up and go to the bathroom. He didn't need to go to the bathroom but complied anyways. It must be Tuesday; he could already hear the shower running and realized that he would be required to have a shower as happened every Tuesday like clockwork. Susan entered the room with haste stating that the bus would be here in 30 minutes so there would be no time for messing around today. She grabbed his night clothes and pulled them over his head leaving his body exposed to the cold of the morning and she directed him towards the shower. The sound of the water beating against the wall was a familiar sound which made his skin crawl. To him it was like the sound of fingernails being drawn across a dusty chalkboard. A hesitation on James' part caused Susan to become frustrated and she physically moved him out of his room across the cold tile floors to the bathroom and directed him towards the running water of the shower. She pushed him into the stream of hot water which seemed to burn as it hit his flesh. He winced but realized that trying to escape the water would just upset Susan and possibly result in him being sent to his room to be in solitude instead of eating a hurried breakfast before getting on the bus to go to school. Not eating breakfast wouldn't have been such a bad thing considering that on Tuesday peanut butter toast was always served and after eating it he could immediately feel a burning sensation in his throat and on his tongue. This would last for most of the day and sometimes made it difficult to breathe. Tuesday's clothes were chosen, overalls with buckles that scraped his skin as they moved back and forth throughout the day, oh how he hated Tuesdays. It seemed trivial but those buckles seemed to be in the way all day long. He had deliberately destroyed his last pair of overalls by constantly pulling on the straps attached to the buckles but as soon as he had accomplished his goal of tearing through the straps the coveralls were replaced by a new pair with reinforced straps which sported the very same buckles that rubbed in the very same places. Once on the bus Chuck the burly bus driver proceeded to place him in his 6 point restraint. He couldn't be trusted to stay seated on the bus. He loved to look out the window and watch the cars go by but he wasn't assigned to a window seat and the time that he had tried to move into one had caused an altercation with another student who also liked to took out the window. As a result James had been in a 6 point restraints system ever since. The chest trap was winched up so tight it was difficult to breathe let alone move and of course it fell right across those overall buckles. Tuesdays used to be his favorite day at school because it was swimming day. He loved to swim and play in the water. The feeling of weightlessness and the pressure of the water on his body was something that he longed for. Three Tuesday's ago a ball that he was playing with had drifted into the deep end of the pool and he had decided to go and get it. He was confident in his abilities to swim but everyone reacted with alarm and he was hauled out of the pool and held at the water's edge by three large men. He just wanted the ball back but no one seemed to understand what he wanted and he was eventually removed from the swimming area and subsequently he now had lost his swimming privileges. Tuesdays were now spent in a wheel chair at the pools edge buckled in with a seat belt that had been buckled behind the chair so that he couldn't reach it to free himself. All he could do is sit and watch as everyone else enjoyed the activity that he loved the most. Oh how he hated Tuesdays.

This story, though a creation of the author, may not be far from the realities faced daily by many individuals. The story of James was intended to be representative of the experience of an individual with autism who is struggling in his ability to express himself in a way that those around him might understand his feelings and desires. It is difficult to fathom what life would be like if our lives were directed by another rather than being self directed to experience life in a way that accounts for our individual needs and wants.

This introduction will identify some current ideas about autism and discuss its prevalence. The individual perspective will be discussed outlining the concept of how programs and care aught to be focused on the personal needs and desires of individuals with autism. The problem of coming to understand what these particular needs and wants are and how they are expressed is addressed briefly. This difficulty leads to the purpose of this study which is outlined. A brief overview of the completed dissertation is presented for the reader which concludes this introduction.

What is Autism?

Autism is a unique disability with as many definitions as there are people who are affected by it (Rutter, 2002). Some of these definitions have been formulated through the progression of various theories that have been developed to explain the causes of autism (Bettleheim, 1967; De Minzi, 2006; Kanner, 1943; Leerkes, & Crockenberg, 2006) and others have been developed in an effort to treat and fund individuals with this pervasive disability (Lovaas et al., 1966; Lovaas, & Simmons, 1969; Schopler, 2000; Tutt, Powell, & Thornton, 2006).

Autism is a developmental disorder primarily characterized by severe impairments in social interaction and communication. Impairments in social interaction include (a) an inability to engage in developmentally appropriate play interaction, (b) atypical non-verbal behaviors and gestures, and (c) a lack of empathic awareness of other people's feelings (Harris, Glasberg, & Ricca, 1996; R.L. Koegel, Koegel, Frea, & Smith, 1995). Communication impairments affect both verbal and non-verbal skills and may include (a) non-use of gestures and (b) delayed or no language development. Expressive language in particular is affected and there may be oddities of speech such as echolalia and pronoun reversal. Deficits in social communication and interaction are so universal in individuals with autism that many hypothesize they may be the primary underlying cause of the disorder (L. K. Koegel, 1995; L. K. Koegel, Valdez-Menchaca, & Koegel, 1994). Other characteristics of autism include repetitive and stereotyped patterns of behavior, interests, and activities. Individuals with autism may engage in self-stimulatory motor behaviors such as hand flapping or unusual body postures like waking without their heels touching the ground. These individuals will insist on rigid routines and environmental arrangements, and they become upset and anxious when these are altered. Routines and rituals can become so rigid that they become nonfunctional and time consuming (Auxter et al., 2005; Berkeley et al., 2001; Houston-Wilson, 2005).

Associated features of autism may include mental retardation or abnormalities in the development of cognitive skills, unusual responses to sensory stimuli especially sound and touch, abnormalities of affect, and self-injurious or aggressive behaviors (Schreibman, 2005). Several factors make diagnosis of autism difficult. A difficulty with diagnosis as noted by Province (1995) is that individuals diagnosed with autism vary widely in intellectual ability, adaptive behavior, personality characteristics, severity of symptoms, and the degree to which symptoms improve over time. Symptoms of autism overlap with other disabilities, particularly mental retardation and language disorders. Another issue is that the characteristics of autism often vary as a function of age or level of development. In particular, the intellectual level and language competence among children labeled autistic are highly variable. In response to the heterogeneity, statistical clustering techniques have been used to attempt to identify subgroups of children with autism (Eaves, Ho, & Eaves, 1994; Sevin et al., 1995). Even with these clustering techniques problems have arisen with trying to distinguishing a group with core autism.

Prevalence of Autism

Childhood autism has long been reported as a rare disorder happening in less that about 5 in every 10,000 births (Lord & Rutter, 1994). Recent studies suggest a much higher incidence of autism to an alarming rate of 0.3%-0.8% when considering the spectrum of autistic disorders (Croen, Grether, Hoogstrate, & Selvin, 2002; Gilberg, & Wing, 1999; Yeargin-Allsopp et al., 2003). The rise in the diagnosis of autism in the United States has been viewed as so alarming that in 2002 a United States congressional hearing declared autism a national health emergency stating that autism had become an epidemic (United States Congress House Committee on Government Reform, 2002). It is estimated that today autism affects as many as 1,500,000 individuals in the United States alone and is rising at an annual rate of 10 to 17 percent. There have been some critics of the autism "epidemic" stating that the information used to determine the prevalence of autism comes from administrative data and information collected for the purposes of program management as opposed to scientific research (Newschaffer, Falb, & Gurney, 2005). Regardless of these criticisms the numbers are representative of individuals who are receiving services for autism spectrum disorders which represents a serious public health burden. Another difficulty faced with determining the prevalence of Autism Spectrum Disorders is that the prevalence numbers may include an over-expansion of the diagnostic category of ASD such that children receive a false positive diagnosis. There is at present no specific biological or genetic marker available to determine true cases of ASD (Charman, 2002). Thus, case definitions are reliant on the behavioral and developmental picture alone. The increase in prevalence is not limited to the United States. The increase in diagnosis of individuals with autism has been reported world wide to be on the increase (Schreibman, 2005). The costs involved in providing care for individuals with autism are staggering. The Autism Society of America (2003) estimates that the annual cost in the United States to care for individuals with autism over the next 10 years will be between $200 and $400 billion dollars.

The Individual's Perspective

The individual perspective is the process of recognizing the needs and desires of the individual when developing programs and treatments for them. Billington (2006) describes the fundamental errors that can occur when we focus on the triad of impairments in autism, which are communication, interaction, and imagination (Wing, 1996). Billington states that by focusing on these problems of social integration we could in practice lead to the development of services and professional practices that struggle to address the individual needs of those children who are identified. Billington (2006) challenges practitioners, service and policy makers to "develop professional/assessment practices and also new ways of talking about autism that concentrate on assets rather than deficits; attempt to conceive something of the immensity of the human quest for meaning, mind and consciousness which is raised by consideration of autism; and search more vigorously for ways in which we can access the views of autistic children in order to identify the way in which they currently manage their “worlds”” (pp. 11).

Understanding the Needs of Individuals with Autism

Due to the complexity of autism it can be very difficult to identify the ways that individuals with autism express their desires and needs. A common component of autism is difficulty in verbal communication. Even when there is verbal communication it can often be restricted to echolalia which mimics others rather than expresses individual wants and desires. Efforts have been made to teach communication techniques such as PICS (picture image communication system) and sign language but these too have been fraught with difficulty and potential misunderstandings between individuals with autism and their caregivers (Schreibman, 2005).

Due to the nature of autism there are many risks involved for the individual which necessitate having a guardian who can participate in making decisions in society for these individuals. This places a tremendous burden on guardians who must make choices for the individual’s care based on their best understanding of what the individual needs and wants. Guardians are also influenced greatly by the demands of society to socialize individuals with autism. These pressures can often cause guardians to make choices that are “best” for the individual with autism based on socially accepted ideas but may be distant from what the individual would want. Finding ways to help caregivers understand the unique and often subtle expressions of individuals with autism can be a difficult and emotionally stressful experience for both the caregivers and the individual with autism.

The Researcher-Practitioner

Practitioner research is conducted by an individual who assumes a dual role both as a practitioner or provider of services and as a scientific researcher MacLeod (2004) defines practitioner research as "research carried out by practitioners for the purpose of advancing their own practice." Dependent upon the research discipline this type of research may be referred to as "participatory research" or "action research" and it is conducted by a reflective practitioner (Schafer, 1995). As in all research, dual roles must be managed carefully as to not place the individuals served by the practitioner at risk because of the relationships that have been previously established. Researchers must consider the advantages and disadvantages of using a population with whom they have a prior and often ongoing relationship. This becomes especially significant when the existing relationship involves an unequal relationship. In order to mitigate the potential risks to the participants in the research, the researcher must be mindful throughout the process of the research that the participants may feel an element of coercion in their participation. Consideration also needs to be made concerning the effect that the research may have on the future relationship that the researcher has with the participants in the study.

In this study, due to the researcher's role as a service provider for individuals with autism the act of becoming a reflective inquirer concerning how we come to understand the needs of individuals with autism placed him in a position where he needed to actively manage the dual role of being a provider of services and a scientific researcher. Though this dual relationship offered an opportunity for research that represented a formidable impact on our knowledge in the area of autism the potential for harm was equally considered and managed to protect those who were part of the study.

The Significance of the Study

While there has been much written about the history, etiology, assessment and treatments of autism there is relatively little known about the individual perspective of the individuals themselves. Very little research is focused on understanding the needs of individuals with autism; rather, it is focused on developing new ways of treating the inabilities that researchers and society see as detrimental to social involvement. This focus has been on developing, through behavioral methods, trained behaviors in communication, social interaction and a decrease in abnormal, stereotypical behaviors. The participation in these methods of training is at times restrictive and traumatic to the individual. The individuals who are of particular interest in this study are those individuals who have been diagnosed with autism and are considered to be in the severe range or having "classic" autism. These individuals are most vulnerable to being programmed, perhaps contrary to their individual perspectives due to the disparity between the way that they communicate their needs and wants and the way that we understand their experience.

The purpose of this study is to gain a greater understanding of the ways that parents, caregivers and teachers come to understand the specific needs and wants of individuals with autism and the ways that they have become aware of the communication of these needs through their work with these individuals. Billington (2006) stated that we need to search more vigorously for a way to understand the way in which individuals with autism currently manage their own "worlds." Once we have a better understanding of how we come to understand the needs of individuals with autism we can then be more sensitive to the individual perspective and treat and care for individuals with autism in a way that is respectful of their desires and wants.

Overview

The following is a brief review of the chapters in this study. This is included to give the reader a greater understanding of the process of this research and its results.

Chapter Two is a comprehensive review of the literature on autism giving a concise background into the past and current trends in the field. The diagnostic criteria related to the autism spectrum is presented to help the reader understand the various symptoms and subtypes of classifications which exist under this broad diagnosis. Theories of autism are discussed primarily in terms of the developments that they have either contributed to or caused in the field of autism research. The theories are in no way exhaustive of all the theories that are currently being studied. The theories presented are rather those ones that have been the most influential in creating the current body of knowledge surrounding autism. Treatments are also discussed in terms of their common usage in treating individuals with autism. Many treatments though common are criticized for being validated only through anecdotal evidence given by select researchers and parents who have had success with these various treatments and techniques. This is done to show the common programming trends that individuals with autism are exposed to. These programs highlight the efforts to help individuals with autism express themselves to caregivers and teachers. The needs of individuals are then discussed in an effort to introduce the idea of understanding the needs of individuals with autism from an individual perspective. This perspective focuses on recognizing the individual's experience in making decisions and programming for them.

Chapter Three describes the researcher's interest in the study of individuals with autism. The interpretive inquiry research paradigm is described as well as the specific hermeneutic method that was utilized in this study.

Chapter Four is a presentation of the narratives that were created from the interviews with the individuals who participated in the study. They are presented to help the reader gain a better understanding of their experience and also see the data from which the findings and the conclusions were drawn by the researcher.

Chapter Five is the presentation of the findings of the thematic analysis that was undertaken. Common themes are presented with exemplars from the narratives to give a deeper understanding of these themes. The common themes are then summarized and the paradigm cases are presented with a summary.

Chapter Six is a discussion of the main research findings and recommendations presented by the researcher. An evaluation of the study is undertaken and the limitations of the study are expressed. Ideas and recommendations for future research are shared and the chapter is concluded by some final reflections of the researcher.

CHAPTER TWO

Literature Review

A review of the literature will provide a historical overview of our current understanding about autism along with an analysis of current trends in diagnosis and treatment. The literature will then provide a foundation for understanding the field of autism and the controversial issues facing those who desire a greater understanding of how we come to understand the needs of individuals with autism and how these individuals express their unique needs to others.

Historical Overview

Autism was first defined in 1943 by Leo Kanner, a psychiatrist. Through his research with eleven children with "peculiarities", he noticed a similar set of delays that he described as delayed speech and speech abnormalities, need for sameness, repetitious behaviors, lack of awareness of people's existence, and feelings and the absence of imaginative play with other children (Kanner, 1943). Since 1943 there have been a number of theories to explain and identify the cause of autism. For many years, there was a controversy over whether autism was a separate disorder or simply an instance of schizophrenia in childhood. However, it is now generally agreed that infantile autism and schizophrenia are separate disorders (American Psychiatric Association, 2000). Happe (1994) noted that though there may be some similar symptoms between the two disorders (e.g. emotional blunting) people with autism rarely experience other characteristic symptoms of schizophrenia such as hallucinations and delusions. Another difference between autism and schizophrenia is that schizophrenia tends to have cycles of symptoms followed by relatively stable periods whereas autism is stable over the life of an individual without any occurrence of remission. Historically the cause of autism was founded upon psychodynamic principals focusing on the parents' personalities and their specific styles of parenting. It was suggested that parents of children with autism were cold, formal, humorless, detached, highly rational and objective (Bettelheim, 1967; Kanner, 1943). Supposedly parents did not provide their children with interpersonal warmth and nurturance, and it was assumed that the children then turned away from these parenting practices and turned inward to find comfort and personal stimulation. Though the idea of the "Refrigerator Mother" dominated the autistic community for many years, research has shown that parents of autistic children did not differ from parents of non-autistic children or from parents of children with other types of mental disorders (Cox et al., 1975; Koegel et al., 1983; McAdoo & De Myer, 1978). According to Cohen and Volkmar (1997), Bettelheim's opinion and its popularity "is a black mark on the history of autism" (p. 949).

More recent explanations have come to identify differences between individuals who do and do not suffer from autism in terms of brain structure and chemistry, all strongly suggesting that autism is some form of brain dysfunction (Bauman, 1996). While etiology remains undetermined a general consensus has been that some type of aberrant neural development underlies the disorder of autism (Bailey, Phillips, Rutter, 1996; Delong, 1999). One theory of abnormal neural development implicates early brain growth that results in larger brain sizes and thus head sizes in autism (Courchesne, Carper, Akshoomoff, 2003; Hardan, Minshew, Mallikarjuhn et al., 2001; Lainhart, 2003; Lainhart, Piven, Wzorek et al., 1997). A finding that has been replicated many times is the increased prevalence of macrocephaly, defined as head circumference greater than the

97th percentile for age and sex. By definition using standardized head circumference norms less than 3% of the normal population would have macrocephaly but about 20 % of individuals diagnosed with autism meet criteria for macrocephaly (Fombonne, Roge, Claverie, et al., 2000). Interestingly Leo Kanner in his original description of the disorder noted the preponderance of "large heads" in the group of patients he described (Kanner, 1943). Unfortunately, we do not understand the nature of the dysfunction or how it results in autistic behavior.

Diagnosis and the Autism Spectrum

Autistic Spectrum Disorders, which include Asperger's Syndrome, Rett's Disorder, Childhood Disintegrative Disorder, PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified), and Classic Autism, commonly produce deficits across multiple domains of psychological functioning. Symptoms can include: Mental retardation, motor stereotypies, restricted range of interests and behaviors, reduced imaginative capacity in play, verbal and non-verbal communication difficulties and sensory/perceptual processing disturbances (American Psychiatric Association, 2000; Kanner, 1943; Rutter, 1980; Wing & Gould, 1979). Early editions of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM) contained only the diagnosis of childhood schizophrenia to describe and classify children with autism. Children with autism were labeled with symbiotic psychosis, severe emotional disturbance and mental retardation. After the creation of the Autism Society of America (ASA) a definition of autism was created and included in the DSM-III (APA, 1980). In this edition autism was included along with other subtypes under a new category of Pervasive Developmental Disorders (PDD). The subtypes for PDD were

Residual Infantile Autism and Childhood Onset Pervasive Developmental Disorder. While revisions were being made by the American Psychiatric Association to the DSM-III-R, the World Health Organization (WHO) was revising the International Classification of Diseases. Several Disparities existed between the DSM-III-R and the International Classification of Diseases (ICD). Preparations were quickly made for the fourth edition to the DSM to be more closely aligned with the ICD. At present the DSM-IV remains the most current diagnostic manual available to clinicians. Medical practitioners use these guidelines to identify individuals who qualify for specific treatment programs and specialized funding. The DSM IV-TR offers the following criteria for Autistic Disorder:

> A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
>
> (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
>
> > (a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
> >
> > (b) Failure to develop peer relationships appropriate to developmental level.
> >
> > (c) A lack of spontaneous seeking to share enjoyment, interest, or achievements with other people (e.g. by a lack if showing, bringing, or pointing out objects of interest).
> >
> > (d) Lack of social or emotional reciprocity.

(2) Qualitative impairment in communication as manifested by at least one of the following:

(a) Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).

(b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.

(c) Stereotyped and repetitive use of language or idiosyncratic language.

(d) Lack of varied, spontaneous, or make-believe play or social imitative play appropriate to developmental level.

(3) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

(a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

(b) Apparently inflexible adherence to specific, nonfunctional routines or rituals.

(c) Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements).

(d) Persistent preoccupation with parts of objects.

B. Delays or abnormal functioning, in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

(American Psychiatric Association, 2000)

In order to give a better understanding of the subtypes within the autism spectrum each of the five subtypes will be discussed. This is done to help differentiate between the different diagnoses and give clarity to the focus of this research which is to understand the needs of those who are diagnosed with the "classic" form of autistic disorder. Aspergers disorder is often confused with classic autism and vice versa (Eisenmajer, Prior, Leekam, Wing, Gould, Welham, & Ong, 1996; Firth, 2004; Freeman, Cronin, & Candela, 2002; Kulger, 1998; Macintosh, & Dissanayake, 2004; Mayes, Calhoun, & Crites, 2001) therefore, Aspergers disorder and autistic disorder will be discussed last to help clarify the difference between these subtypes.

Rett's Disorder

According to the DSM-IV-TR Rett's Disorder typically is identified when children are between 1 to 2 years of age and is primarily found in the female population. Children diagnosed with Rett's Disorder usually develop in an apparently normal fashion during the first 6 to 18 months of life (Scott, Clark, & Brady, 2000). Neurological development is then arrested and begins regressing in a predictable pattern comprising of four stages. In stage one, girls cease to acquire new skills; they display decelerating head growth and autistic features such as emotional withdrawal and diminished eye contact. In stage two affected children lose learned skills such as speech and purposeful hand use. They develop irregular breathing patterns, truncal and gait ataxia and apraxia, and stereotypical hand wringing. About half these individuals also develop seizure disorders. During stage three there is some stabilization of the disorder (American Psychiatric Association, 2000). During this stage girls may learn to communicate preferences using eye pointing. They still have gross cognitive and motor impairments and commonly experience epileptic episodes. In stage four seizures become less frequent but motor deterioration continues (Shahbazain, & Zoghbi, 2002). Prevalence rate for Rett's Disorder is approximately 1 in 22,800 live female births and the identification rate is considered to be low due to the lack of awareness of this disorder on the part of physicians and educators. As with all Pervasive Developmental Disorders it is considered that an individual with Rett's Disorder will experience lifelong pervasive limitations (American Psychiatric Association, 2000; Van Acker, 1997). Through genetic mapping it was found in 1999 that mutations on the X-linked MECP2 gene were responsible for Rett's syndrome (Amir, Van den Veyver, Wan, et al., 1999). Due to this identification autism is often referred to as a secondary symptom of Rett's syndrome such as in fragile X and Joubert syndrome questioning its classification on the autism spectrum (Barton, & Vokmar, 1998; Jamain, Betancur, Giros, Leboyer, & Bourgeron, 2003; Ozonoff, Williams, Gale, & Miller, 1999).

Childhood Disintegrative Disorder

First described by Theodore Heller in the early 1900's, Childhood Disintegrative Disorder (CDD) differs from autism in that it has a distinctive pattern of developmental regression following at least 2 years of normal development. The most discernable diagnostic feature of CDD is the age of onset. Children with CDD experience at least two years of normal development in all areas before onset of a significant loss of previously acquired skills. The behavioral and clinical features of CDD resemble autism. Social skills are markedly impaired, communication skills are limited and unusual stereotyped patterns of behavior are present. The prevalence of CDD is small and is believed to be under diagnosed due to physician's unfamiliarity with its differentiation from autism. Prognosis as with all Pervasive Developmental Disorders indicates that symptoms will remain relatively stable throughout life after onset (American Psychiatric Association, 2000).

Pervasive Developmental Disorder Not Otherwise Specified

Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) is used when clinicians rule out all other disorders within the Autistic Spectrum but specific developmental deficits remain. Children identified with PDD-NOS do not meet the criteria for other pervasive developmental disorders. These individuals are often considered to have mild autism or autistic tendencies (Towbin, 1997). The prevalence rate for PDD-NOS has been greatly influenced by changes in the diagnostic criteria therefore until specific criteria are applied to this population the prevalence rate will remain speculative (American Psychiatric Association, 2000).

Asperger's Disorder

Though Asperger's Disorder was first described over fifty years ago, it has only recently gained interest in North America since its inclusion in the DSM-IV (American Psychiatric Association, 1994). An Austrian psychiatrist named Hans Asperger identified a group of high functioning children with autistic-like symptoms in 1944 (Asperger, 1944; Wing, 2000). The diagnostic criteria in the DSM-IV-TR includes: impaired communication skills, social skill deficits, and restricted areas of interest (American

Psychiatric Association, 2000). Children with Asperger's Disorder do not appear to have significant delays in language acquisition (Klin & Volkmar, 1997). Children with Asperger's Disorder are socially awkward and demonstrate pedantic patterns of speech and odd, eccentric interests (Wing, 1981). Social skill deficits include a lack of empathy, difficulty forming friendships and trouble adjusting to change. Individuals may appear to be aloof and insensitive to others, but in actuality are hypersensitive to relationships and are frustrated with their inability to engage in meaningful and appropriate relationships (Donadee, Buckshaw, Cameron, Snyder, & Milligan, 2000; Firth, 2004). Individuals with Asperger's Disorder have restricted patterns of behavior and unique interests which might include an in depth knowledge of sports statistics, the memorizing of birthdays or the study of insects. As the individual becomes older these interests tend to narrow and become more focused. Due to these narrowed special interests, children with Asperger's Disorder are often shunned by their peers and suffer from low self-esteem (Scott, Clark, & Brandy, 2000). The lack of generally accepted diagnostic guidelines for Asperger's Disorder makes it impossible to determine exact prevalence rates or outcome data. Some estimates put the range of prevalence at 84 per 10,000 which is much higher than the prevalence for autism (Charman, 2002). Prognosis appears significantly better than in Autistic Disorder, as follow-up studies suggest that as adults many individuals with Asperger's Disorder are capable of gainful employment and personal self-sufficiency.

Autistic Disorder

Autistic disorder is the most commonly known diagnosis under the more general category of Pervasive Developmental Disorder. Autistic Disorder is a spectrum of characteristics that range from children with significant cognitive and verbal impairment to those children who are extremely high functioning (Olley & Gutentag, 1999). The Autism Society of America (1999) states that "Autism is a severely incapacitating life-long developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects functioning of the brain, autism and its behavioral symptoms occur approximately twenty out of every 10,000 births. Autism is four times more likely in boys than girls. It has been found throughout the world in families of all racial, ethic and social backgrounds (p.2)." The majority of individuals diagnosed as having Autistic Disorder are considered to have moderate to severe cognitive disabilities and approximately 75% of individuals with Autistic Disorder function intellectually at a level of mental retardation (American Psychiatric Association, 2000).

Impairment in social interaction includes an inability to develop social or emotional connections to others. These individuals have difficulty developing peer relationships or seeking interactions with others. Along with social integration difficulties, individuals with autism also experience impairment in communication. The communication and language impairment of people with autism range from failure to develop any functional speech to the development of functional but idiosyncratic language. If functional speech is present the child may lack the ability to maintain meaningful conversation. Individuals with autism may also experience difficulties with conversational skills such as voice intonation, pitch, fluency and speech rate (Frith, 1989; Morton-Cooper, 2004; Schreibman, 2005; Scott, Clark, & Brady, 2000).

Prevalence of autism is an issue that is currently being debated (Croen, Grether, Hoogstrate & Selvin, 2002; Gillberg, Cederlund, Lamberg, & Zeijlon, 2006; Gilberg, &

Wing, 1999; Lord, & Rutter, 1994). The DSM-IV-TR reports Autistic Disorder as having rates ranging from 2 to 20 cases per 10,000. Schreibman (2005) reports that the "hottest" issue in the field of autism is the reported tremendous increase in the incidence and prevalence of the disorder. Over the past several years a truly dramatic increase in the number of children diagnosed with autism has been reported worldwide. In 2002 a United States congressional hearing declared autism a national health emergency. It is estimated that today autism affects as many as 1,500,000 individuals in the United States alone and is rising at an annual rate of 10 to 17 percent (Twenty-sixth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2003).

Theories of Autism

When a definite etiology for a disorder is unknown, it is common that theories of etiology proliferate. In the field of autism this is the case. Michael Rutter stated at the Second Annual International Meeting for Autism Research (2002): "It's a dull month that goes by without a new cause for autism." Autism has been conceptualized as a disorder of affect (Hobson 1993) a disturbance of sensory-perceptual processing (Ornitz, 1985) of social cognition (Baron-Cohen, Leslie & Firth, 1985) as well as a disturbance of psycho-genic origin (Bettleheim, 1967; Roser, 1996). Research into genetic mutations and brain malformation has also been viewed as possible causes for autism (Hardan, Minshew, & Mallikarjuhn, 2001). The following ideas are presented to give a rounded perspective to the theories that have been viewed as potential causes of autism. The reader must also consider that these theories have been developed on the premise that there is a specific cause for the disorder described as autism. These theories have been used to drive treatment efforts for individuals with autism. Another consideration in understanding the nature of autism is that autism may well be the result of a number of these potential causes and may be a presentation of a set of symptoms which are common to a larger population with a variety of unrelated causes. As research progresses we may gain a better understanding of which of these paradigms is most appropriate. The following theories are discussed to provide the reader with an idea of what the current theories that are prevalent in the literature are.

Psychogenic Theory

The most influential theory of autism was the psychogenic theory which proposed that autism was primarily the cause of environment and parenting styles (Kanner, 1943; Bettleheim, 1967). This theory was not the most influential because of the great outcomes that it produced for the study of autism but rather the social reaction that it caused with families and educators who reacted to the idea that poor parenting or parent personalities were the cause of their children's mental disorder (Schreibman, 2005). Two elements of the era played a substantial role in the fostering of this theory. First, in 1943 psychoanalytic theory was very influential and played a large role in the then current understanding of mental disorders. Both mild and severe mental disorders were manifestations of internal underlying conflicts based in early childhood experiences, primarily relationships with parents. Secondly, in the era early attachment was seen as pivotal to many theories of childhood attachment. Lack of attachment in childhood was seen as detrimental to future growth in a wide range of areas (De Minzi, 2006; Leerkes, & Crockenberg, 2006). Considering the effects of poor attachment on the future development of children it was easy to accept that parents who where described by Kanner (1943) as aloof, cold, obsessive, intellectual, and emotionally detached as unable to provide proper attachment to their children in childhood. The lack of attachment was believed to have lead to the pervasive and severe symptoms characteristic of autism.

The psychogenic theory gave impetus to families and professionals to organize and become a strong force in showing that this theory was incorrect and unfounded. In 1965 the National Society for Autistic Children now known as the American Autism Society was founded. This force has been very influential in supporting research and advocating for education for communities and for individuals with autism.

Learning Theory

Charles Fester (1961) proposed the idea that basic principles of learning that had been convincingly demonstrated with animal subjects in the laboratory could be extended to help understand human behavior and especially how learning environment lead to autistic behaviors in children. He proposed that behaviors in autistic children were a function of frequency of reinforcement. Behaviors that were reinforced by attention, access to desired objects or avoidance of aversive situation were strengthened. Behaviors that didn't lead to reinforcement or were punished were weakened. From this theory a new approach to studying the learning environments of autistic children became a new focus for research and treatment (DiSalvo, & Oswald, 2002; Huber, & Zivalich, 2004). Though this theory again blamed the child with autism's environment for the disability the idea that children with autism could have behaviors trained into them through the basic principles of operant conditioning was the foundation of what is now the most popular form of treatment for children with autism (Schreibman, 2005).

Genetic Involvement Theory

Early geneticists discounted the idea of genetic transmission of autism because individuals with autism rarely had autistic parents and few autistic people reproduce. More recently the genetic argument has been supported by a vast number of studies which show familial links to autism (Courchesne, Carper, Akshoomoff, 2003; Rutter, Bailey, Simonoff, & Pickles, 1997). Genetic arguments are supported by the fact that siblings of children with autism have a 2 to 7 percent probability of also being autistic. Also in studies with monozygotic twins there has been a concordance rate reported to be between 60 and 90 percent and the concordance rate for dyzygotic twins has been reported at between 5 and 10 percent (Schriebman, 2005).

Many researchers believe that a broader form of the disorder is inherited of which classic autism is the most severe expression (Bailey, Palferman, Heavely, & Le Couteur, 1998; Bolte, & Poustka, 2006; Yirmiya & Shaked, 2005). This idea of a broader phenotype of the disorder has fostered a new way of looking at the heterogeneity of the disorder. The idea that there could be different presentations of severity of autism revives old ideas related to psychogenic theories related to the social and emotional environments that play a role in the presentation or severity of autism.

These theories have all focused on identifying the core cause of autism and very few theories take into account the idea that autism may not be the result of a specific cause but rather the presentation of similar symptoms with unrelated causes. As we come to better understand autism we may begin to view new ways of conceptualizing autism and may change the way the treatments are formulated and implemented.

Treatment

The treatment of autism has also been a rather controversial topic for many years. Rutter (1985), after reviewing a variety of approaches used to treat autism, concluded that nine were found to be consistently effective. Another review of treatments was completed by Schreibman (2005) and conclusions were consistent with those of Rutter's findings 20 years ago except that there seem to be some promising behavioral programs that are gaining acceptance but still require more study before they become proven effective. Many different interventions have been suggested as possible treatments, some even claiming to result in recovery from the condition of autism. However, adequately controlled studies in this field are few and randomized controlled trials, other than for pharmacological treatments, are virtually non-existent (Howlin, 1998; National Research Council, 2001; Rumsey et al., 2000). To better understand the current situation in relation to the treatment of autism it is valuable to understand the history of the treatment of these individuals.

Lovaas: Behavioral Intervention

In the early 1950's to early 1960's a great deal of attention was devoted to intensive, long-term, psychodynamic treatment, but there was virtually no evidence that it was effective. In the mid-1960's exciting developments were introduced by Dr. O. Ivar Lovaas. He introduced a number of behavior modification treatment programs for children with autism. Children with autism were rewarded for appropriate behaviors and punished for inappropriate or self-destructive behaviors (Lovaas et al., 1966; Lovaas & Simmons, 1969). Thousands of trials were required in which children were given bits of food for desired responses in order to teach the child simply to say one word. These programs required a great deal of time, effort, and money, but the initial results were very encouraging. Regrettably the long term outcomes of these treatments were less than expected. Another critique of these programs was that they often used aversive stimuli in order to obtain the desired social results. In a film produced by Lovaas in 1969 he showed children with autism running across the room with outstretched arms to their therapist in the hope of being picked up and hugged. However, what is not made clear in the film is that the children were barefooted and the behavior occurred in a room that had a shock grid on the floor that would be used to administer punishment to the children (Lovaas et al., 1965). The children ran across the room to be picked up by the therapist to avoid getting shocks to their feet and not in an attempt to get or express affection. The trained behaviors were never found to successfully generalize to other environments or social situations. Each of the children portrayed in the 1969 film eventually lost all gains from the behavioral treatments and were subsequently all returned as full-time residents of psychiatric institutions (Holmes, 1994). Lovaas (1987) modified his approach to his behavioral treatments and focused on children at an earlier age and changed the intensity of his program from 14 one-on-one hours a week to 40 one-on-one hours a week. This new program also had an increased duration of a minimum of 2 years. It also involved parents and school attendants who would be trained in the techniques and eventually become the therapist to their children. There have been many critiques of the Lovaas program the most compelling are those made by Schopler, Short, & Mesibov (1989) who after examining the effects of intensive early behavioral intervention on children with autism felt that there were many inconstancies in methodology and in publications. Their conclusion was that it is not possible to determine the effects of Lovaas' interventions on individuals with autism.

TEACCH

Treatment and Education of Autistic and Related Communications handicapped Children (TEACCH) was developed at the University of North Carolina beginning in the late 1970's and continues to be studied at this university to this day. This approach originated from the work of Mesibov, Schopler and colleagues. It is one of the few approaches that views autism as a life long disorder instead of a treatment to cure the effects of autism (Schopler, 2000). This program, like the Lovaas treatment, follows a behaviorist approach to teach social independence and reduce negative behavior. The focus of this program is to develop appropriate communication skills and personal autonomy rather than uniquely decreasing problem behaviors. Communication is a focus of this program and typically the spoken word is reinforced by means of visual materials such as pictures, and sign language. TEACCH also focuses on helping individuals with autism to become better at social interactions and communications with others through a specially created environment in which the individual with autism can function through this adapted teaching method (Mesibov, Adams, & Klinger, 1997; Tutt, Powell, & Thornton, 2006).

Each pupil has his or her own workstation, which is kept free from as many distractions as possible. Visual timetables are used in the classroom settings and the room is divided in to specific task areas. This is done in order to create a sense of predictability in the classroom for the students and give a sense of routine. Parents are encouraged to utilize the techniques that are learned at school in the home environment in order that the child will have greater continuity of experience.

Though the TEACCH method has been studied a number of times (Panerai, Ferrante, & Zingale, 2002; Van Bourgondien, Reichle, & Schopler, 2003), there has been very little effort to compare outcomes of this method with other methods that are currently being employed with individuals with autism (Powell, & Thornton, 2006). Though this method is widely used especially in the school setting, studies need to be undertaken to study the issue related to the fact that with autistic individuals behaviors learned in a specially adapted environment are unlikely to be generalized to other situations (Tutt, Powell, & Thornton, 2006).

Sensory Based Treatments

Sensory based treatments have been primarily based on the theory that if an individual with autism could be helped to process information that they receive through their sensory modalities like other non-autistic individuals their social and emotional behavior would be ameliorated (Baranek, 2002; Bettison, 1996; Edelson, Rimland, 2001). The AIT (Auditory Integration Training), and SIT (Sensory Integration Therapy), will be discussed briefly to outline a few of the sensory based therapies that are regularly practiced with individuals with autism.

Auditory Integration Training (AIT) was first introduced in France by Guy Berard (1982). The process of this therapy is to help individuals with autism that have hyper or hypo-sensitivities to sounds to normalize their hearing experience. The belief is that the symptoms of autism are a result of an avoidance reaction to their over-sensitivities to sounds. The process of treatment is to create music to be listened to by the individual with autism that has modified frequencies, limiting high and low frequencies from popular music using a specialized recording machine. Over time the music is altered in frequencies to teach the individual with autism to listen appropriately. The outcomes of this treatment are claimed to be calming for the individual with autism which translates into improved attention, arousal, language and social skills as well as a reduction in autistic symptoms.

Schriebman (2005) states that "the effectiveness of AIT is a hotly debated and emotional issue where proponents and skeptics have taken firm positions" (p. 184). Much of the support for this therapy comes from anecdotal evidence and has not fared well when subjected to scientific scrutiny (National Research Council, 2001; The American Speech-Language-Hearing Association, 2003).

Sensory Integration Therapy (SIT) was developed by Jean Ayres (1972), who was an occupational therapist. This therapy is based on the same principles as the AIT therapy except that it takes into consideration more than just the auditory experience of individuals with autism. Individuals with autism exhibit abnormal sensory responses to being touched, engage in repetitive movements, sniffing objects and obsessions with particular sensory experience. These activities are viewed as evidence that there is abnormal processing of different modalities in the sub-cortical regions of the brain. Controlled sensory experiences are then created to help individuals retrain their sensory processing system. Once retrained it should lead to improved learning and a reduction in the behavioral symptoms of autism (Edelson, 2003).

Multiple treatment approaches are used based on the individual with autism's specific needs or sensory deficit. Examples of treatments are weighted vests and blankets, adjusted lenses in glasses to limit specific spectrums of light and color, and suspended or swinging chairs.

Very little research has been done to verify the results of the SIT program and most evidence to support it comes again from anecdotal reports from parents of children with autism. When subjected to scientific scrutiny, SIT's effectiveness is not substantiated. Very little research has been done on this form of treatment simply because of the ever changing approaches used to treat sensory modalities. Sensory treatments are developed on an individual by individual basis and no two treatments are alike (Baranek, 2002).

Pharmacological and Nutritional Treatments

Several treatments have been devised through means of medication and nutritional supplements to treat the symptoms of autism. It would be impossible to discuss all of them due to the ever developing and progressing field of research (Erickson, Stigler, Corkins, Posey, Fitzgerald, & McDougle, 2005; Gingras, Santosh, & Baird, 2006; Symons, Thompson, & Rodrigues, 2004). Secretin, Glutin free diets and medication will be discussed in the following sections. These treatments have been chosen to highlight some of the most common and at times controversial treatments of individuals with autism.

Secretin was first introduced as a treatment for the symptoms of autism in 1998 by Karoly Horvath who reported that a gastrointestinal peptide hormone called Secretin may show benefit in improving symptoms of children with autism and pervasive developmental delays who also exhibited diarrhea (Horvath, Stefanatos, Sokolske, et al., 1998). This treatment was published by word of mouth, through newspaper articles and television reports and soon parents across North America and the United Kingdom were seeking Secretin infusion treatments (Schriebman, 2005). Although no empirical evidence was found to substantiate the use of Secretin in the treatment of individuals with autism (Esch, & Carr, 2004) there was such a demand for Secretin that the national supply in the United States was jeopardized (Rimland, 1999) and The Autism Research Institute in San Diego and the University of Sunderland's Autism Research unit in the United Kingdom began to post regular research updates and anecdotal evidence supporting the use of Secretin (Sandler, et al., 1999). This type of reactionary treatment of autism is common and families are often watching for the "silver bullet" that will cure their child of autism (Esch, & Carr, 2004).

Gluten-Free Diets have been applied as treatments for individuals with autism to combat the effects of what has been termed a "leaky gut" (Schreibman, 2005). This is the idea that children with autism have a metabolic disorder that results in gastrointestinal problems and specifically that their intestines are abnormally permeable. The result of this overly permeable tract membrane is that digestion products of food such as gluten and cow's mink pass through the membrane into the blood causing antigenic responses and interfering with the function of the central nervous system. It is believed that once the central nervous system is affected symptoms of autism and behavioral problems result (Elder, Shankar, Shuster, Theriaque, Burns, & Lindsay, 2006; Shattock, 1995).

Treatment involves placing the individual with autism on a low gluten and casein diet which are found in foods like wheat, barley, rye, oats, or their derivatives and all dairy products. A difficulty with this treatment is that the food choices for these individuals become very limited and with the sensory and eating peculiarity of individuals with autism it must be managed very carefully.

Most reports of success have been anecdotal from parents who have restricted their child's diet and have seen results in levels of functioning. Research is still being perused in regards to this treatment (Elder, et al., 2006). Due to the diversity of the autistic spectrum disorder, studies have been inconclusive or unable to draw conclusions in the general population.

Medications have been used by medical practitioners to treat the symptoms of autism but to date no medication has been found to treat the core symptoms of autism which are deficits in social interaction and communication (Kwok, 2003; Volkmar, 2001). Medication has been influential in improving symptoms of autism making life better for individuals with autism and those around them. The dopamine system has been studied as a contributor to the symptoms of autism. Drugs that block dopamine have been shown to have some positive effects on hyperactivity and behavior. Drugs that enhance the effect of dopamine exacerbate autistic symptoms. Specific drugs in the dopamine agonist category include haloperidol, chlorpromazine and thioridazine. These medications have proven effective in treating agitation hyperactivity, agitation, withdrawal, self-stimulation and mood in individuals with autism. Serious side effects such as dystonia and tardive dyskenitia can result due to the extended use of these drugs (Santosh, Baird, Pityaratstian, Tavare, & Gingras, 2006). Constant research is under way to find and develop medications that treat the symptoms of autism but have limited side effects. One of the greatest problems encountered with the study of medications is that there are no animal models of autism available for testing and therefore testing must be completed on individuals with autism. Due to this process many medications are used with very limited understanding of their long-term effects (Rappley, 2006; Woodard, Groden, Goodwin, Shanower, & Bianco, 2005).

Needs of Individuals with Autism

Understanding the needs of individuals with autism is a difficult process taken the extent of communication barriers and affective responses of individuals with autism. The following section will undertake to describe the needs of individuals with autism using an individual perspective. The individual perspective makes efforts to understand a situation from the individual's perspective rather than from the commonly accepted perspective. According to Hobson, (2002) studies concerning individuals with autism invite some fundamental considerations about the ways in which all individuals with or without autism come to feel, think and learn in the world; how we make sense of our experience; "autism forces us to think more deeply about what human perception, or human relations, or human intelligence, or human language, or human creativity actually are" pp. 182.

Social Behavior and Attachment

One of the most profound symptoms of autism is the marked lack of social behavior and evidence of attachment. Children with autism do not appear to bond with their parents, play with other children, and tend not to participate in social groups preferring to be alone. Individuals do not participate in social eye contact and often avoid eye contact with other individuals. Individuals with autism tend to not show empathy or appear to understand the feelings of another individual. Other people are often avoided and seemingly actively ignored and play times tends to be repetitive and appears to lack imagination or pretending from an observers point of view (Schreibman, 2005).

Narrative accounts of the experience of individuals with autism tend to be rare due to the language delays so common in its diagnosis. The following are some accounts from individuals with autism who have the ability to express their experience in a form that can be comprehended by non-autistic individuals. The first of these accounts is from Donna Williams who is an author, educator and advocate for people with autism and who herself has been diagnosed with autism. In her book, Somebody Somewhere (1994), she writes:

> *"Autism is something I cannot see. It stops me from finding and using my own words when I want to. Or makes me use all the words and silly things I do not want to say. Autism makes me feel everything at once without knowing what I am feeling. Or it cuts me off from feeling anything at all. Autism makes me hear other people's words but be unable to know what the words mean. Or autism lets me speak my own words without knowing what I am saying or even thinking. Autism cuts me off from my own body, and so I feel nothing. Autism also can make me so aware of what I feel that it is painful. The most important thing I have learned is that autism is not me. Autism is just an information-processing problem that controls who I appear to be. Autism tries to stop me from being free to be myself. Autism tries to rob me of a life, of friendship, of caring, of sharing, of showing interest, of using my intelligence, of being affected. It tries to bury me alive."*
>
> *(Williams, 1994, p.237).*

Another personal account is taken from Temple Grandin a well known author in the autistic community. In her book Thinking in Pictures (1995) she wrote:

> *"If I could snap my fingers and be non-autistic, I would not. Autism is part of what I am, In contrast, Donna Williams says "autism is not me. Autism is just an information processing problem that controls who I am." Which is right? I think we both are because we are on different parts of the autism spectrum. I would not want to lose my ability to think visually. I have found my place along the great continuum."*
>
> *(Grandin, 1995, p.61).*

These individuals are remarkable in the ability to express what autism is for them. Other individuals with autism have a more severe disability and are not as able to communicate their experience or their needs to their caregivers and loved ones.

Many of the treatments that have been created and implemented with individuals with autism focus on helping individuals with autism become more “normal” in their social functioning. The concept of understanding what individuals with autism want or desire is relatively new in the literature concerning autism. Billington (2006) stated that a greater focus needs to be made to understand the autistic experience in a way that is not restricted by the primary consideration of impairments or deficits in autism, but rather focuses on the thoughts and feelings of individuals with autism. Most of the literature reviewed refers to the desires of the parents or guardians of individuals with autism and not the individuals themselves. The needs that are addressed are needs that have been identified as barriers to societal and educational functioning as opposed to the individuals wants and desires (Baron-Cohen, Tager-Flushberg, & Cohen, 1993; Baranek, 2002; Bettison, 1996; Edelson, Rimland, 2001; Happe, 1999). Sinclair (2004) describes the problem with current research in that it focuses on the individual with autism as an individual who is impaired in their abilities to conceptualize individual experience. “I believe in differences in autism rather than disability in autism” (Sinclair, 2004).

The narrative accounts that are available concerning individuals with autism such as Temple Grandin and Donna Williams are few but they give insight into the unique experiences that individuals with autism have. The accounts emphasize the need to find ways to help individuals who fall on the classic autism end of the spectrum and have greater communication difficulties, find ways for them to make their needs and desires known.

Much of the current research is focused on the need to teach social behavior to individuals with autism and to integrate them into social environments (Baranek, 2002; Edelson, 2003; Horvath, Stefanatos, Sokolske, et al., 1998). Other treatments are designed to decrease negative behaviors such as aggression and self stimulation to help individuals with autism become integrated into society and to alleviate stresses on caregivers and society (Kwok, 2003; Volkmar, 2001).

Due to the unique affective presentation of individuals with autism their emotional expressions are frequently odd and do not appear to give indication of internal desires (Schreibman, 2005). Their emotional responses may be excessive and exaggerated or may be relatively stable and minimal. Some individuals with autism can be extremely labile and move quickly from being hysterical with laughter to becoming inconsolable and in tears. There is very little that another individual can do to help them deal with these problems because their emotional responses are neither a good predictor nor clue to the amelioration of their problem (Norbury, 2005).

Social integration for individuals with autism can be a difficult and anxiety producing experience for them. Irrational fears are often noted for individuals with autism and they are often related to the individual's need for sameness in their environment. When environments are adjusted individuals with autism can respond in a number of ways which could be classed as abnormal for individuals without autism (Allen, 1991; Tuchman & Rapin, 1997).

Communication Needs

Failure in the acquisition of language is one of the primary symptoms of the autistic disorder. Approximately half of children with autism fail to develop functional speech and those that do acquire speech often develop non-communicative speech patterns that are very different from those of ordinary individuals or even those with specific language disorders (Kanner, 1943; Schreibman, 1988; Schreibman, 2005). Without intensive treatment individuals with autism remain nonverbal and neither learns receptive nor expressive language. Echolalia, the repetition of words or phrases spoken by other individuals is a common form of communication among individuals with autism. Language is often repeated back immediately after being expressed by another individual and often contains pronominal reversal. Pronominal reversal is when an individual refers to him or herself as "you" as opposed to using I or me. Due to language comprehension problems, speech often is used for non-communicative purposes by individuals with autism. Speech could be used as a form of sensory feedback or self stimulation. The goal of this interaction is not to communicate but rather for the stimulation that the speech experience provides (Ingersoll, & Schreibman, 2006).

Non-verbal communication is not a reliable form of communication with individuals with autism due to the fact that communicative gestures tend to be absent. Individuals with autism tend not to shake their heads to indicate no or nodding to indicate yes. They rarely participate in other social gestures such as waving hello and goodbye and pointing to objects in their environment. Individuals with autism will often take an individual by the hand and take them to a desired object rather than pointing and looking at it to identify it at a distance. Due to the lack of eye gaze, communicating non-verbally through visual eye contact and facial expression is non-existent. When facial expressions are used they are often exaggerations of expressions that they have seen in others in response to select training experiences that they have had. These expressions generalize poorly to other social situations and can often appear awkward and out of place when used out of context (Mundy, Sigman, Ungerer, & Sherman, 1986).

Physical Needs

Individuals with autism do not attend to their environment and relevant stimuli in that environment. This trait puts them at danger of becoming seriously injured and killed as a result of not learning potential dangers in their environments. Individuals with autism tend to have over or under responsiveness to touch, pain and temperature. Due to these sensitivities individuals with autism can put themselves at potential risk due to the lack of reaction to uncomfortable environments (Bogdashina, 2003). An example of this type of danger would be an individual with autism who's skin is sensitive to touch may find a winter coat unbearable to wear and would remove it in a sub zero environment exposing them to dangerous temperatures. Due to the individual's under-responsiveness to cold and pain they may jeopardize their life due to this reaction and/or under reaction.

Individuals with autism are not able to protect themselves from people who would take advantage of them due to their socially innocent behavior. Abuse is common among individuals with disabilities (Kelly, 1992) and particularly among individuals who are unable to communicate their needs and desires in accepted communication styles (Firth, Balogh, Berney, Bretherton, Graham, & Whibley, 2001). Financial, physical and sexual abuses are all areas that an individual with autism needs to be protected from by an external agency or guardian.

Guardians play a major role in the lives of individuals with autism. Due to the individual with autism's inability to access the basic needs of life, food and shelter, guardians are a necessary need for individuals with autism. This need for a guardian places many stresses on families and communities (Hutton, & Caron, 2005). Families often play a major role in guardianship of individuals with autism in a number of different settings and environments. An inherent problem in caring for individuals with a life-long pervasive developmental disability is that often times individuals with autism can outlive family members who generally serve as guardians (Carpenter, 1997). Due to the lack of bonding and non-empathetic responsiveness of individuals with autism caregivers must provide supports for these individuals without the expectation of a reciprocal or appreciative relationship. Government agencies play a role in guardianship of individuals with autism when families are unable or refuse to participate in daily living and life planning choices. The cost of caring for individuals with autism's financial and caregiver supported needs can be staggering (Jarbrink, Fombonne, & Knapp, 2003; Mandell, Cao, Ittenbach, & Pinto-Martin, 2006;). The Autism Society of America (2003) estimates that the annual cost in the United States to care for individuals with autism will be between $200 and $400 billion dollars.

Limitations of Existing Research

The field of autism is still a relatively new area of study. The first studies being published only 50 years ago. Much research has been done to determine the cause, classification and treatment of autism. New theories are developed daily to explain the causes and course of this pervasive disability. Treatments are still limited in scope and many of them lack verification through validated studies. Much of the justification for treatments in practice today are based on anecdotal evidence offered by parents and researchers who have tested their theories on select groups of individuals with autism.

The body of research is very limited in terms of clarifying the expanse of the autistic spectrum. Very little information is available identifying in a qualitative or quantitative way the different classifications on the autism spectrum. Within the autism spectrum disorder individuals can range from verbal to non-verbal, affectively labile to emotionally blunted and violent towards others or self mutilating. This causes difficulty in developing studies that could give clarity to various treatments that are broadly applied to individuals in the autistic spectrum of disorders. Treatments that are beneficial to one subgroup of individuals with autism may be inappropriate and even detrimental to another group of individuals with the same diagnosis but a different presentation. Due to this wide range of classification within the autism spectrum it can be difficult to clarify the population that researchers and therapists are working with.

Another gap that exists in the research is the search for a way to evaluate the individual needs and desires of individuals with autism. Focus in the research is still based on treatment techniques and on training social behavior. Due to the nature of autism other individuals often are required to fulfill a guardianship and choice making role for these individuals. A greater focus needs to be made to identify the needs of the individual as opposed to the desires of the parents and government appointed guardians.

The Research Question

This study aimed to contribute to the body of research a greater understanding of how we come to understand and take into consideration the needs of individuals with autism. A qualitative research method was employed and the study was completed in an exploratory interpretive inquiry in that it examined the subjective feelings, experiences and perspectives of individuals, who live with, work and teach individuals with autism.

The research question that was the basis of this inquiry was "How do we come to understand and make sense of the needs of individuals with autism?"

CHAPTER THREE

Method

My Interest in Researching Autism

My first experience with autism was supposed to give me a break from the difficult experience of working the dark streets of Edmonton apprehending underage prostitutes. Little did I know it would become one of the greatest and fulfilling changes of my life. In my third year of my undergraduate degree in psychology I had the opportunity to be the first student in the Arts faculty at the University of Alberta to participate in the Industrial Internship in Psychology. I would have the opportunity to work full-time for a period of 18 months at a job where I would learn about psychology in practice. I was immediately hired by community care agency as a community crisis intervention worker. Due to my large stature I was quickly funneled into working around the clock on the, at times, mean streets of Edmonton. My job entailed working daily with suicidal teens, violent young men and apprehending young women who at a very early age had engaged in the sex trade to survive. After a year of working in these conditions I realized that the work was beginning to take a toll on my family. I had been noticing a coldness creeping into me which left me feeling nothing but anger, hate and distain for the situations which I saw in our society. I noticed while I was at work I would deal with life threatening experiences each day and not feel any sense that I had made a difference. I realized that I needed a change in my life and aspects of my work. I went into work the next day and said “give me something completely different.” To my surprise the office manager was more than willing to comply. She asked me if I would be willing to work with an autistic boy. I didn't know what autism was but the idea of something different really appealed to me.

As I walked up to the house where I would meet my first person with autism all I remember was hearing screaming and crashing sounds from inside the house. I burst into the house to find my new client all 6'2'' and 280 pounds of him tossing his uncle around the room like a broken toy on Boxing Day. I immediately went into action and restrained the young boy and held him in a way that was safe for him, me and the other people in the room. As I lay on the floor grappling with this young man I immediately felt something different inside of me. I didn't feel the expected anger, hate or vengefulness but rather I felt a sense of compassion and a respect for innocence that to this day has not left me. In reality I think that day saved my emotional life.

My next visit to the office I located the manager who had assigned me this particular case. When I greeted her she sheepishly looked at me and said "how did it go?" I replied with exuberance and said "I loved it; give me everything that you have that is similar." From that day on I became known as the guy who worked with violent males with autism. For the next 2 years I worked almost exclusively with young men with autism. In those two years I made many contacts in the community and began developing my own ideas and understanding of this condition called autism. In my experience working with other community crisis workers, I remarked that often the minute a unique or "abnormal" behavior started it was met with extreme forms of behavior control and even at times punishment. As I watched these experiences transpire I would say to my self "is that behavior wrong or is it just different from how I behave?" More times than not I found the behaviors to simply be different as opposed to wrong and requiring intervention. I realized that most times dangerous and wrong events could be avoided by simply adjusting the environment rather then adjusting the child.

Due to my adherence to these basic ideals I was eventually approached by a number of families who had children with autism and asked if I would provide care for their children in a shared living environment. This venture culminated in the formation of a corporation. Today this corporation is in partnership with Family Services to Children with Disabilities (FSCD) and provides long-term care for children with autism who, for various reasons, can no longer live in their family of origin. In the now ten years that I have been providing care for children with disability I have come to refine many ideas about autism and how it affects individuals and families.

Over the years that I have worked with children with autism I have found that regularly new directives about how to care for children with disabilities are implemented causing an uncomfortable time for me and the corporation until a way to apply those new directives is identified in a healthy and respectful way to the children that I care for. Part of the difficulty faced is that the children I work with don't always fit the standard "child with disability framework" (I often question if any do) nor are the needs of children with disabilities representative of the needs of children with autism. I have found that a number of children with various disabilities have difficulty with gaining acceptance from and access to the community. I have also found that some children long for interactions where they are accepted for who they are and are free to express themselves in happy and healthy ways. In my experience with children with autism these issues are not theirs. A classic characteristic of autism is a marked disinterest in society and great anxiety in trying to interact within it. I have often been perplexed in efforts to meet the many directives encouraging social participation and at the same time not causing undue distress and unhappiness for the children I care for. I believe in having directives, and I wish that there was some way to have those directives be more focused on the specific needs of children with autism. This desire to give a voice to these children is what drives my current preoccupations and occupation.

Through my personal experience with autism I have come to realize that more growth and understanding is needed in order to develop a more sophisticated approach to working and evaluating that work with individuals with autism. Part of what drives my present interest is the love that I have come to feel for the children that I care for. I hope to become a better care provider. I believe I will be a better care provider as I gain a greater understanding of what it means to be respectful of individuals with autism and at the same time provide them with the skills that will help them to function in society at a level they would choose.

Rational for a Qualitative Method

The type of research question to be studied is often what determines what research method should be employed to gain the desired results from the study. Qualitative research attempts to answer questions about what an experience is like for an individual or group of individuals. When there is very little known about the particular phenomenon being studied qualitative research can be effective in exploring this phenomenon from the perspective of individuals who currently experience the phenomenon. In qualitative research the goal is to learn the perspectives of participants and gain greater understanding of how they experience a phenomenon and what significance this experience has for them. This is achieved by allowing the study to unfold through the interpretive inquiry process. The primary purpose of a qualitative study is to understand how people make sense of the phenomenon or experience of interest. The qualitative researcher understands that reality is socially constructed (Denzin, & Lincoln, 1994), and makes efforts through the qualitative process to better understand the meanings behind what is presented by others. The purpose of this study is to gain a greater understanding of the ways that parents, caregivers and teachers come to understand the specific needs and wants of individuals with autism and the ways that they have become aware of the communication of these needs through their work with these individuals. It was believed that this could be best achieved through the qualitative approach and was therefore selected for this study.

Interpretive inquiry is not only the process of becoming aware of our assumptions or interpretive frameworks that guide our actions but further taking on the responsibility to look closely at the way that we have come to those assumptions or interpretations. Interpretive inquiry allows the researcher to gain new understandings that were not previously available on a conscious level. This is done by looking at the different ways that one views the world and what ideas and beliefs could be contributing to their current world view. The deliberative process of interpretive inquiry allows the researcher to come in conflict with one's own limited views or prejudices and realize new ways of interacting and interpreting the world. Packer and Addison (1989) explained that

A person uses fore-structure to make some initial sense of the research participant, text or data. In other words they use their existing preconceptions, pre-understandings or prejudices, including purposes, interests and values to interpret. This initial approach to interpretation is unavoidable.

An interpretive inquiry begins with a question that is drawn from a practical concern or wondering about something that is cared about. Children with autism have been a passion of the researcher as well as a preoccupation that has caused him to reflect repeatedly about their place in our culture and how they are best served in the caring field. The process of illuminating new understanding concerning how they can be best served followed a process that resembled an unfolding spiral. Ellis (1998) stated:

> *"When a study is viewed as a series of loops in a spiral, each loop represents a different attempt to get closer to what one hopes to understand. One enters each loop, or separate inquiry with a question. What one learns in the loop provides direction or a reframing of the question for the next loop. What one learns may in fact change the direction of the study quite dramatically." (p. 20).*

This spiral allows researchers to recognize the unfolding and generative nature of an interpretive inquiry. The first loop of my inquiry was controlled at first by my pre-understandings of how children with autism are best cared for. In the process of trying to make sense, through my fore-structure, of their needs I eventually needed to re-examine my initial interpretations and find areas that I had over looked, discounted or even omitted. As I did this the new uncoverings or new ways of understanding the needs of individuals with autism emerged. As new uncoverings were identified new interpretive questions arose that then influenced the next interpretive loop in this unfolding spiral. These uncoverings played an important role for the researcher. At the end of the study I was able to look back at the unfolding spiral and see the points in the study that my understandings were transformed and I moved to a new level of understanding relating to the needs of individuals with autism.

Due to the potential risk of disrupting the lives of individuals with autism by having them participate in the study, it was impossible to have individuals with autism participate as the primary participants themselves. The idea to gain insight from those that had a vested interest in the wellbeing of individuals with autism was proposed. It was assumed that by studying the experience of a parent of an autistic child, a teacher who provides a school program for individuals with autism and a caregiver from a residential group home for individuals with autism, greater understanding could be acquired concerning how they came to understand the needs of the individuals that they worked with and cared for.

It was anticipated that the stories and experiences presented by the participants in the study would be helpful to others who cared for, taught and raised individuals with autism. A final and important anticipation which would be consistent with the interpretive inquiry paradigm was that the researcher's understandings of the phenomenon being studied would be transformed.

Interpretive Inquiry: A Historical Overview

The philosophical foundations of hermeneutic human science research date back to the 19th century writings of Wilhelm Dilthey, a German philosopher. At this time positivist theories were becoming defined and widely accepted. This focus on positivist ideals was due in part to the ideas of Compte and Descartes who had put forth the claim that objective truth could only be derived through the method of the natural and physical sciences which generate and then seek to validate hypotheses. The focus of the epistemologically oriented natural sciences was to build a body of knowledge consisting of objective facts. Dilthey challenged the positivist philosophies of these philosophers and in contrast, recognized and valued those subjective methods of understanding which Descartes and Compte viewed as hindrances to the search for truth. According to Dilthey, "human, social, and behavioral science—human and cultural expressions and institutions that involve the subjective experience of individual persons—call for a different method" (Gallagher, 1997, p. 3). The method that he proposed was one which was based on understanding rather than the search for explanation and proof.

Dilthey and his followers studied and employed the processes of textual hermeneutics developed by Schleiermacher (1768-1834). Schleiermacher was a philologist who argued that the only way to truly understand the ancient written texts of theology and history, one had to consider not only the specific meaning of what was actually written in the works but also the intentions of the individuals who had written the texts. Dilthey and his followers viewed the hermeneutic process as a novel way to build knowledge and understanding of the complex inner thought processes of the human mind.

The existential philosophy of Martin Heidegger (1889-1976) also played a key role in the development and fostering of the hermeneutic or interpretive style of research. Heidegger shifted the attention from questions of epistemology which concerned itself with how we know what we know, to a focus on ontology which concerned itself with what is means to be a human being, and how we come to understand what we know about the world.

In shifting philosophical concerns to ontology, Heidegger challenged the Cartesian view of the person as a combination of a number of traits that could be identified and classified using the scientific method. Once these traits and variables are identified they could then be studied, predicted and manipulated. Heidegger argued that "traditional science is itself a theory screen that constrains our ability to understand human agency (that is intentionality in human action constituted or shaped by concerns, purposes, goals, and commitments), limits our imaginative ability to generate questions, and further, limits the answers we can generate for those question that we do manage to pose" (Leonard, 1994, p. 45). According to Heidegger human beings have a natural tendency to be interpretive and that their experiences are formed through interpretation of the world around them.

Through these ideas, Heidegger expanded the role of hermeneutics beyond being a process for interpreting text to a broader interpretive method particularly applicable to the complexity of human science research (Gallagher, 1997). In this interpretive approach to understanding the world around us described by Heidegger, the research's role in the interpretive process is fundamental. In the interpretive process efforts are not made to minimize the effects that the researcher has on those that he participates with in the study, rather the researcher experiences, beliefs and understandings are the means by which the study happens.

Key Role of the Researcher

A characteristic of all forms of qualitative research is that the researcher is the primary instrument for data collection and analysis (Merriam, 1998). The techniques described in the following sections are all fundamentally reliant on the abilities and training of the researcher who uses them. It is therefore important to recognize the key role that the researcher plays in all parts of the process. Guba and Lincoln (1981) explain that:

> *"Data is mediated through this human instrument, the researcher, rather than through some inanimate inventory, questionnaire, or computer. Certain characteristics differentiate the human researcher from other data collection instruments: The researcher is responsive*

> *to the context; he or she can adapt techniques to the circumstances; the total context can be considered; what is known about the situation can be explained through sensitivity to nonverbal aspects; the researcher can process data immediately, can clarify and summarize as the study evolves, and can explore anomalous responses." (p. 64).*

In understanding the role of the researcher in qualitative research it is important to also recognize the fallibility of the human experience. Again, the idea of fore-structure becomes paramount. If a researcher doesn't recognize that his or her perceptions and pre-understandings influence their ability to analyze data they will not see the embedded meaning of their own or another's experience. A temptation exists to accept one's own perspective as correct and see all data as either confirmatory or unhelpful in their research pursuits. This temptation is one with which I particularly struggled. Having worked with individuals with autism for many years and being a consultant for many agencies it was easy to believe that my perception of what was best for children with autism in care was correct. I needed to continually remind myself that the purpose of the study was to gain greater understanding and depth into how best to care for individuals with autism and come to understand their needs. Philosophically, I needed to often reiterate for myself that understanding is valuable in itself. Nothing need be proven in order to make a valuable contribution to the body of research and to myself who will continue to play a role in the field of autism for many years to come.

Interviewing. In this research study as well as most qualitative research, the interview played an important role as a form of data collection. Research interviews are often described in terms of the construction of the questions to be posed to the participant, often stating whether they will be presented in a formal or informal interview or as open-ended or closed-ended questions or a combination of these presentations.

When considering the interview in the qualitative paradigm, the interview is much more than a static tool for the collection of data. To better understand the nature of the qualitative interview I would discuss the following points. First, the interview is a co-creation of understanding between the interviewer and the participant. Second, interviews have a paradoxical nature. Lastly, the importance of remembering participants as the data is gathered and analyzed.

The potential for greater understanding becomes evident when the interview becomes a collaborative work rather than a researcher trying to get his or her questions answered. Weber (1986) states that:

> *"Through dialogue, the interview becomes a joint reflection on a phenomenon, a deepening of experience for both interviewer and participant. It becomes a conversational relation between two people, one in which they come to learn as much about each other as they learn about whatever the topic of conversation." (p. 65-66).*

If an interview is an experience where the participant feels that his thoughts, ideas, and experiences are valued then the interview has the potential to became a vehicle for the co-creation of new understandings and greater insight into the phenomenon. This co-creating experience elevates the interview from a simple tool to gather data to an actual mode of learning. Carson (1986) describes this relationship as "a community of cooperative investigation." (p. 26).

Concerning interviews, Weber (1986) indicates that they are paradoxical in that they are conducted in a private and interpersonal way with the intention to be used in a public and social way. Learning to mitigate the effects of this paradox will create an environment for interviews to obtain depth in understanding and be collaborative in nature. Participants are aware that the information that they share in the form of an interview will be used in some public way. Being aware of this, they may be influenced by their social perceptions as to what information they share. Friedman (1983) stated "human beings, know how to shut others out; they know how not to reveal themselves to the other. This is especially true when they are confronted with someone who wants to see what makes them 'tick'." (p. 11). In this conversational mode of inquiry the relationship between researcher and participant is fundamental in the process of overcoming intentional or even unintentional concealment on the part of the participant.

Once the results of interviews are transcribed into "data" it is possible to forget the relationships and the human experience that created the data. Weber (1986) echoes this statement by stating "unfortunately, in our haste to publish, to analyze, and to write, we may forget our commitment and responsibility as human beings, turning the interview into "data," overlooking or destroying the experience of its very creation as we jump immediately to typed transcripts, substituting without hesitation the printed work for the lived experience." (p. 69-70). Efforts need to be made to not lose the meaning or the power of verbal experience through transcription. Researchers need to be responsible with the interviews that they acquire, to regularly return to the participants and the recorded interview to recapture some of the things that are lost when the interview is transcribed.

With these points taken into consideration the qualitative interview affords the researcher the ability to gather information in a way that can be both powerful towards gaining understanding and fraught with potential difficulties. As researchers make efforts to be genuine with participants, recognize the human component of an interview, and be aware of how their own process affects the outcome of interviews, they can capture data that will further their understanding of the phenomenon being studied; at the same time, honor the individuals that co-created this new awareness and understanding with them.

Interpretive Inquiry as a Formal Research Process

The interpretive work of hermeneutics is an inherently creative method of research. The interpreter works holistically to discern the intent or meaning behind another's expressions (Ellis, 1998). The process of interpretive inquiry can be described by explaining the metaphors of the unfolding research spiral and the hermeneutic circle, The research process is essentially question driven, The researcher begins with an initial question, and each loop in the spiral represents a separate inquiry activity which further addresses the research question, the forward arc of the hermeneutic circle is based upon and limited by the researcher's forestructure or understanding, his beliefs, values and pre-understandings (Smith, 1991). The interpretive process happens when the researcher's forestructure is applied to the participant's responses to the questions that they have been asked. Interpretive inquiry implies that the researcher comes to the question from a particular experiential and knowledge vantage point. In this particular study the researcher began with a set of beliefs and ideas concerning the needs of individuals with autism. It would be impossible to extract the experiences and knowledge of the researcher from this process in that these beliefs and ideas were the foundation from which the questions were first formulated.

Once the interpretation of the participant's responses has happened the backward arc of the hermeneutic circle begins. The backward arc of the circle refers to the researcher's attempt to evaluate his interpretation of what went on in the inquiry, this evaluative stage of the inquiry shapes future inquiry. As the researcher views the interpretations he then calls into questions previously held ideas and beliefs and from this experience new questions are formulated and shaped. The process of the forward and backward arc of the circle can commence again. Following this process the researcher hopes to come closer and closer to what he desires to understand.

This interpretive work often involves numerous loops of inquiry, each involving a forward and backward arc. Each loop may represent a separate episode of data collection and analysis, or as in this study, it may represent a return to the same set of data with a different question. The result of this interpretive process is that it generates findings. These findings are best described as ideas that were not previously available to the researcher due to the limitations of forestructure. In hermeneutic terms these unexpected findings are referred to as "uncoverings" (Ellis, 1998). The research process is continually shaped and influenced by various uncoverings that are discovered through the process. The data collection and data analysis can be viewed as being ongoing and concurrent. The researcher continually moves back and forth from the part to the whole, seeking to understand the part in relationship to the other parts and to the whole

Use of Narrative as an Approach to Data Collection

I have always been an interpretive inquirer; I just didn't know it until I became familiar with the terminology of interpretive inquiry and that of hermeneutics. I have always had a penchant for learning through the stories and experiences of others. As I encountered ideas that I didn't understand or didn't make sense with what I already knew I would begin a questioning process that would lead me to a new level of understanding about that concept or idea. I love to spend time with others listening to their stories comparing their ideas to those that I had formulated. The hermeneutic narrative approach seemed a natural way for me to begin to understand the needs of individuals with autism through the accounts of individuals who cared for them.

Reissman (1993) noted that telling the stories of one's life is a very natural and universal activity which human being use to make sense of their experiences. The type of questions that were asked in this study were intended to foster open communication with the participants of this study. Mishler (1986) suggested that the open ended research interview allows the respondent to create a self-narrative which reveals what is important to them. The interview serves as an instrument for story making and story telling. The experience of the narrative interview is truly one that is a flowing of ideas that are born from the experience of communicating freely with another person on a particular topic. The experience is even more powerful when both of the individuals in the interview are passionate about the topic which they are exploring.

Schwandt (2001) defined narrative research as an interdisciplinary method for analyzing the stories people tell of their life experiences. The stories that the participant tells, can be analyzed by the researcher who seeks to make sense of the story and to discover their meaning within the context of the interview. This is done through the process of transcription and analysis to find vignettes that are descriptive of the meaning filled stories. This process will be discussed later in this chapter.

I chose a descriptive narrative approach to collecting the data for the study because I wanted to give the participants the opportunity to tell the story of how they have come to understand the needs of individuals with autism. I believe that these stories have value in that they may resonate with another individual who is struggling with the demands of living with or working with an individual with autism. For this reason this study used a narrative approach in that it solicited and examined the accounts of individuals who through their experiences have come to a deeper insight into the needs of individuals with autism. One in-depth interview was conducted with each participant which was followed up by one or more follow-up interviews to clarify points and to gain more ideas about certain stories or events shared. On the basis of these stories shared in the interviews, I constructed a narrative of each of the participant's experience. This narrative provides the reader with a rich description of the context and meaning of the experience of coming to understand the needs of individuals with autism. The narratives were then further analyzed using the hermeneutic methodology described by Leonard (1994). This process was employed by taking the narrative accounts and uncovering themes through the process of interpretation and analysis

Research Design

The following sections will describe the participants of the study and their selection process as well as the data collection and analysis procedures used. Finally, a discussion of the ethical procedures followed and the ethical difficulties encountered in proceeding with this research study.

The Participants

Participants were acquired through a non-random purposeful sample intended to identify individuals who could give a rich description of their experience of working with and understanding individuals with autism. Individuals were drawn from the communities of Northern Alberta and were identified by the researcher communicating with various teachers, parents and caregivers to identify individuals who would have valuable stories to share. The Autism Society of Alberta and Family Services to Children with Disabilities also served as reference points in identifying and contacting these individuals. A minimum of 8 years experience working with individuals was set as the minimum amount of time required to be considered for this study. It was also determined that these individuals currently be active in the endeavor of working with or caring for an individual with autism. A focus was also placed on individuals who had experience working, living and teaching individuals with autism who were non-verbal or exhibited echolalia as their primary communication style and were formally diagnosed with autism according to the DSM IV criteria. Participants were contacted directly by the researcher by phone or by letter to their places of residence and they were invited to participate in the research process. Participants were informed both verbally and in writing that their participation is completely voluntary and that they had the ability to withdraw at anytime without prejudice. As an active participant in the autism community I had social ties to many individuals in that community. Those individuals that I invited to participate in the research may have had social contacts with me in the community but there were no invitations extended to people who I may have undue influence over. Three individuals were identified as fitting the criteria previously mentioned and were invited to participate in the study. These three individuals were Donna, a nurse in her 40's who had 10 years of experience working in residential group homes for individuals with disabilities and had worked with the same complement of individuals with autism for the entirety of that time. Brian who was in his 50's was a parent whose oldest son was diagnosed with autism as a child and now as an adult continues to live in the family home. Breanne who was also in her 50's was a school teacher and had worked with individuals with autism for approximately the last 15 years, first as an aid then as a teacher.

Data Collection Procedures

The primary data collection procedure for this research study was the use of interviews with a personal care attendant for, a parent of, and a teacher to individuals with autism. The following sections will discuss the participants, and a discussion of the logistical aspects of the interviews.

Interviews

In order to gather the information required for this study I conducted a number of audio-recorded collaborative interview sessions with a personal care attendant for, a parent of and a teacher who worked and cared uniquely with individuals with autism. I requested one formal interview of approximately 45 minutes in length and up to 3 follow up interviews of 10 minutes in length to clarify ideas and thoughts expressed in the initial interview. Interviewing is one method of gathering "descriptive data in the subjects' own words so that the researcher can develop insights on how subjects interpret some piece of the world" (Bogdan & Biklen, 1992, p. 96). These interviews were intended to happen throughout the process of data collection as experiences emerged. It was vital in the interview process for me to help individuals know that they were co-creators and authors in this research process. It was necessary to approach them with humility and ask for their input. If the participant felt that I was questioning them as the expert on autism the conversations would have moved away from a co-creation opportunity and simply become at question and answer period. Stake (1995) states that, "The purpose for the most part is not to get simple yes and no answers but descriptions of an episode, a linkage, an explanation" (p.65). As I proceed in an inviting, non-expert manner I hoped to learn from the participants in a number of ways. One of these ways of learning was by being a good listener and hearing not only what was stated but what was implied. Through proper listening I was able to help the participants understand that I was truly interested in their viewpoints and understandings. As I showed understanding of their viewpoints it was hoped that they would feel more and more comfortable to share knowing that I was neither judgmental nor critical in my investigation for greater understanding.

Interviews were semi-structured in order to allow the participants to share their experiences in a way that was comfortable and respectful. Stake (1995) explains that "One needs to have one's mind organized yet be open for unexpected cues. Research questions should be carefully developed in advance and a system set up to keep things on track." (p. 68). The prepared questions were of the open ended nature to commence a conversation on a specific topic. A sample question that was used to stimulate a conversation was something like "what is it like to care for a child with autism?" or "what was it like when such and such happened?" Patton (1990) states that "effective interviews should cause both the interviewer and the interviewee to feel that a two-way flow of conversation is going on." (p. 327). It was desirous that the interviewee felt comfortable to express their viewpoints freely with as much depth as possible. Later when the interviews were reviewed and transcribed there were points in the interview that need further clarification or were of interest to the researcher. These points of interest became the platform for follow up question in the future collaborative interviews.

The Interview Guide

Questions from the Initial Interview:

1. What was it like for you today working with individuals with autism?

2. What are some of the greatest times working with individuals with autism?

3. What are some of the most difficult times working with individuals with autism?

4. When you first started working with individuals with autism what were some of your ideas or beliefs about them?

5. How have your ideas changed since working with individuals with Autism?

6. How do the individuals with autism express to you their wants, desires, and needs?

7. What have you learned about how individuals with autism express their needs?

Follow up questions:

1. The other day you mentioned something about..... I was wondering if you could clarify what you meant?

2. The other day you mentioned something about..... I was wondering if you could tell me more about that experience?

All of the individuals were interviewed at times and places that were convenient and comfortable for them. One interview was done at the individuals home which required considerable travel on the researcher's part. The participant lived over 250 kilometers from the city of Edmonton. The other two interviews were done by the request of the participant in my counseling office in the city of Edmonton. Each individual was given prior to the interview a primer activity. The primer activity was intended to help the individual begin thinking about their experiences working with individuals with autism. These primer exercises where first discussed as a way to transition into the interview. Participants were given a number of primer activities to choose from and were encouraged to identify one that they were comfortable with and take a few minutes prior to the interview to ponder and complete the primer activity. Some examples of the primer activities that were offered were as follows:

1. Take a few minutes and write down what you think it would be like if someone from another planet where to encounter a person with autism as their first contact with humans. How would they describe their experience?
2. Take a few minutes to draw and/or color a picture that would represent how you view autism.
3. Take a few minutes and create a time line or a graph that represents your growth and/or experiences that you have had working with individuals with autism.

The primer activities were well received and the first primer option was chosen by both individuals who participated in the primer activity. One individual did not complete the primer exercise expressing the rational that they "lived autism every day of their life" and didn't require any priming to discuss ideas and experiences. Each interview was originally planned to be approximately 45 minutes in length but each of them was much longer than expected, the longest being nearly two hours in duration. The first interview was completely transcribed and reviewed by the researcher prior to any follow up interviews. Provisions were made to have as many as 3 follow up interviews with each of the individuals but only one follow up interview per individual was necessary. The second interview served to clarify any ideas that emerged from the initial interview that were not clear as to meaning to the researcher. Questions that arose from the transcription and preliminary analysis also influenced some of the questions that were asked during this interview.

All of the interviews were digitally recorded and transcribed by the researcher. The researcher had a large easel and paper that was rolled up and taken everywhere during the interview process and especially during the transcription and analysis steps of the research. This cumbersome method was used to journal thoughts, write ideas, and visually organize thoughts, ideas and theories. Formal analysis was first begun after the transcribed interviews were printed. The researcher would read and reread the transcripts and when thoughts and ideas came to mind they were written in the margins as impressions, thoughts and ideas to come back to at another time. This memoing was very useful in helping the researcher conceptualize certain ideas and find them again when further review was happening. Merriam (1998) suggests that memoing will allow the researcher to capture "reflections, tentative themes, hunches, ideas and things to pursue that are derived from this first set of data" (p. 161).

Data Analysis

The interviews for each participant were transcribed verbatim and then integrated into one narrative which gave a richly detailed account of each participant's experience of working with individuals with autism. The narratives were created in such a way as to follow the natural sequence of the interview with the participant with the exception of the clarifications that came later in the second interview. Each of the interviews ended with advice for anyone who would eventually read the study. Advice ranged from warnings to pleadings to those who work with individuals with autism. Each narrative is particularistic in that it focuses on each person's particular experience of working or caring for an individual with autism. Each narrative is also heuristic in that it illuminates the reader's understanding of the phenomenon being studied (Merriam, 1998).

Chapter Four is the presentation of the narratives which are supported by extensive notes to give the reader the context of the quote and to clarify ideas expressed. The participants were given opportunity to review the information in their narratives and make corrections if necessary. Once the narratives were approved the researcher proceeded with a more intensive interpretive analysis using the hermeneutic methodology described by Leonard (1989; 1994). In this Methodology all data were analyzed through the three interrelated processes of thematic analysis, identification of exemplars, and the search for paradigm cases.

Thematic analysis involves "the search for and identification of a common thread that extends throughout an entire interview or set of interviews" (Morse & Field, 1995, p. 139). Thematic analysis was accomplished through several important steps. In the first step, all the data from the transcripts, the narratives, the field notes and the journaling that were placed on the large easel and paper pad were read and reread as a whole to identify themes that consistently emerged from the data. Once the researcher identified themes of inquiry based on the themes that appeared to be emerging from the data, these themes of inquiry guided the systematic analysis of the data. Many times it was believed that the themes were identified and decided upon and then another thought or experience would create a new theme of inquiry to be tested. Due to the nature of the hermeneutic spiral it became necessary for the researcher to end this process and the findings became the general themes that formed the basis of the studies findings presented in Chapter Five.

The next stage of the analysis involved the identification or exemplars which were stories or vignettes that "capture the meaning in a situation in such a way that the meaning can then be recognized in another situation that might have a very different objective circumstance" (Leonard, 1994, p. 59). Exemplars were identified and organized on the large easel and also in a digital format so that they could be moved and grouped again and again as needed.

The researcher used both digital and easel paper methods of assigning the exemplars to the themes. A system was developed by which all of the common themes were positioned so that they could be viewed independently. Each narrative was then reviewed and vignettes that were suitable exemplars of each emerging theme were identified. These exemplars were then combined under this theme digitally and this new document became a work in progress as it was reviewed at different times in the interpretive process. Once all of the vignettes were chosen and applied to a particular theme the process of writing on that theme commenced. During this writing process it became evident that some exemplars fit better with others themes. Any exemplars that overlapped themes were reviewed again for appropriateness of fit. After the exemplars were determined for each of the theme groupings the final title of the theme was created. Efforts were made to have equal representation in all of the themes from the various participants but in some cases this could not happen.

The final stage of the interpretive analysis involved the development of paradigm cases. These paradigm cases are described by Leonard (1994) as "strong instances of particular patterns of meaning" (p.59). Paradigm cases are different from exemplars in that they "embody the rich descriptive information necessary for understanding how an individual's actions and understandings emerge from his or her situation context" (Leonard, 1994, p. 59). Exemplars illustrate the particular themes but paradigms cases are intended to serve as reference points to help foster the understanding of the particular cases (Leonard, 1994). The paradigm cases that described the individuals who participated in this research give an overall sense of how these individuals make sense of their experience with individuals with autism. The reader also gets insight into the particular social and emotional stressors that play a role in their perception of these individuals with autism and how they come to deepen in their insight of their needs.

Ethical Considerations

Prior to beginning this research an application for the approval of the study was submitted to the Ethics Review Board in the Department of Educational Psychology. Approval was granted with the following ethical considerations.

The researcher met with each potential participant prior to any interviews commencing and they were given both a verbal explanation of the research to be conducted and a written copy of the things that they would agree to. They were informed that they could withdraw at anytime from participation in the project and that their choices would be respected without hesitation or coercion. At this time they were informed of the expectation of one 45 minutes interview and three possible follow up meetings of approximately 10 minutes in duration. They were informed that they would have choice in the time and place of the interview so that it would not disrupt their schedules or be a burden on them in any way. It was at this time that they were informed that the interviews would be digitally recorded for analysis purposes and that the recordings would be kept confidential and stored in a secure format and then destroyed after a specified amount of time. Participants were also informed that due to the nature of sharing ones personal experience the potential for powerful feelings to emerge was expressed and they were informed that if they desired to meet with someone to discuss these feelings an appropriate referral would be provided to them. All of the participants agreed whole heartedly and each signed a copy of the information and consent form for their particular participation. (See Appendix A: Information and Consent Form for Personal Care Attendants, Appendix B: Information and Consent Form for Parents and Appendix C: Information and Consent Form for Teachers, to see copies of the consent forms). During the interviews the participants were informed each time that the digital recording mechanism was started and stopped and they were informed that they could ask that it be started or stopped at any time during the interview process.

Gaining Ethical Entry.

The process of getting the proposal for this research approved by the ethics committee was a task of considerable effort and consternation. The researcher will outline some of the difficulties that were encountered and how the original study was affected by the limitations that were imposed.

The original desire of the researcher was to have individuals with autism participate in and be part of the research process. A plan for observation was developed following the process outlined by Boostrom (1994). He shares a possible model of inquiry where he describes his observation experience through a number of interpretive stages. Stages include the researcher as a video camera, then as a playgoer, then as an evaluator. He then describes the progression of then becoming a subjective inquirer who then becomes an insider and member of the group and then finally fulfilling his role as a reflective interpreter. The intent of the research presented was to use a similar process and become a reflective interpreter while experiencing the way that individuals with autism express themselves and their needs.

The first difficulty faced was in helping the research ethics board members understand the unique qualities of qualitative research. The first ethics application was returned to the researcher with without having been sent to the ethics committee for review. The independent reviewer thought that there was no way that the researcher could collect and interpret data in an impartial way due to my involvement with the individuals identified to be participants. There were also questions about how the observations would be used as a data collection tool because there were no parameters identified as to how behaviors would be operationalized, and no checklists of behaviors to be studied were submitted. There was also a concern about the field notes. The reviewer was wondering who was involved in the collection of field notes and how would they be used as a form of data collection.

After numerous emails and meetings to discuss the qualitative method, understanding of the method was achieved. The problem that still remained was that the researcher's connection to the individuals with autism was viewed as being too direct making it difficult to be objective. It was determined to find an alternate research site from which to gather the data from participants who did not have a connection to the researcher in any way. This adjusted proposal was again submitted to the research ethics board and was tabled for discussion.

An unforeseen difficulty with the Research Ethics Committee became appearent in that the two individuals who sat on the board who best understood the qualitative process that the researcher was proposing were both part of my supervisory committee. Due to this connection to the research proposal they were required to recluse themselves. The committee struggled with the method and again asked that the proposal be sent to an independent individual who had experience working with autistic individuals to be evaluated. The evaluation was completed and it was determined that for an independent researcher to come into a situation where he would be uninvolved with the individuals with autism had too great a potential to cause disruption in their lives to allow the observations to proceed. It was then recommended that if the researcher had a connection to the individuals it may be a different and a less disrupting situation. This evaluation brought the ethics proposal full circle and it became obvious that tying to give voice to non-verbal individuals with autism through a qualitative observation technique was not going to proceed. The last statement made by the independent reviewer did offer hope in that he stated that the researcher didn't need to provide an argument to support the use of qualitative methodologies rather continue to focus on what this research could do for individuals with autism, their caregivers and guardians.

The proposal was rewritten with more of a focus on acquiring how caregivers of individuals with autism come to understand these individuals' needs. The opportunity to participate in observation was removed and the Ethics Review Board cleared the new proposal without hesitation nearly 8 months after the first submission.

Though frustrating as this process was for the researcher appreciation is given to those individuals who make efforts to protect the innocent and guard the ethical standards of the university. I do appreciate the extra care that was taken to protect individuals with autism from any potential disruptions and hardships regardless of the limitations it placed on the researcher and this study.

CHAPTER FOUR

The Narratives

Donna's Story: The experience of a caregiver

An Introduction to Donna

Donna came highly recommended to the interviewer by many of her peers as an individual who possessed a capacity to love and care that was astounding, an insight in relation to caring for those whom others could not care for that few have ever obtained. She had an attitude that exuded a desire for more people to understand the need to treat all people in and out of care with an equal measure of courtesy and respect. When I heard of such a person I could hardly wait to enter into conversation with her and try to learn of her experiences working with individuals with autism. I was not disappointed. The accolades I had heard were confirmed and I was duly impressed by the way in which she made me feel comfortable during the conversation process. We truly engaged in conversation that was purposeful and at times it was difficult to determine who was directing the interview. We shared ideas and thoughts that built upon our shared experiences in working with individuals with autism.

At the time of the interview Donna was in her early 40's and was the mother of four boys. Donna has been a caregiver most of her life beginning at a young age when she was required to care for her own siblings due to family dynamics. She learned how to care for those-in-need through hands on practice and to this day makes a point of caring for those in her community who stand in need. Her caring capacities led her to study at college and she became a licensed practical nurse. For many years she worked in hospitals and extended care facilities with a penchant for working with people in the last stages of life in palliative care. Palliative care is an area of nursing that takes a special ability to deal with weakness and failing abilities in people who were once very able and active. Approximately 10 years ago she began working as a caregiver/youth worker for children diagnosed with autism. Due to their violent behavior these children could no longer reside in their homes of origin and a group home was created to meet their specific needs. Donna first worked as a supervisor in the home and has worked for the past 8 years as the home manager. Part of her present duties are to train new staff in the philosophies of caring for children with autism and helping caregivers to deal with difficult and sometimes violent behavioral outbursts while maintaining a caring and respectful attitude.

Donna shared openly her ideas, beliefs and even tears as she discussed some of her experiences working with children with autism. Her experience was so entwined with stories of the individuals that she cared for that most of her experiences were shared in a retelling or experiential format. These experiences brought to light many of the realities of caring for individuals with autism and gave a true sense of how Donna understood their needs and desires.

Describing a Person with Autism

At the beginning of the conversation Donna was asked to describe an individual with autism to a person who had never encountered such an individual before.

> *Oh man... ummm. Well they are very highly capable of receptive language. So they receive what you say to them very highly. But whether they are able to take the information that you speak to them and transpose that in their own mind and follow through with that or understand and comprehend to the degree that they can follow through, that is a very individual thing for each of them, right. If they are verbal and they can reply back to them you may get some sense. If they are*

> *non-verbal then it's just a basic of discerning and reading their outward appearance and the body language that they display.*

When asked if a person could recognize an individual with autism by simply his non-verbal behaviors or actions she shared more details regarding what would be different or noticeable.

> *You would know that they are autistic from their body language. That is some of it. Their tendencies might be to a...flicking of the hands or the sounds vocally they may make that may be very unique for each individual. With one young man I work with it is very difficult for example when you take him on the bus, at first nobody would detect that he may have autism, right that's where we tend to have the most amount of difficulty when we take him, but once they can view him, you know it's the cocking of the head or the flicking of his head, you know the flicking of his hand up in the air or...or the sounds that he makes. They then begin to get an idea that he is autistic or that there is something wrong with him. He will repeat most of the time the language that he says back to you is a repetitive of what you have said to him. Although for this young man he is capable of qualifying a lot more since we have been working with him in his verbal language.*

Working on keeping verbal skills up seemed to be important for Donna but she also alluded to a deeper form of communication that she is aware of.

> *We are always trying to keep his verbal language up. He is more capable of repeating... giving a straight answer which is really odd in a lot of ways right with them (people with Autism). Like if you'll say "Good morning Jimmy"... "Hello Donna" you know he will say that now or ...and it is funny because we tuck him in bed at night and the staff will say "Good night Jimmy" and the other night when I tucked him in,... you know that he knows who you are but it is funny how he repeats it all through his head and then...until he gets to you almost, sometimes. Not all the time, he will repeat right as soon as you say "Good night Jimmy." Then he says "Good night Donna." Or he'll say "Good night Anna, good night Hariet" or "Good night Nathan." He said the other night (accentuated then laughing) It been a few months since Nathan's been at the house right. But pretty soon he goes "Good night Donna" and I say "That's the right one, good, good night." But I mean first thing in the morning, every morning when I am there at 6:00am he'll say... I'll say "good morning Jimmy." And he*

> *replies "Good morning Donna." I mean he says that and he knows and we can tell that, it is very interesting with Jimmy because they said that he would never be able to establish relationships in the paperwork that came with him.*

Donna takes pride in the fact that medication hasn't been necessary in the lives of the individuals that she works with. She realizes that it plays a role but works hard at keeping it minimized.

> *He would never establish a relationship. We have noticed a lot over the past nine years or a little less than nine years that he does and has developed, formed those relationships. Not only with the other clients we have in the home but also with the staff. And it is just amazing to me how...I mean we have been good at working on getting his medication down and he will be done at the end of this week, all of it. He will have no medication just a vitamin every day. And his doctor said really? He was just excited to see that he wouldn't need any medication. He has been fine. There haven't been any noticeable changes in his focus School hasn't noticed anything different in his behavior or otherwise, because you know, he has trouble with his focus right. And so that is what I would tell somebody their very capable of understanding what you say they may not be able to transpose that and repeat it back or follow through with what you say but with repetition and hand-over-hand help this person is capable of functioning to a degree with you.*

When discussing how a person with autism would react to a social situation, Donna described her experience of watching various individuals with autism each react in a way that is consistent with the diagnosis of autism but emphasizing that each individual had their own unique type of reaction to society.

> *Well first of all they would not right away associate with anybody who is there. They would remove themselves from that position until they feel comfortable. And it is interesting is to how well they feel trust and secure with the people they are with. Right? Because with a group of people with nobody that they know probably would pay very little attention to some degree. Depends on their functioning level, there again you have differences between two of the young men that I work with. The one would... I have three...the one would, the little one is quite social he would go right over right now and want to be part of them. But his diagnosis is not clearly autistic either. I mean they kind of thought that it was, autistic tendencies. But I don't think his is completely accurate I think his is more a*

> *developmental delay. Other than that he is capable of achieving. With the other two, I mean Jimmy his is a...he might be interested in something that another person is doing and just out of curiosity he would go over and see what it is all about but he would go and remove himself to where he felt comfortable and otherwise until he got hungry or something or there was really good music something would have to be the trigger to get him to participate in the socialization group. Shawn on the other hand he would be one who would just isolate himself completely until it was brought to him or he is asked to do something specific or something very rarely draws him. I know when we integrate him into our home which we have done now for nine years... so he knows all of our family very well. All of my boys have kind of grown up with him and are his age group, umm there was this one incidence of ...not to long ago it was Christmas time that was quite interesting to me. We were...he came and visited with us that night and he decided to stay out in the dinning room part of our kitchen but it is open to the family room area so you can see each other and he just sat on the chair tapping you know like he likes to do. And we as a family went down to start the process of doing the nativity scene where we read from the scriptures and sing a hymn. And we got part way through that and we were singing...it might have been Silent Night even but we were singing hymns together and all of a sudden Shawn decided he wanted to join us. He hops up and comes down and squishes into the middle of the sofa where everybody is and sits and starts doing his singing "ahhhha, ahhha," That's what he did and he chose to participate in that group with us. So often times when he is there in our home and we always sing together quite regularly as a family he loves to participate with us. If we sit as a family and sing every evening if I am working late we will come home and join them for scriptures and prayers and sing, we always sing a hymn. He loves that, he likes to participate in that.*

She describes how social opportunities can not be contrived you just have to let them happen naturally. If you try to force a social opportunity it will be met with frustration and refusal.

> *He chooses. He would not choose to... he would not choose himself necessarily. So you couldn't put him down and say "Shawn it is now singing time?"*
> *If you did he might just fight it or not even be interested. And he may choose to sit. If we are going to sing a song, you know, but he may choose but he definitely has his individual knowledge of what he would like to participate in and what he does not want to.*

When discussing how to find the balance between making someone do something for their own good and allowing people to have choices regardless of their disability, Donna shared her experience of coming to learn balance between what was necessary and what was socially appropriate.

> *Things like brush teeth, toileting, clean up after a bowel movement, safety on the street, these are absolutely necessary. But I think one of the biggest keys, and I guess this is where it comes to play with autistic children who are allowed to stay in their own home, if families are capable of functioning with their autistic children. That may be more of a key thing for them, because they would know their children from birth to what ever age. I think the key thing for us has been is that we have a home where they have been together now for nine years. And most of the key staff or the key working people that are with them have been there almost to the same length of time. And these children have been integrated basically into the homes and the functioning of these staff people. They have really allowed them to become part of their life. And I think because they have done that then they can actually perceive some of these things with these children before they happen. You get to know very clearly with Shawn for instance, um… let's say for instance, you're going to walk into a store you can almost guarantee, depending on the size of the store whether he is going to go through that door or not through that door without have strong verbal prompt or whether he will just be quietly happy to go in with you, right. And so you can start to discern something like that. You can discern that if you put scrambled eggs on his plate with no barbeque sauce and no mustard he will not eat those scrambled eggs, right.*

Again individual differences between persons with autism stood out as she described her experience of identifying these individual differences and helping them make choices for themselves.

> *If you put barbeque sauce or mustard or salad dressing on the table and say "which do you choose for your sauce?" He will choose and he will eat, right. But for Jimmy he requires no sauce and he is autistic he requires no sauce for his food. He loves to eat so eating for him is a pleasure, he enjoys that and he doesn't have to be coaxed to eat that. Milk is not his favorite so there might be some things that are a little bit not. But you just have to be aware of their food habits their food likes and dislikes and one thing that my staff have been learning or the staff have been really willing to do is to try and make it so that they would be happy with the food that there is. The things that they really like they know without a question that there would not be a problem when they cook those things right. And the variety of the staff that work with them, Japanese, East Indian, as far as the food wise capability of the hot food. Shawn, he really likes hot food,*

> *spicy. That's really been a plus. So I would say that the more you know them the easier it is perceive or discern what they going to do and how they are going to behave, right.*

Because communication can be very difficult there needs to be a different way to understand and comprehend a person with autism's needs and desires. Donna described this experience like that of knowing your own child and sensing what they want and what they need. She also explained how she shows a personal interest in their lives helping her to want the best for them.

> *As a person working with them you need to...you need to show that kind of interest in their life they discern that from you, right as a worker. I have noticed with staff that I have hired that are new, it depends on those that really take and interest and those that may not take the same kind of interest. I was speaking to someone the other day that if you start to determine how you would feel in their bodies you know when you work with them. How would you feel with what you are asking them to do or having them participate in if you were in their body or in their situation how would that make you feel. And if you start looking at how you would feel and you treat them that way it is amazing what transcribes with them what transforms between the two of you. I have had staff where you have some that are very...that know without a question that if you sing to Shawn, he is the older one, he just loves music. So if you sing to him you can almost get Shawn to do anything. We have a really problem with his finger nails. Those are one of those things that you've asked that have to be done. I have no question, I have scars on my arms actually that I will probably always have because his finger nails are like a dangerous weapon. Not that he meant to hurt me, all he did was grab me, but he squose and because he had long nails that's what injured me, right. And he will injure himself there are scares all on the back of his...he just has that tendency when he has anything that is upsetting him his hands will fly to his head and he will scratch his head and scratch the back of his neck and if he has long nails he will draw blood. There is no question unless staff can get to him and say "Hands down." So that is one thing that has to happen...so hands down and his nails have to be trimmed.*

Donna also expressed how one seemingly insignificant bad experience could have lasting consequence for a young man with autism. Not only would he react to future events with fear and even times violence but he did not seem to have an understanding of cause and effect. This caused him to reacts to any experience that was similar to the negative one from the past. Using data that she had collected over the years Donna was able to make assumptions about causes and gave her understanding as to why he reacted the way that he did to simple procedures that needed to be accomplished on a regular basis.

> *He hates it...he hates it. An interesting thing that has happened over the last little period of time, I have now after going back through my research of the books on him trying to figure out his behavior tendencies this last little while. It was a year and a half ago almost a year to July I believe this July that... because he used to hand us his hands and let us trim them even though he hated it. You would just keep repeating "hand me your hand, now the next one now the next one." But what he tends to do is jerk away. And one of the staff cut his fingernail and it left it hanging and he got to it before she could get to it and he ripped it. Because he ripped it, he ripped it right down to where it was hurting and bleeding and since that day he has been a fight to get his nails trimmed, right, a fight. I have literally had to put it in as a restrictive procedure so that I put him in a corner and I'm almost sitting on top of him, bracing him against the wall while protecting his arms as best as I can, hold his hands and trim them. And one staff sits and sings to him while that's happening. Or watch the other hand so that it doesn't hurt me. Well the last probably five times, so I do it about once every two weeks I've been trying now to make sure that I cut them about every two weeks. The last five times that I have done it, I've done this for a long time but it has been just this last five times, where he is starting to trust again. What we do is I sit him at the Kitchen table I put the clippers on the table I put too suckers or two kinds of candy on the table and then I say were going to cut nails Shawn. Now hand me your hand and as soon as we have this hand done you can have one of these suckers or candies. And he likes them but he does not like food to the degree that you can use it for him to do anything, because he will choose otherwise. And this is one thing that he really hates.*

For nail cutting Donna had developed a routine that she uses each time that she performs this procedure and was finding that over time and due to consistency this individual with autism was again beginning to trust.

> *So I put it there and I try to trim his nails but it is a continual verbal, like for the whole how long it takes you, which the first time took me over an hour where he actually let me sit at the table with him and let me do it and I didn't have to move him to the corner. I had to repeat, "If you do not let me cut your nails here we have to move to the corner because they have to be done." And he has been choosing lately to let me do them at the table it takes a lot of verbal prompting but he has been letting me do them. And I will give him the sucker in between. I can file his nails until the cows come home you know it doesn't matter I can file them no matter how long I want to file them. He doesn't have as big of a problem with that, it's the clippers. And I couldn't use scissors or anything like that because it would be far worse it would be so dangerous. It would injure someone seriously, him or the staff. I just couldn't, so, it was suggested once by staff but I just couldn't. So, then I switch and go to the other hand, right. But he has a long memory and still has to choose whether he is going to allow you to do that thing or not. And he has been better. He is at least sitting there and letting you and handing them to you and trying, right.*

When discussing what would happen to this young man if he were to be found without a caregiver that understood his routine and specific needs, Donna shared that it would be a terrible disaster. It would be difficult to the point that the young man and the people who tried to care for him may be at risk for their safety.

> *His nails would be five feet tall or they would have five men or more holding him down laying on him. Because literally the last time he went in, not this last time he went in for his teeth because we figured another way to trick him, poor guy, but um the time before that and he probably, and it was four years ago, so he would have been about 14 or 15 years old and it literally took five of the hospital staff to hold that young man down on the floor to give him the mask...the anesthetic enough to put him out to put him on the bed and put him to sleep.*

When asked if she thought that this last hospital experience was traumatic for this young man she shared how difficult it had been to get him to return and even visit a hospital. Donna also described her endless efforts to decrease these anxiety causing moments for this young man by taking hours and hours to desensitize him to what she knows would be an uncomfortable yet necessary event.

> *Traumatic! I mean he does not forget a hospital. Even to this day if you take him to a hospital you can be guaranteed that it will be one of those things where he will have to be forced to go. We had an incident just recently with he was going to go for his pre-check-up with the doctor before he could go in for surgery because it had been so long she wanted him checked thoroughly over she told me that "I want to check his heart with the stethoscope and I would like to check his ears." I said "good luck." (Laughing) And of course the office…I asked them where they were going to put us I said if it could be bigger, it would be better if it was a larger room because it gives you a little more than a tiny room. And what I had done pre-ahead of time, the week before I took everybody I took this young man plus the other two and the other staff and we all went to the clinic as a visit. He knows it is a clinic and he is already weary but you know we have been singing and priming him for this and we are going to go and visit the office and that it is OK and their not going to do anything to you we are just going to visit. Well he walked in and he wasn't super happy and I had him sit down on the chair and just sit there for a bit and he calmed down and he could see that the other guys and all of us were sitting there and so he was perfectly happy. One of the nursing staff at the clinic came up and said hi to him and met him and he seemed to be ok. And then I told him I need to go to the bathroom because it didn't matter if he needed to go to the bathroom. And I had him come to the back area where the tiny little rooms are where they have a bathroom. Just so that he would move a little further than the front area. So I took him in back there and he actually let me wash my hands in the sink because that is all I wanted to do was wash my hands. He stood outside the door but I washed my hands. I wasn't making him go in anywhere. Well it was the next week that I had to take him right, and they didn't have a bigger room available they had a smaller room. And his guardian was with me and my self we walked in and he walked in perfectly fine, they were prepared but walked in right back to the tiny little room and as soon as he realized that he was going to have to go in there it was not a happy camper. Of course they wanted to move him then to a bigger room and I said no you have already asked him to go into this one. And I think that is one thing that is very particular. If you are asking him or them and autistic person to do a real tough thing you need to follow through with that tough thing. Because otherwise you, if you let up at all they do not comprehend or understand and it becomes a worse fight.*

Donna put herself into a mode where she tried to understand what his experience was so that she could extrapolate what it might have been like for him to be going through this experience. She used this as the basis of how she made decisions concerning how to care for him and calm him in a time of crisis.

> *It gets worse. To have moved him from the smaller room to a larger room then would have even been, to me a more traumatic thing for him, right. Because then it puts him into even more concern. "What are they going to do to me now?" Right, they have moved me from where they forced me to try and go into to a bigger room, now what is going to happen to me? He has no clue so to put him right in and then calm him down and explain...and I let him touch the stethoscope. Letting them touch and feel is very good. You know letting them actually feel hands on as to what you are and just really explain everything to the key, to the key points right. It makes a difference. But he went in the doctor was unable to get the stethoscope completely to his heart he would not even allow me to place it even though he would let me take his hand and place it on the stethoscope he would not allow me to place the stethoscope on him.*

When asked about her experience of seeing this young man held down for a medical procedure she discussed what it was like for her to watch him react to the situation that he didn't understand.

> *Personally I would prefer to not have to hold him down for anything. When it comes to his nails I think that is something that has to be done, has to, has to, right. The stethoscope if they got him to sleep which they did, they gave him a...this last time at the hospital they actually gave him a drug. They used Ketamine. And it just took him down really quick. And because I know him so well you could see that he was really worried as to what was happening to him. He did not comprehend. Even when he was drugged he did not comprehend and understand he does not like to be out of control at all, right. He likes to be in control and that is really hard for him to be out of control. He has to have control. I don't know where that stems from for him. I know he went through difficult times when he was a young boy in his family associations.*

Donna stated that this type of reaction was not typical of an individual with autism. Reactions to different situation seem to be determined by the autistic individual's experiences in the past rather than being a set of autistic behaviors.

> *It tends to be just him. Ah...Jimmy is fine, you know to take him to the doctors he walks in and he is perfectly happy, you give him a popsicle and he is perfectly happy he lets you put the mask on him. I mean you let him touch it and feel it and you know giving him an awareness of what is going to happen to him or explaining to him is better for him. I don't know if it is just the...and maybe that is the key too is to look at the different traumatic backgrounds of these people,*

> *where they have come from how they have been treated. And then go from there as to how you deal with them and realize that you may have a few more difficulties with trust issues with them.*

Donna was asked how she would know if one of the individuals she works with didn't want to do something that she was requiring of them. She responded by telling her experience of working with a young man in her care who couldn't express himself verbally but was able to express himself clearly in non-verbal ways.

> *He will actually strike out. For instance, in the morning time he has quite a rushed period of time to getting on the bus, right. He gets on at 7:00am. He is up at 6:30am. That's not a real long time to wake up especially if he hasn't settled down at night time really early. That's the other thing for Jimmy that is hard, is to go to sleep. His body is just a bouncy flouncy little tiger. He just moves moves, moves, moves, moves. He has more energy than you can even imagine. I don't know if he will ever slow down. Shawn used to be like that he would just walk 3 hours you could go 3 hours straight one way take a 5 minute breather and then go three hours back the other way he was like that. But now he has slowed a lot down now that he has gotten a little bit older. But Jimmy I am telling you he could run for ever. Like, he could move forever. Just do everything forever. So that period of time when he is trying to settle down and lay down he just doesn't drop off to sleep so when he wakes up he is a little bit tired-er. Now with him being taken off all of his drugs...I don't know that the respirdol did too very much I mean it might have had some calming effect, but he was on such a low dose...that's one of the reasons the doctor decided to remove it. There wasn't really enough for his body size for how old her is now to be doing anything. So take it off and see how he does without it. So it is just a matter of getting him to learn how to focus on relaxing for night time. To slow down that mind that goes a hundred miles and hour. But when he gets up in the morning and you see him down at the table and he has to have something for breakfast. At least we try something. And he loves to eat most of the time but if he is still really tired it's that slow going process to get him moving, right. For instance I have found that if I get him to help me do something...he may not want to particularly want to help me because he is still feeling that tired groggyish feeling. And I will say "ok now Jimmy help me take the garbage out. And if I get him out on to the step where it is fresh air which livens him up a little he will come back to himself and seems to be ready to eat. So I can help him to do that. But there is times when you put something down in front of him to eat in the morning that early and he will be unhappy and he will either hit himself or...he'll just slap at himself, you know angry...ouf...and he will make an ouf sound like a I don't know how do you say that in words...a vocal ... not a word of any kind but a vocal acknowledgment that*

> *I am not happy about this like ouf. And then you just have to talk him through the process. Jimmy I know that it is early and your tired I know that you are not feeling very happy about having to eat this right now but it is time to go to…and he will say "school" yes time to go to school and you got to go to school on, and he will say "the bus." On the bus you are going to school on the bus so you need to eat something so that you are not hungry. Usually with some coaxing you can get him into it or it into him.*

Donna has searched for balance between letting an individual with autism be free to make choices for him or her self but had come to the realization that some things just needed to be decided for them regardless of their immediate desires. She stressed some of the common problems that she dealt with working with different systems that take responsibility for individuals who need daily care. Also, she shared how difficult it was to give them choice when they do not regularly express their needs or express them in a way that was easily comprehendible.

> *If you didn't make him eat his breakfast he just would not eat it, not in the morning he would probably not eat it in the morning so he would go from 7:00am until 11:30-11:45am or noon before they would feed him in the school system being that they…and then if you put him in the school system and say: "Oh well just leave him he never ate anything that day." Then you have however many children that they have already in the classroom and your going to have sporadic breakfast times? That starts to play into some of the key issues, no one is going to accommodate. He would probably try and find something I would think. He would say "I want a cookie."(Laughing)… Cookies are his favorite; he would go to someone and say "I want a cookie." He won't say I am hungry, he would ask probably for something. You know and there are only a few things that he ever really asks for. You know unless you say…prompt him you could say: "what would you like for supper tonight?" And he may say: "pizza." Or he may say: "I want a drink." "What would you like a drink of Jimmy?" and he would say: "Juice." Or "water." He will ask for water, he will request water. So there are things that he will request but he would probably not go up to a teacher and say: "I am hungry; I didn't have breakfast I need something to eat." He would not do that he would just go ahead with whatever the school day was and do whatever until they said: "Ok its lunchtime go get your bags." Or "come and make your sandwiches."*

When discussing what would happen if the individuals with autism were allowed to make all of their own decisions and not have any supervisory influence, she stated that complete chaos would ensue. Staff would no longer remain and over a short period of time the individuals would be in a situation that could become life threatening without someone to make vital decisions for them.

> *My staff would leave!! (loud laughing) They would just quit working. Partially because they could not go to the kitchen cupboard, well I can't say that they could go to the kitchen cupboard and scrounge for maybe the chips and cookies and things like that. They would probably even eat the straight macaroni or you know thing like that they just...right. They would go to the fridge and clean that out of everything that they thought was ingestible whether it was or it wasn't. That is what they would do. They would never cook for themselves they would never request could you make me breakfast will you make me lunch will you make me supper. They would never ask for a meal, they have never asked for a meal. They will ask please. If they go to the cupboard, because I have some of them that will go to the cupboard, pull out the chip bucket and say please. (Using sign language). So they may request simple things like that. They would never brush their teeth, they would never wash the dishes, they would never vacuum or clean, they would never...the one is actually still in a pull-up he would never take care of himself completely that way, they would never bath, never brush their teeth, If they had a BM (bowel movement) it would never be cleaned up so they would be filthy from head to foot, uncared for and unsafe because...because all they would have to do without anybody saying stop you can not go outside without me, they would be outside in the yard, across the street and in the road. And if I just let them go wherever they wanted...same thing with the boys when we take them out on outings I still have them hold on to my elbows while they cross busy road ways.*

Donna shares an example of how dangerous it could be for an individual with autism with the following experience that she dealt with regarding an individual that wanted to make a choice that was not safe for him or others.

> *We had an incident not to long ago with one of the staff who was a little bit newer but luckily they were right on top of things. They were taking the boys for a walk and Shaun who is the older one who has a tendency when he gets a bee in his bonnet he goes for it. And that is what makes him a little bit dangerous because he has no clue at all about safety, at all. And Um... he doesn't like to be hurt but*

> *he has no clue at all about safety. She was walking on the sidewalk that goes past a main road and there was traffic going back and forth very steadily and there happened to be a McDonalds on the other side. He was determined he was going to go to McDonalds. And he was just going to go! He would have just walked across that highway and he would have been killed there is no question. He would not have waited. She had to sit him down and she literally could not hold him enough that she had to call another staff member and say could you please come and help me because she could not get him to change his frame of mind and go back the other direction or change the direction. Lots of times you can get them to change their ideas but it really does go with knowing how to...if you know them and if you can perceive that there is going to be a problem and how to do safety issues. Now I went and talked with this staff member and I walked through the situation, the scenario again and I asked her that if she had taken a hold of his hand, just taken a hold of his hand and tucked his arm under her arm and held his hand with fingers clasped if she could have just held him in a different direction and moved him off out onto another way and she said that might have been a possibility. And of course the problem had come was that he had already dropped to the ground and he is a large 6 foot man and she could not move him at that point.*

Donna wanted to clarify that going to McDonalds wasn't the problem. The problem was that it was necessary to restrain this individual with autism because his desire to go to McDonalds without a safe route was the issue.

> *No, she (the worker) could have easily walked him across the sidewalk and taken him for a treat that is not the problem; it was the safety factor that he was just going. And she had to grab him and sit him, he just dropped. He just would not, wouldn't change directions.*

Donna was asked about her experience of finding balance between allowing individual choice yet at the same time providing direction to an individual who could not make safe choices for him or herself. She discussed some of the difficulties of trying to make guidelines for individuals with autism. Due to the complexity and individuality of each person this could be a very daunting task even for persons with the same disability.

> *Oh, man…well I believe that if there is going to…if someone is going to have to make a rule, whether it is the government agency that comes in and is able to understand how the staff work with them, there has got to be…hopefully the key person in that home working with those youth could have some say in how things have been run and where they have allowed the issue to be safety wise or to allow them to have what they wanted. Because, personally if Shawn came home and wanted to eat just salsa and chips he would just eat salsa and chips all night there would never be anything ever healthy. He may only choose to eat that thing every single day of his life, right. And that is all he wants right, and that's a possibility for him, that and sausage and whatever else, raw or otherwise. So I would like to see that there is some way that we could come to a conclusion together as to how, individually, very individualistic wise how to take care of the needs and their wants, right. Establish what is a need of safety and what is a need of want that they can. The same with their personal care one is very capable with verbal prompt to do 90% of his personal care. If he had an accident with diarrhea which I think is very normal when you work with them that if he had something go with being sick with the flu, vomiting or diarrhea you would have to clean that up as a staff. He is not capable of cleaning himself up to that degree, right, that he could be healthy or that the people around him could be healthy. The same as with if they injured themselves…one boy for instance he has bloody noses on a regular basis, his nose gets dry and it bleeds so there is blood everywhere. He would not be able to clean up that blood. You can't have that blood lying around everywhere where everybody else, staff and the other children otherwise, right. For someone to come in and just say, Ok they are all going to take care of themselves in there personal care, you are not going to be able to touch them and help them would not work, right. One young man just refuses, we try, we try hand-over-hand coaxing all the time and we go through a routine and we have worked out a specific routine just personally for him in regards to, you know, how to go through a day time. And we work on that continually. We've continually worked on that in nine years. We see little bits of improvement where he will now actually take the deodorant out of the drawer and he will put it on like I can verbally say "put it on" and he will put it on. Not that he will get it in the right spot but he will get it on. If he is close I leave it, no problem but if he is getting it to close to other parts that doesn't need it then I will move his hand out of the way. But I mean that is a good step.*

It is clear to Donna that some choices would have to be made for these individuals and that they may never improve in their abilities to become independent over time.

> *His teeth brushing, he would never walk to that bathroom and grab the toothbrush and actually brush his teeth. You can prompt him to go up and say "get your toothbrush, take out the toothpaste." Then hand-over-hand help him*

> *to put toothpaste on or he will eat the whole tube. See there you go another thing, right he would eat a whole tube of toothpaste, how healthy is that? He would, he would eat it there's no question the one boy would have no problem with that. He walks down the road and he picks up gum, pills, and whatever is laying around and pop them in thinking whatever, candy or whatever it is something to eat. So for his safety issues allowing him to pick up stuff and just pop it in his mouth we have not allowed him to do that. Where as some say that that is a personal right for them but it isn't a personal right as far as this young mans safety goes, because he can not differentiate between medication and candy. Or something like a poison berry on a tree just walking through a park or a strawberry off of a vine which would be normal for them to eat.*

One of the issues that Donna struggled with was watching how others dealt with individuals with autism. She understands the frustrations involved with caring for individuals in care but she shared her fears about what happens to individuals who are cared for in a non-regulated environment such as in the care of their own families. When discussing the reality that at times some parents use corporal punishment to manage their children's socially inappropriate behaviors Donna shared her own experience of having to deal with a guardian who felt that this type of behavior was appropriate.

> *That disturbs me completely, because I believe that there are other ways to deal with it, right. You can be kind and still deal with it. I don't know if you want to record this but I had that exact thing happen the other night. A guardian was visiting and one young man had had an issue at school that day in regards to that. They let him run over to the garbage can and he just picks up whatever and just pops it in his mouth whether it is gum or whatever it is that he thinks is interesting right. And this guardian said: "You know I would just never allow that I would just slap you, I would slap you, just try it and I will slap you now and show you, I would slap you." So that just made me really uncomfortable because I know personally dealing with him that you don't have to be mean or abusive, right. You know, in the process of harming themselves for instance with his fingernails there is some restrictiveness to it right. Which could look like you are trying to be abusive because you are actually having to hold a limb while you sit on him and are doing something. But you are not trying to use anymore of a degree of force than what is capable of keeping everyone safe, right. Whereas a parent is at the park and the child picks up a smarty and the parent cuffs him, to me that is abuse and against the child's rights. Of course. I can see how this happens in a normal functioning family. And maybe…I do think that…to me the ideal situation is the*

> *group home that I provide and that I work in. That is the ideal situation dealing with these young men with autism. I can not think of anymore blessed boys than they are. Because for one thing, they still have contact with their guardian but you have removed the frustration and the degree of frustration to the point that you feel that abuse is the only way that you can deal with it. And to me that is probably what happens in these homes is that the family gets just exhausted. They are there 24/7 and they are dealing with this young man or young lady 24 hours a day, right, with no help. And even with the information that can be taught to them it takes patience to deal with that. You have to have a patient, quiet, happy moment lots of times for these young people who have autism to even trust you enough to even try these things that you are dealing with, right. So I can see how in a family situation that just gets so frustrating.*

Donna shared her feelings concerning finding someone who cared enough for the individual with autism that they would make decisions for them that were in their best interest. Due to the nature of autism the requirements on families could be overwhelming causing them to be overburdened and even become burned out making it impossible for them to make healthy choices for their children or young adults. It was apparent to her that funding to keep these individuals in their homes of origin just wasn't feasible or at least at present not a reality.

> *Families can be overwhelmed and overrun by the demands to do that (caring for autistic individuals) thus causing them to live in a way that they would rather not live, right, the families, the parents. It is an almost what do you do situation. They need to be cared for 24 hours a day, night time too. It would depend on the behaviors of the individual, right? You could take for instance even in my home the things that I have dealt with we have two that sleep perfectly fine through the night without behavior problems. You could wake up to one having picked his nose and there is blood everywhere because he does just when it gets dry he doesn't do it as an abusive tendency, right. But the one young man he can poop his pants in the middle of the night just out of shear funny business, right that is a goofy thing for him. BM...Feces is a real happy thing for him, I guess, you know, he just loves that, so he uses that. You know it is interesting thing you know as I have calculated that over a period of time, he doesn't necessarily use it to particularly irritate anybody. He just...he just likes it and does it and it's getting him to realize that he can not do that kind of thing. But if you where dealing with a family who had support staff maybe through the day and then at night time you*

> *didn't have support staff they are going to still be tired having to deal... having dealt with this individual, lets say that have those behavior tendencies in the night that they don't sleep and you are going to either use drugs or you are going to have to have the support staff do a 24 hour period of time. If you had someone to come in who had the patience, knowledge and capability of showing the parents how you could deal with the individual in a non-abusive manner I think that there could be a lot of happy support in that sense. They would have to have respite of some sort where that individual was removed from the home at some point right and put into a spot where they could be taken care of and the parents and the family would have a break.*

When discussing the realities of parents and caregivers getting old and becoming unable to care for their individuals with autism, Donna was asked if she thought that individuals with autism could ever progress to the point that they could become independent of their families prior to this natural separation.

> *No. Now I do know that autism is very varied right so you have some that are functioning quite well on their own at a quite a high level. The exciting thing is the younger you catch them to be able to give them the chance to develop those things, everyday living skills that we all have, the greater chance that you will have in having that individual function on their own to a degree and a greater degree in the future. So that has made a big difference you can see that already in some of the young children that I see. But if they are already established at a certain age, anyone like 8 years old... this one young man was 8 years old when I began dealing with him. He is pretty well the same young man that he was then except for he has become less abusive to you, right. He does not physically hit you all of the time. He might every once in a while whop you one but he does not bite anymore he does not hit anymore like he used to and he is learning to actually listen to what you say as you explain it and make a choice in some degree. But he still may choose not to, you know in that process. And so his safety is still a concern even until now. And he will still be the same as he is now as he will be when he is 45. I do not see a great change for him. Just anything that we can keep that he is capable of now is a positive.*

When faced with the realities and difficulties that these individuals will face one day, Donna became quite emotional discussing her feelings about what would happen when these individuals that she cares for must move on to another living environment with different caregivers. Due to the reality that they will most likely out live those that know them the best, it would be necessary to make a transition to another caregiver one day. Donna hoped that the information that has been compiled for these individuals would be considered carefully so that it would minimize the negative effects on them during this transition time. Trust would be a necessary component to make this transition successful.

> *Well I think that if the information was there and the person coming in took the information seriously and would actually act upon what had been said and had been advised on how to deal with this young man it is possible that positive things would come about quickly because he would judge his trust level on the familiar things that he has had before. I have often thought what would happen if we were all of a sudden just determined out of his life. It would be very (tearing) sad for him... (Quiet weeping for 10 seconds)...I believe that these individuals are capable of love and trust. (Voice still trembling) And a...I believe that if they are treated with that respect that they are capable of adjusting to a certain degree. I think where we get into the problem and the problem that I foresee for these young men is that you take them from a child situation where you have to teach them to develop and to learn some things that may be just some daily living skills which would make them more capable with dealing with life or more capable on a day to day basis. And they go from that child level and all of a sudden they are an adult and you want to remove them from where they have been and been comfortable and possibly trusting the staff that are there with them to all of a sudden in a whole new environment with people who do not have the same kind of awareness or discernment to their behaviors, their tendencies, their wants, their dislikes and I think that you put them in a position that they regress. And they will regress to the degree that could put them in a real serious problem. For this one young man for instance I thought about that if he was removed and put into another total whole home with total new staff and no one who has known what his likes and dislikes are I can almost guarantee that they would number one up his medication to where he could not even function. He is now presently on a little but of...he is still on a very minor dose of medication with us. And the other young man that was with us came to us... he came from a foster home that had...she was a very busy lady, she had two very young ones, she had a quadriplegic that was a feed tube and then she had this bouncy flouncy little tigger with just energy to the degree that it was unreal, right. And because she was in that situation she could not give him the attention so he had a tendency to BM smear and that is how he would act out against being stuck doing nothing. He would BM smear and he would pick his nose and make it bleed and smear blood...um he just had a lot of behaviors and very self abusive behaviors to himself, very aggressive to himself.*

> *And when he came to us, because we had the opportunity to work with him and there's a number of staff, it wasn't just one person who was really busy, we had more time with him. We have not seen the BM smearing, maybe once out of the whole six years that he has been here. We have seen none of that, right and he has been able to go on walks and he gets food that he really enjoys and you know that he likes and he enjoys that and he gets the affection he really…he has a behavior that he likes. He is very sensitive, his skin is very sensitive, he likes…he loves to get butterfly kisses and of course it is not always appropriate in the public school to go up to somebody and want them to give you a butterfly kiss, right. He gets pretty close and personal. So we as staff have had to not do butterfly kisses with him anymore when he was little it wasn't so much a big deal. This is the hard thing, right because they don't quite understand or comprehend what has changed. You can't all of a sudden cut out the affection for that young man, right. And so now we ask him "would you like a hug?" and he will say "Yes." So then we will hug him appropriately, or um…we'll kiss him on the cheek, you know "would you like a kiss on the cheek?" And you will ask him and you will give them. You know he can be sitting still and you can just rub his hand and his little arm or play little hand games with him and he loves that, he loves that touching, he loves to cuddle you know he does that. So his is a very individual thing right. But you take this young man this older one that I was talking about and remove him to another home where no one knew him, meds would be the first thing that would be upped to the degree that he would not, no longer function. Because he is very capable of being abusive right to the degree that he could really hurt someone or somebody. But without them having any idea how to deal with him or be aware of what his triggers are they would really throw him into a tizzy. Because they would want him to eat this and he wouldn't eat this. He would probably go hungry for I don't know how long. Because the have no idea how to deal with his food or how we get him to eat. He would not brush his teeth; he would not bath for them he would poop on them. He would be a mess, he would be a mess. And that is what they are dealing with. One great big huge psychotic mess, because that is what it would look like to this other staff. "He is a psychotic basket case what are we going to do with him?" Now at his age he is a huge man. "We can't deal with him like this." And that is how they would do it.*

The age of 18 seems to be a very important age in our society. It is at this age that an individual is considered an adult and has more freedoms and privileges. Donna expressed some frustration with the social expectations that were placed on individuals with autism once they reached the age of majority. To her, these individuals continued to be and always would be children in understanding and social capacity.

> *They are very much the same child that you have just started with. To them they do not change. See personally I don't see anything wrong with those butterfly kisses but because we take him out into community and he just walks up to any old man or any old lady and decides that he is going to want a butterfly kiss from them…I mean his cheek is cheek to cheek with theirs right. That is where it becomes socially inappropriate, right. So that is how society views it.*

Donna shared that the people who have worked with these individuals with autism truly have become family and sometimes the only family that they may have due to the differences in backgrounds and family composition.

> *That's right. Another thing as an adult is that working with the staff that he has been with; they have been truly his family. With no family, he has no family that is involved with him at all. So no one comes to see him, no one takes him out, we are his family. He participates with our families with the staff and that is the only family that he has ever known. The only place that he will have ever gotten a hug from that is the only place that he will have every heard the words "good job that is super." "Stack me those blocks and make me a tower, can you do that?" No other place he would have had those things. There would have been no other place where he would have been taught to sled down and hill or rollerblade and he is capable of doing those things. Some others are not capable of doing them but they are capable of trying some of those things. We try. One boy likes his sled, he will slide down a hill. He will choose after a while to not if he doesn't want to. He doesn't mind sledding down the hill. So it is trying all of those things and seeing how they respond and then determining whether it is a pertinent thing for them to have to do or a thing that it is just nice if they would like to do that kind of thing. But with the whole age thing they do not change from that. There will never be a time on one of the boys life that he will say "please don't hug me." "Don't come near me." "Don't hug me I don't want you near me, don't even come near me." And I have seen that in the whole 8 years that he has been with me he has never not wanted that affection or that participation with you. You know having fun and laughing, singing or playing games with you, you know. It is very interesting to sit with him. At Christmas time he was given a Whack-a-Mole toy where you take a stick and you whack it, you know and he loves to have you sit there with him and he will do it. You know you have to help him focus using verbal prompts. "Ok focus." But he is capable but he would never necessarily…I can't say he would never go get it, but he would never play with it, play with the toy without some supervision in the way the toy is mean to be played. He will just bash them and not necessarily specifically. But he is capable of learning to do it the specific right way, right.*

When asked about what she feels would be most helpful in helping others understand and determine the needs of individuals with autism she discussed the need to focus on maintaining individuality and being cautious of over regulation in what were and were not appropriate activities for these individuals with autism.

> *There has to be a way that society can help these people these individuals keep their identity individualistic to who they are. Without taking them and saying and demanding that they live under the same regulated rules. That we have to be able to work key-to-key in how to deal individually with their behaviors with their wants and desires and what they are capable of and how they are capable of functioning. To put them in a situation where they would be all lumped gumped together like in an institution for instance then they have lost every of having a change of having the same kind of pleasures that you and I as adults have. Where I can ask you for a fudgesicle and get one. But because I know that they want a fudgesicle I can give them one (voice wavering with emotion) because I know they like those. So we have got to get to a point where we can do that together, where we can work together and compile this information individually so that we can help these people function where they are capable of functioning. Instead of pegging them all as since an autistic person is capable of this then all autistic persons are capable of this. They just are not all capable of the same things. But they are capable of things it is just finding out what they are capable themselves individually of doing.*

Brian's Story: The experience of a parent

An Introduction to Brian

Brian was recommended to me by his peers who saw him as one who was tireless in helping individuals and families understand their abilities to deal with life events such as having a child with a disability. He had worked numerous hours making sure that his son, who was born with autism, had access to all programming that was available to him in the community in which they lived and he was often seen by others with his son participating in social and community events. His son's ability to participate fully in the community had always been and continued to be a focus of Brian's life. He expressed a desire for his son to be seen as normal in and by society. He understood that his son had some limits but he regarded them as temporary obstacles that could either be removed by changing society's expectations or overcome by training social skills into his son.

Brian was in his fifties and had worked for the Canadian Armed Forces all of his working life. He was married and he and his wife had three sons. Their oldest son was diagnosed with Autism while they were posted in the military to Germany. Brian and his wife have devoted their lives to caring for and preparing their son to participate in the community by putting in at times 16 hours a day of care and training. Due to the nature of military service they have been required over the years to move to various different locations throughout the world and have faced particular challenges at each of the placements. They had also become experts at learning how to contact and contract the services for their son and family that were available for them in the various countries and communities that they have lived and worked in. They have used their expertise to help other families access resources for their children with disabilities and are regarded as experts in their community.

It was a unique interview experience with Brian. We began by discussing the purpose of the primer that I had requested him to complete prior to the interview. He felt that it was unnecessary and wanted to begin directly by telling me his story. It wasn't that he didn't think the primer to be appropriate, he just felt that he was always living and thinking in the mode in which his son and his sons disability were always on his mind and in his thoughts. We began the taping of the interview and stopped it a number of times at Brian's request so that he could clarify the purpose and breadth of information that I wanted. At first our conversation was very practical and focused on the medical nature of dealing with autism. At length our conversation began to delve more specifically on his experience of raising and working with his child with autism and how he had come to understand his son's needs and desires.

To begin the dialogue, Brian shared how he and his wife first reacted to finding out that their son had autism and gave a history of the process that they went through.

> *How we found out was a... we had all the baby books; everybody... parents have those books which have a chart of child development. Our son was a bit behind... a little behind at the beginning. When we found out was when we were sent on a course to Canada, we were in Germany at the time, of course everything always happens when you are away from home. Our son started to hit himself. That started at about 24 months of age. Very young and since we were at a Canadian base we had to be evaluated at an American base. We had to wrap our son's hands with bandages and gauze so that he wouldn't damage his eyes further, he had black eyes. It was fun going public with our son in Germany, it was lucky we didn't get beat up by the people. They don't hold to child abuse over there. It wasn't abuse but they didn't have any way to know that. Once they saw the bandages they would figure out there was something going on.*

When they were referred to the psychiatrist they were surprised and shocked by the recommendations that they were given and this experience was the beginning of their advocating for their son and his needs.

> *The Psychiatrist in Germany told us that our son was so bad off that we would be better to put him in an institution and leave him there. I don't think he had ever seen a kid at 2 years and a half hit himself, abusing himself as hard as he can. That was kind of a shock.*

After their experience in Germany they had an opportunity to return to Canada and that is when they began to gain most of their training and information about autism.

> *The rest of it well, we began to learn information about autism, but we are talking 1980 there was very little information about autism in 1980. We got back to Canada and lucky for us I had a choice between Halifax, Toronto, and Ottawa So I have family in the Ottawa area so I chose Ottawa. Ontario at the time, I believe was way ahead of everybody in Canada at the time in mental health. We got back to Canada and our son was 3 years and a half... four years because I got back into Canada in the spring of 1984.*

Behavioral programming seemed to be the most effective way for them to work with their son and this was the training that they received from the government at the time.

> *I had ordered a helmet when I was in Germany with a cage so that every time he would hit himself he hit his little knuckles on it and he would go "Ow" then he would stop. He would do that about every 2 to 3 minutes. It was fun going around with a kid in a hockey helmet. He was four when we got back to Canada. We couldn't start doing anything with him until that summer which would make him four. At that time he couldn't dress himself, he couldn't speak, he could point to the milk in the refrigerator, which was as far as he could go. So by the time he was 5 he could dress, he could talk, a year later he could ride his bike. It took 16 hours a day of therapy. This is was the Ontario Government did for us. They gave us an 80 hour course on charting, identification and charting and changing behavior. It was a behavioral management course. And when we went through*

> *this we found everything that was really stopping him from learning. And slowly we would use rewards to change his behavior. Since he was so far gone we had to cut the Smarties into little 8ths, that was a big chore right there. ...laughing... cutting those Smarties in 8ths, and to stop him from hitting we would have to sit with him and hold his hands and extend the time of not hitting by rewarding him with little Smarties and that is how we got him to stop hitting himself And that's pretty well it for 2 or 3 years, those interventions are what did it.*

These behavioral therapies were seen as very effective but very time consuming for Brian and his wife. It was also difficult to make a comfortable living because of the demands on their time as parents to implement these programs with their son. They had workers assisting them during the day but their time was limited.

> *Oh ya. Exellent. Oh ya oh ya...Because we were, we could, my wife and I, spend 16 hours a day and we had workers. We had a worker everyday 5 days a week, 4 hours everyday and that was our break. Other than that we had to do that and this was actually breaking technology at that time in Ontario. I was working two jobs. In Ottawa you need two jobs to live.*

When discussing how difficult this might have been on the family Brian discussed the realities of his situation and that he also had other children that needed his time and attention. It seemed though that the majority of his time was spent helping his son overcome his developmental delays.

> *Well we had other children but somebody had to teach him how to swim and ride a bike. When I got here in 1989 our son was nine years old. And he took about 6 months and then he could swim and jump off dive boards and stuff like that. So he's been improving ever since.*

When asked if there was ever a time that he encountered a situation in which he didn't understand what his son wanted or had difficulty understanding what he wanted or desired he responded in the following way.

> *There was no way. The only thing he would tell us was for milk. He would point. And that was when he was over three years old. So since we had another child close to his age he ate when the other child ate we made sure that he did the same things. And he followed his younger brother in school as well. I think he skipped Kindergarten I'm not sure but he did start first grade with his brother. And he went through 12th grade… with a teacher's aid. He is able to read and write now, count, do math, a little bit of math.*

When asked how he now knew what his son's needs were he relied heavily on the necessity of teaching his son to function in society as opposed to simply understanding what they wanted. Understanding their desires for society is based on how they can be trained according to their individual needs to be part of society.

> *In society? You don't. Each one goes on needs and how he expresses his needs is more like a young child. That's all you go by. And they (government programs and school) teach him now to express themselves what they want and what they don't want and what they like and what they don't like as well, and pretty good at saying so. What he wants to do and what he doesn't want to do. Their wants and desires are socialized into them. That's the purpose of the program of reintegrating disabled people into communities. Mental health is also doing it. Their primary concern is reintegration. And school, that was expensive but we had a teacher's aid for our son all his life and I think in the long run it saves society a whole bunch of money. Because now he does not need 24 hour care by a person who can be paid 15 bucks an hour.*

His son is now completed school and now works in the community but still needed an aid to help him work in society safely. Brian felt that his previous work with his son has really made a difference in the cost to society and the amount of care that his son would require over a lifetime.

> *The only time he needs an aid now is to go to work. He works at an oil well company. He is their janitor. He could probably do the job without the worker... just... he doesn't drive. (Laughing) Having a worker will also ensure that nothing goes wrong. If anything goes wrong.*

When asked whether he was worried about his son while at work he shared the following ideas.

> *I trained him to be safety conscious. He is very safety conscious. With children with autism that tends to be one of the main concerns that they aren't aware of the dangers in the world unless they are taught every danger.*

When asked about what he would tell a family who realized that their child had autism, Brian was very adamant that he would have to know that family and the situation before he could give any specific advice.

> *Umm...it would depend, how well I knew them. But if I didn't know them, it's not my job to diagnose I would just point them to specialists or to regional health counselors. They will take it from there. I would have to know them. You would have to know the situation. I have a strong focus on the person by person approach.*

When asked further to give advice in general to a family who may be faced with working with a child with autism he discusses a very generic medical approach to dealing with a disability.

> *If anyone would ever suspect something wrong with their child we have child specialists in Edmonton like Dr. {Dr's name}, he is great. Make an appointment through the family doctor. You need to identify your problem and you need people who know what they are doing. Other than that there is nothing that I can tell them. Because from there on, today they have programs. And they will refer them back to where they live, if they have anything in the community. Where to go and what to do and how to get aids and how to get the workers. I don't know if they still train the parents like I was trained but if they don't have these components their just wasting a lot of time and money.*

Brian saw the responsibility resting heavily on the parents to provide for their own children by getting the proper training necessary to ensure progress. For him parents were a major component to the success of their child's social integration.

> *For parents there is very little funding to have a worker come in and work with the parents and the child. Umm...if they have that 80 hour course they don't need that worker to work with the parents. Because they will know how to identify a problem and how to solve it. I forget the name of the group, it was an organization. Its probably any behavioral management course, its just that this one was 80 hours and it taught us how to baseline, identify and baseline, to keep track of what we were doing and how to chart it and see if we were successful or not. So we are taking a month for a baseline of certain behaviors in order to see a difference and then it became a design after that.*

When asked why they didn't place their son in a residential hospital as was recommended by the first psychiatrist who diagnosed their son, Brian talked about his personal beliefs and how each family relies on their personal beliefs to make these kinds of decisions for their children.

> *Ah...there was no question for us to do that. Umm... it depends on their background, their coping levels and their religious background I believe. It takes a lot of faith to go through something like that. And most marriages won't last, a lot of divorces, breakups come because of these types of problems. Autism is very hard on the marriage. So ya, that's one of the reasons why other families may choose differently than we did.*

When discussing some ideas that he might have to help other families deal with the stresses of working with a child with autism he shared the following, stressing the need for a theological background to rely on.

> *If they have no religious background to help them they are in trouble. It depends on the level of commitment. Maybe a counselor could get a commitment from the parents and talk to them on a regular basis because they will get discouraged and they will need to know where to vent and put there frustration because there will be a lot of frustration. And their lives are on hold until their problem is alleviated. And if there is no help from the province they have no choice both people have to work they can't work and come home and do 12 hours of therapy at home. So it depends on the government.*

When discussing the different programs that were available to families, Brian stressed the need to make ones self aware of the government resources that were available to individuals in their communities.

> *I think each RHA (Regional Health Authority) has somebody, a name, a person that you can contact like a counselor, we have one here it's their job to navigate people. Other than that there is the Autism Society number, if you need to know anything you just contact these guys.*

In conversation we began discussing if and how Brian knew that his son loved him or appreciated the things that he had done for him. In view of the considerable amounts of time that he and his wife spent as parents to help their son assimilate into society, it was asked if Brian ever felt that he was appreciated by his son for his efforts.

> *In autism they don't express emotions very well. Or they express them not properly. It is something that you can teach them. You can teach them a behavior*

> *but you must also teach them to do, what they want and what they like, these behaviors become something that they want to show. But autistic people do not like to be touched. Their senses are heightened. Auditorally and visually and sometimes tactile. If one is more heightened than the other for example tactile, for them they will just close in when you touch them. When they wear their cloths it may be difficult, so it depends on each child.*

Brian was asked to describe how he would overcome some of the obstacles that make it difficult for an autistic person to express affection and love in a typical manner. He discussed again the need to program and change the environment and the individual with autism's reaction to that environment.

> *I don't know if there are ways to desensitize a person with that one (touch) but there is a way with sound, you expose the child to loud sound for a long time, you probably effect his hearing but that has an effect of... they say for some autistic some sounds sound like a jet aircraft the only way to change that is to desensitize the part that is causing the most problem. Now when you do desensitize them they can then begin to concentrate and to learn.*

Even with these difficulties in connecting with a child with autism, Brian mentioned that there was still a connection that happened between parents and children that can not be explained. He states that these connections are there to help parents continue to work with their children regardless of their disability. Voluntary behaviors become visible to parents who have cared for their children over a long period of time. These voluntary behaviors become recognized as an expression of emotion or affection.

> *I don't know there is always a bond between parents and children. It's not describable but it's always there. And sometimes it is even stronger because you put in so much work. And you don't need the physical hug to know; just a smile or sometimes they will just come and sit near you. As long as you have taught them what they want to do then you know by certain actions that it is voluntary and they are showing emotion. But that will have to be taught as well how to show it.*

> *They do show caring especially when he can sit anywhere else in the living room. He chooses.*

Brian saw helping children with autism understand and make choices a necessary part of helping them to be integrated into society. This choosing behavior could be trained into children with autism. Brian felt that at times he had been trained to ask specific questions and to give specific choices to his son by his son.

> *Helping them make choices first, then you can give them the tools. You have to notice you have a choice and that's the hard part. So you always have to put a choice to every question. Do you want milk or do you want orange juice? Do you want to go to A&W or do you want to go for a walk? You are teaching them choices, that they have choices. If you do this every time you are proposing something. Propose always 2 things or even three things then they begin to think what do I like the most. Then that is how you get them to choose that. Often they will always choose the first things that you offer them but that is because he trains us. He trains us to ask him what he wants us. They…some of them can manipulate over time it's not a bad thing, because manipulation is also part of society. It's good…they get this way but we know it because we have had those courses and we don't mind because that's the way that people are.*

When discussing the realities of families getting old and being unable to care for their children with autism anymore Brian shared his belief that the government would provide care for these individuals. This again showed his trust and reliance on the government structure.

> *Yes and there's government, Alberta where we know of their programs, group homes and how they work and…and he wouldn't be by himself he will always be with other people with his type of problems. They are not always the best because my wife works for them in group homes but it is better than no environment.*

Brian was asked if government and programs could ever be as good as family or replace what he receives at home for care.

> *No. But he has brothers. So there may never be a day when he has to go.*

Brian was then asked what his son's connection with his brothers was and he described it in an interesting and unique way.

> *His relationship with his brothers is very good. He is our cook…laughing…we need something done he does it. He also is the one who does repairs, little stuff around the house, he understands electricity, like I said he has come along way and he is our cook and my wife also…part of his behavior modification was doing things with him. So cooking, he likes to eat so cooking is a good thing. (Laughing) Our son can do a lot of stuff unsupervised. He keeps us all alive.*

When asked if he thought that his son enjoyed cooking for the family he stated the following

> *He enjoys eating so…it is in his benefit…it is a good benefit for him.*

Brian believed that his sons who do not have autism would care for their brother when he was gone. He saw this caring responsibility as something that he had built into his family and hoped it will continue.

> *Yes his brothers will care for him it is just build into the family? In Ottawa they were too young. They did baby sit for us when say he was say 11 or 12 because we couldn't leave him still at that age, but after that no. Our son is the oldest. He*

> *just has two brothers younger than him and they get along fine. Like I said he is their cook.*

When asked if there had been any difficulty between the brothers due to the high needs of their one son he expressed that they had never expressed any dissentions except when they were younger and their son with autism would often tattle on his brothers when they did things that they were not supposed to do.

> *No, no problems except our son is a... used to be a tattler. (Laughing)...Our son likes to report other people and getting into trouble. And he doesn't like it when his brothers do it to him. He really likes order in his life and in his world that's part of having autism.*

His tattling was seen as fulfilling his need to have order in his life and when things were organized and followed according to plans his anxieties were often allayed and he was able to participate more in society.

> *It's a security blanket. And his schedule has to be the same. It changes...they don't adapt well to changes. It is something that you can train in them though. It's a lot more work to train them to adapt to new environment every day. It could be done but it's going to be a huge amount of trouble and besides once you go back to your routine you will lose that. Ya...you might as well setup a routine and vary it from time to time and ask him to deal with it.*

During the interview I had the opportunity to interact with Brian's son who had autism when he came into the room and was very anxious because a specific battery charger was missing and it was necessary for him to complete a certain task that he was working on. The interaction between him and his father was interesting to behold because Brian simply stated that it wasn't a problem they would just have to get another charger another day. Immediately his son calmed and was able to continue with his project. Discussing what happened in this interaction, Brian stated that his son was checking him to see how to react to the lost battery charger.

> *Sometimes he will do that to check your reaction. He is waiting for you to get angry or …so he can react to something. To see how you are going to react to a situation. Even though at first they don't look at you… that's one other sign, they won't have eye contact with you. We don't know why. Probably has a visual…because they would rather see you from the side then right on, ya…and I guess their visual is refined, too refined; probably hurts their eyes, so they are always looking at you sideways.*

In an effort to help his son be socially appropriate he had trained him to make eye contact so that he could participate with others in a way that they would be comfortable with.

> *You have to train them early on to have eye contact again with candies, little pieces of candies, and then you can begin to hold eye contact. Every time you talk to my son if you notice that he starts to not look at you again you say "Look at me son" and then you will notice his eyes go straight to yours. You have to train him at the beginning to do it because that's a social norm to look at people when you talk to people. So you have to make them as normal as possible and they can be trained.*

This ability to read people for emotional reactions was not limited to his parents. Brian stated that his son watched all people either directly or from the side in order to be aware of how he should react when he is around others.

> *He can read your emotional reaction from the side of his eyes or straight on, but he really uses you as a cue as to how things are running. Not just his parents but everybody. Yes, they learn to manipulate on a very basic level, which is fine. It is a game that two can play. (Laughing)*

When asked if there was anything else that he would like to share in the interview or if there was anything that he would have done different as a parent he stated that he was content with what he had done and again reiterated how much work it was.

> *No... well it's a lot of work. I don't think that we could have been anymore intense. No, we practically spent every waking moment for the first two years and we kept alive on that big time, I mean... Our son is also our janitor in the house he vacuums, washes the floors, does the bathroom my wife and I work and one of the reasons we allow him to do so much work is because he only has a four hour work period with his worker. So once he comes back from work he has nothing to do and a lot of time we have to suggest stuff to do. In a four hour work day it is not enough for him to... he needs more work yet and we allow him to do...which benefits us big time to do work around the house and he is able to do it properly. Plus he takes care of these fish (pointing to the large fish tank in the room) that's his.*

On the topic of his son's fish tank, Brian stated that he had made a point of teaching his son who had autism to share because sharing was a social behavior.

> *We are about to donate that to a person who wants to start breeding fish and we are helping him out because he is a disabled person as well. And he knows how to raise fish so our son is donating his fish to him. He is happy to donate it. We have taught him to share. Toys that he doesn't like anymore he gives them away.*

At the end of the interview Brian again stated how much work it had been to raise his son and then gave all of the credit to his wife for all of the success that they had seen with their son.

> *It has been a lot of work though. It is mostly due to my wife. I just take the credit.*

Breanne's Story: The experience of a teacher

An Introduction to Breanne

Breanne came highly recommended by her peers as a teacher who had a well rounded experience working in the field of autism. She had worked as a teacher's aid and then later completing her education degree she became a substitute teacher in the public and private school systems. In this capacity she worked in a number of different settings and participated in many different programs that were offered for children with disability and specifically with individuals with autism. Eventually Breanne gained a full-time position as a program director and teacher. She had over 14 years of experience working directly in the field of autism and had shown a fortitude that was uncommon among her peers. She had been able to maintain a practical and objective view point while dealing with what could be classed as some of the most difficult and taxing programs and children in her field.

Breanne was of an exceptionally cheery attitude. She made the researcher feel at ease when meeting with her. She loved to talk and share experiences with the researcher that related to the topic of autism. She found the whole process of researching the needs and desires of individuals who have difficulty expressing themselves the way that most individuals do as exhilarating and exciting. It was obvious that she had experience working with individuals with autism by the way that she made easy reference to many of the common difficulties that arise in autism for families, society and especially school and government systems.

Breanne was married to her husband of 35 years and had successfully raised 4 children of her own. She was now a grandmother and thrived on the joys that came from this new endeavor. Her motherly instinct was obvious in her words and her actions. She referred to the children with autism that she worked with as “her children” or “her kids.” She was well respected in the community as a person who was always willing to help those that were in need and was always willing to share ideas and feelings with those that sought out her advice.

In the stories that Breanne told from her experience it is plain to see the care that she had for individuals with autism. She honored them by placing expectations upon them that were commensurate with their level of progression and then lovingly helped them along the, at times, difficult path to accomplishing all that they were capable of doing. Her realistic demeanor didn’t allow her to become upset with difficult progress but rather helped her to reframe each situation as a new challenge rather than a failure.

After completing the primer exercise we began discussing how a person would recognize a person with autism. Breanne began to describe a person with autism to me as though I was a person from another planet and I was experiencing meeting an autistic person for the first time.

> *I would probably say it is an individual who looks the same from the outside but inside the wire is wired differently. So they communicate, feel and understand and sense differently totally different than the rest of us do and understand those things differently than the rest of us do. That is probably the way that I would explain it.*

She also gave some advice that would be helpful in working with or interacting with an individual with autism.

> *I would say go slow, protect yourself (laughing), I would say try and do two different methods at the same time to communicate. Like use both an auditory and a visual method at the same time to try to communicate with that person and be prepared for lots of wait time. Wait for them to…respond…don't expect things to happen quickly that they have to process because their processes are different than ours and so that could take them a while to come back with a response. They may not understand what you are asking them to do at least not in the same way that you and I would understand something.*

Breanne also discussed the nature of autism and the need to have someone who could make sure that they were safe in society. Protection was a common theme in the interview not only for the individuals with autism but also for those that work with them. Part of the need to protect came from her experience that society in general doesn't understand autism.

> *They may be alone but mostly they would be with someone to protect them from the world, which doesn't understand them. They need to be protected from dangers from other people and dangers from not understanding dangers. Walking out in front of traffic, being terrified of things that aren't dangerous and running into areas where there could be dangers that they don't understand. And being taken advantage of by unscrupulous people who could twist their disability to their advantage in many different ways, financially, sexually, whatever, violence wise but mostly it is the total different understanding of what could be dangerous to them and what could cause them to put themselves in danger.*

Dangers would be seen differently for a person with autism and they wouldn't understand the risks involved with different social or recreational activities.

> *They would process things differently. They may see a car but not understand that it is hard. Or even if they touch it they may not understand what that means as far as if it hit something going at a certain speed. Whereas; if there is a loud noise from…maybe not even a loud noise like the noise from an air conditioner that*

> *might be terrifying to them. They may see that noise as a really high noise and traffic is a soothing noise, you know.*

While discussing the difficulties inherent with working with individuals who have difficulty expressing themselves in a way that most people are familiar with, Breanne shared an experience that she had trying to create a form of communication for a non-verbal young lady with autism. Her hope was to find a way that she could allow this young lady to express her needs and desires in a way that could help those that cared for her provide her with the things that she desired. The belief was if this communication was possible perhaps her violent behaviors would decrease along with her frustration and anxiety.

> *As a teacher I give and pull back out information both expressive and receptive. We had a girl this year and she started out 13 years old with no communication at all, none. So we went through everything that they tried which was basically everything (laughing). Except that they never counted large body movements, like they never thought of accepting that as a whole communication system. So we started to do that instead. She had a semi-understanding of language and pictures put together…not pictures so much at intake but she did look at them but we are not sure how much was going in because she would pat the pictures but we don't know what she was seeing really. It could have been just a jumble of colors or whether… because you have a 2 dimensional image for a three dimensional object right. Or she could understand water as how is sooths her throat as it goes down or satisfies a need and not even as a liquid or a… you know. So what we did was whenever we gave her a drink we took her with us to the sink and we made that a movement and whenever we fed her she sat in the same place. Even if it was a snack food or if we were cooking, we made sure that if we were going to feed her it was in that place to feed her and then we had a different place for being calm and quiet and other kids had to leave her alone when she was there. We made actually four different…was it four or six different spaces in…we have three classrooms so… and they are always open to each other and it's not like this classroom and this classroom or anything, we flow between them. And so we made four places that meant different things. One was I want to be…we kind of had to make up what we thought she might want so water, food, a drink, food, a place to be quiet and alone a place to play, a place to listen to music, and a place to be with other people or to be comforted, hugged or have tactile things happen.*

> *Then we made sure that those things always happened there and as soon as she would go to there we always gave her a drink, we would always giver her something...you know it would always be like if she started for that chair someone would run and get the granola bar and runs there so that she always goes there. And we actually did find that the play place clicked in really quickly. That was right away because we kept her sensory toys there so she had to go there anyways to get her sensory toys so that she could play with them. The drink place was catching on and then they moved her to a different program (laughing).*

One of the difficulties that Breanne expressed concerning working with individuals with autism was that there was never any guarantee concerning how long she would be working with them. There were so many factors that played a role in the length of time that they were in a program, funding changes, parents move or individuals are removed from a placement due to their behavior levels. At times the changes in placements make for difficult and even halting progression for the individuals with autism.

> *The drink place was catching on and then they moved her to a different program (laughing). She was a child that that was another problem with her I think that she had been in you know in 8 years of school she had been in about 10 schools and this year alone she has been in three. Because after setting her up in the one school that she moved to and giving that teacher lots of information about her, two months later I get a call from and different teacher who is actually a friend of mine saying "this new girl just moved in and I need help! What does she do and how does she communicate?" You know. How far it went from there I don't know but that is different for her and at least she could kind of start to tell us because she has never been able to do that before and she could be quite violent.*

Breanne saw the length of time in a program as one of the primary keys to success in developing a communication program. As staff and teachers come to know an individual they can then make better, more informed choices on what programming and training to attempt and implement.

> *Yes and when I went to see her in another town, so I went out to visit her and they were doing PICS (Picture and Image Communication System) hand over hand like it was taking three people to do them for every bit of food she had to hand them the PICS and it was on a sensory thing that she liked to hold. She had to hand that across the table to that person who then took it and said "good girl you want a bite?" And then the other person sat her and was holding her because she doesn't like to sit still. You know and I thought, not doing that. And then I went back to her cum file and guess what, every single year since she was 2 ½ they had tried PICS and a...we weren't even sure of her vision. Ya so we though well we won't be trying PICS (laughing). Oh ya and I don't know, it would have been nice to have her for three years and then we could have really seen if it clicked in for her.*

Concerning this young girl and other individuals with autism the best thing for them was to have stable placement over time.

> *Overall some consistency, definite consistency. A program where she goes on the bus everyday because she also could be very violent on the bus...she had to wear a harness on the bus because she would try and leave the bus while it is driving down the road and stuff like that.*

Restriction to protect individuals with autism and others was a topic discussed at length. In order to give understanding around some of the restraints that were necessary Breanne shared her experience of seeing harnesses used on buses to keep individuals with autism in their seats while taking the bus. Though she saw these systems as uncomfortable and very restricting she also saw that these systems were necessary and at times could be therapeutic for some individuals.

> *Ahhh, (laughing) straps over the shoulder with clips and two sets of straps around the body and they also have clips that hook into a special harness system seat on the bus. And there's also a place where the seat belts go through but not always. Once you have all of that harness hooked up you are not going anywhere. Even if the bus crashes you are stuck there because it is screwed in tight. So ya (sigh). Actually I have seen the harness before used with a child with autism and it had*

> *the whole body harness clipped in and then they had another one that went around and through the seat and was done up at the back of the seat. Then they would winch it up and then if they started squirming out of it they would just cinch it up tighter. It would hurt. You know that could have been a child who almost craves pressure though too you know because wiggling out they could be…they might be trying to get loose but they almost might be giving themselves extra pressure. They use weighted vests with children with autism and weighted lap things and weighted shoes and weighted…like all kinds of weights to kind of give them that deep pressure and they wrap them in the spandex and tie it around their hands so that they can sit still. You know like those therapeutic bands that you use for Pilates, wrap that around them and stuff so ya.*

Breanne talked about another individual who she worked with who needed extra stimulation in order to help him stop self abusing himself. She mentioned as well that it was difficult for society to see some of the treatments that were applied because they do not look conventional and at times even looked torturous.

> *We had one boy who was in a wheel chair he could do some walking but not really, some weight bearing rather than walking actually but we call it walking you know. He would be really, really…smash himself in the face all day long but if you put a band round his upper body so it would go around his wheelchair and around here (pointing to upper arms) it looks like you have strapped his arms down but really you haven't. But it looks like he is tied in. He could still bend his arms, which is exactly how he hit himself by bending at the elbow, he could still do that there but it gave him that pressure and he would not abuse himself all day while that was on. Other than it looked dreadful to the other people who saw it, you know it would look like "Oh dear what have you done to that poor child?" But you actually were…I don't know how that worked and I don't know how that is wired into their brain but for him that was the pressure required to keep himself from whacking himself in the face. It just seemed to be that extra stimulation or sensory thing.*

When asked how she knew to try the extra sensory approach with this individual with autism she stated that her successes have often been found through the process of trial and error, always looking for something else to try and implement.

> *How did we know to try that, we didn't, (laughing) we just kept trying things. We tried...another thing we tried was inflatable...which also worked but it was really in our way and the other kids would pick at them, was the inflatable splints. Which also did work because he couldn't bend his arms then and they were stuck like that (holding her arms out straight towards me). And they seemed to kind of amuse him and he liked them and they didn't allow the abuse but the other kids liked to come over and start bouncing his arms. So that wasn't a good idea (laughing). It was like the kid was made out of rubber, "hey looks he's a live ball."(laughing) So we did away with those, ya. Because everyone is different. They have some commonalities but that is about as close as it gets.*

Breanne stressed that you have to look at every child as an individual and this whole blanket diagnosis called autism doesn't allow you to say "Oh people with autism they will do this, this and this." Each individual had to be understood as a unique person with unique and individual challenges. What some may respond to can not be applied to another individual with autism simply because they are autistic. It was necessary to learn their particular style and way of interacting with caregivers and society in general. If you are not careful the consequences could be quite alarming and dangerous.

> *Ya because some of them are so violent towards others and themselves, well mostly themselves. I have seen autistic kids who are blind because they have made themselves blind because they have caused so much brain damage to themselves. But on the other hand I think that autistic kids are I couldn't say cuddly but they almost are on their own terms. You go over and cuddle them they are going to scratch you, but they come to you and all of a sudden they want that, you know and there was an autistic boy that I worked with a number of years ago and if you got into his space oh my goodness you would bleed. But he had the weirdest think because you could tickle his aura around him and he would giggle.*
> *Not touch him, no but you would tickle around him and you could come up behind him and do that and he would start laughing and we didn't even know how he knew that you had done that but it was almost like he had this electric field around him that...and you couldn't go into that field, you know because then your not going to be feeling to good later. Ya, that was an interesting thing which I have never seen with another autistic child where you can tickle that space around them and they can giggle or you know but as soon as you got inside that field that is when he would react, ya, ya.*

When asked if she could tell her experience of recognizing emotions and feelings with autistic persons she stated that they had feeling but they were expressed in a very different way than most people would express them. The following story details how she recognized that some individuals with autism followed through with the procedure of expressing emotion but don't always have the same reaction to the emotional experience that others without autism might.

> *I have met some autistic individuals who can talk but not emotions. I used to sub in a program a lot with...I am trying to think there were six kids and four were very verbal and they actually did things like integrated grade 10 math and stuff. A really interesting...play fish but emotion, no. That was in the year 1999-2000 and I remember we were doing the calendar for December and aid had the stuff up on the projector and what are we doing here and they would say "Oh Mr. Smith on that day." And what are we doing here? "Mrs. Smith will be back on that day and we are going to go to the mall." And what is going to happen on this day? Which was December 31 and it was so funny because one of the kids goes...one of the kids says "it is New Years Eve." And he said good and wrote that down and then asked "what else is important that happens on that day, he was trying to get someone's birthday out of them and the other kids goes "It is the end of civilization as we now know it." (Spoken in a robotic mono-tone of voice) And I am like what? Nathan, what are you talking about? And he is like "It is in all of the papers Mrs. B you should be reading the papers, you should be reading the papers with me, I read the papers and it is the Y2K problem and it will be the end of civilization as we now know it." You know when I was back in January I wanted to say look it didn't end you know but I couldn't do that. Ya and he was quite determined and I would say what if... and he was like nope, nope it was in the papers and they would not put it in the papers if...and it was just like and even the way he talks you know but he sincerely and firmly believed that. He had read it in the papers. And I thought boy you had better watch what you print in the papers because he believed it. But as far as emotions or anything I was called terrible by one of them so it is a bit of an emotion. He would...one of their jobs was to get the news paper in the morning and take a quarter or fifty cents whatever and go across the street and one would get the sun and one would get the journal they would come back, they would each pick and article, they had to read it and summarize it in their daily journal and also say the weather and they honestly didn't have a clue as to the weather until you would tell them. "You walked in the rain and you have no clue?" and they would have to go and look again. And the same with...they would read the article and the one boy he read it and he said "It is about computers and kids, computers are good for kids." And the article was actually about Y2K and I said "Well that isn't exactly what it is*

> *about read it again." "Yes it is Mrs. B. right there is says computers and kids." You know and then I said "no read it again." And I made him read it four times and the last time he read it, well the third time he read it out loud to me but he still... word for word and he had no idea what that was about. He could tell you sports stats from twenty years ago perfect. I couldn't believe it so finally I said "Ok read stop, make a picture in your mind, read stop make a picture in your mind." And if he couldn't tell me what picture was in his mind I wouldn't let him read on then he summarized the article perfectly because he was obviously was thinking in pictures and he was reading words. He wanted to get it done because once he got his article done he got to look at the sports stats (laughing), which is really highly motivating for him. They also did a little thing each day that they wrote in their journal. Today is this day and we are going to this and our favorite sub is here her name is Mrs. ... so this boy... and I can't remember his name... they asked: "what is her name?" and he said: "it's terrible, Mrs. Terrible and she is here to drive me crazy!" But I don't even know if he knew what crazy was or was it just a saying he heard on TV you know, cause he could also quote movies word for word. So it was very funny. But the aid was like, oh you can't call her that and I am like that is a pretty cool name for a sub. "I am your sub today and my name is Mrs. Terrible." Every kid in the class would be like, Ok it's a good day we are going to be good today (laughing).*

Breanne emphasized that though they had trouble expressing some feelings that were common to most people there were other emotions that were expressed regularly and clearly such as frustration and anger. Learning to read an individual took time and a person could never let their guard down because individuals with autism would react according to the situation without thought of future consequences.

> *They can express frustration, definitely. And I got also definitely a feeling that oh you're here again it is nice to see you, you know? Like... a very, very big kid who threw one of the aids, who was very big man, across the food court at a mall and broke his back after I had been told that no none of them are violent you know but they told him to put his burger away because it was time to go swimming and he wanted to eat it and that was it. The guy went flying and I would have told you that he liked that guy but not right then he didn't. Get between me and my burger I guess. And he was like "Oh Mrs. B. remember we played fish come play fish with me. Come go for a walk around the school with me." You got the feeling that he liked you but there was no... like sometimes you would go back to classes and kids will, every grade will, and give you a hug or be like cool your back you know but there wasn't that kind of a reaction but there was a I know what you do*

> *routineness I like that kind of thing more, you know. So I think it is as close to being welcomed as you are going to get in an autistic room but it was very interesting because they spoke and you could kind of see how their minds worked.*

When discussing whether she had developed any feelings towards individuals with autism that she had worked with she responded in the following manner.

> *Oh ya (laughing). Irritation for one (laughing). Fear, fear when I went back and I'm like, "oh crumb they just told me that he broke so and so's back. He tells me he wants to go for a walk around the school with no one but me." But do you know what? Then it was right back into...he was the same cute guy you know that I had fun with before this incident with the teacher. You could get very attached though.*

Concerning attachment, the researcher was interested to know how a person could become attached to an individual with autism when there was very little in the way of a reciprocal emotional relationship. Breanne saw the development of attachment as something that comes from within someone who gives and serves another person. A reciprocal arrangement isn't necessary to develop feelings and an attachment.

> *I think it is the same way that you get attached to babies because trust me they don't care about you a heck of a lot (laughing). I think it is the same way to be quite honest. When you give care to someone I think you start to really like that person. I think you do. You attach almost in a maternal kind of way.*

When asked about how she would proceed if she wanted to get input from and individual with autism concerning life decisions and program planning, Breanne at first wanted to know if the individual was verbal or non-verbal. She then rephrased her question in consideration of the fact that regardless of the individuals verbal abilities they may not be expressing their true desires and wants to you rather they could be expressing what they have been taught to express or what they believe you want them to say.

Learning to understand their personal wants and needs was a very sensitive and difficult process.

> *Are they verbal or are they non-verbal? Or even if they are because your not even understanding, like I said that young man who was reading the paper, he could read that and not verbalize what it meant and so if he was saying I would like to go to Disney Land, does he have any clue what Disney Land is or did he see it on TV last night or did he hear someone else in the hallway say that or they just think that that will make you go away so that he can read the stats page. Where as in reality he may what to go and see the New York Yankies or something.*

Breanne described the process that she followed in her educational programming as and example of how planning was done for individuals with autism. The goals for the progress plans were based on the caregiver's expectations as opposed to the individual's wants and needs.

> *Well I can tell you how we do it at the school and how we plan an IPP (Individual Progress Plan) but unfortunately they don't have much input. They are supposed to but it is difficult right. So we sit down with parents and the child and we try to look at where the parents and the child want them to be in five years in 10 years and how…rather than a developmental model where the child has to go through these stages because you are never going to get far that way. Because you are stuck there for how long because you can't go on to the next stage till they supposedly haven't learned what they need to learn at this stage. So what we do is we need to get to here (holding hand about 2 feet apart) what skills are going to be needed to have a good life at this stage? How can we help at this stage to get him to this stage and have the happiest best life possible here? (holding hands about 1 foot apart) That is how we do it. Now when he is here and he wants to do something to make that happy life that is going to be difficult unless you can just read what he has always liked in the past almost, that which is familiar and for some kids that is not going to be there for them. Especially the ones who are very high maintenance because they beat up their caregivers or they have worn their parents out you know or what ever and so they haven't lived with people on a continual basis or interacted with the same person. I mean the burnout rate for teachers alone is about two years, aids just as quick. So when you look at the burnout, people who should have been there for all of junior high haven't been you know or that little girl who gets moved every year or three times this year ya.*

> *Where does that put her? There's not going to be anyone there who is going to be able to say "you know she really likes…this kind of music." You know?*

Breanne shared that sometimes there are not guardians who were still in contact with their children with autism or played a very limited roll in their life planning and development. In these cases she hoped that there was someone invested who would take the time to insure that the individual's needs and wants were taken into consideration. She mentioned that she saw some of the decisions made for these individuals were done to suit the programs and staffing budgets that were established rather than what was best for the individual. She saw this action as abusive but felt hopeless when considering the realities of who was going to do anything to help a disabled person especially one who was non-verbal.

> *You hope that there is someone involved who knows and cares enough to make sure that the decisions are for the benefit of that child and not for the caregivers. Because it is really easy to go, lets group these two kids together in a home or what ever because this one is hard and this one is easy so the easy one will make up for all of the time that you spend with this one. And then what happens to that poor kid who is actually sitting twitling his sock in the corner because he is easy and hasn't bit anyone, you know and he is just going to go deeper into himself maybe and not having the care that he needs to become the best that he can be. And if there is no parent involvement it is easy for an agency or a group home to go with that model I think and the government too. The government wants the easiest way out as well for their paycheck, the biggest bang for the buck as well or what ever. So I think that there are a lot of people…if you look at abuse from a very wide angle, financial, mental the whole way through I think that there is a lot of abuse that is going on that is not noticed or cared about. Maybe it is noticed but no one is going to make much effort to stop it for a non-verbal person.*

Finding balance in programming was an area that concerned Breanne in that there were some individuals with autism who were very capable of many things but they seemed to be placed in roles and work environments that served very little purpose.

Though an individual with autism may complete a task consistently and accurately it didn't mean that he was enjoying his experience. He may have even been taught to express satisfaction with his duties but she didn't trust that these expressions were representative of their true feelings and needs.

> *And how much has he been exposed to other choices so does he know that is what he wants to do? is that better than twittling a sock in a corner in a group home with nobody that cares for him or participates with him? This is the balance that I am struggling with. Not to be negative toward government agencies but government agencies will take advantage of these people. If they can stay at home then we don't have to pay for it, excellent.*

Funding played a big role in decision making in many programs. Breanne shared that her experience had been one of uniqueness in which her administrator has made sure that funding that was allotted to the school for her programming was used for appropriate programming. From her experience she knew that this was not the case in many other funded programs that she has been a part of and participated in. She counts herself very fortunate to work in the environment that she was in at present.

> *From my experience...for us we are lucky in that... or maybe I shouldn't say we are lucky, I am lucky. I am lucky in that I have had good admin that have made sure that my bucks comes to my kids and will even slate extra dollars to us and not all of them do that. The province is supposed to be checking that but I know that there are lots of special needs children that have money attached that are just seen as a paycheck to go and by new computer systems for everybody you know. My staff...I work very hard to get a staff that is really determined for what is best for the kids and they are quick to say: "We are ignoring this one or this one is starting to withdraw a bit, you know. We need to focus on this little girl's needs right now because you know the three boys have been hitting and biting all week and we haven't done anything with her. So I would like to do such and such." And just the fact that my calendar...I should bring you a copy so that you could see it...this group is going here and this group is going here and this group is back at the school so since it always rotates through everybody is always getting*

> *some…and when you are out you are basically one on one with your inspiration or gone to the mall or gone to West Ed for the day or the river boat queen or whatever so during those times it is really nice to have that extra one-on-one.*

Breanne had tried a practice of reverse integration in her programming in which she brought in children and students who did not have disabilities and gave them opportunities to work with and associate with individuals with autism. She has found that it was very socially informative for students and the individuals with autism in her classrooms seem to respond favorably to this peer interaction.

> *We also have kids that come in as reverse integration, we have work experience students and stuff and um, we had our two boys there last weeks and we were planning for them being there and I was telling them "Wednesday your not coming into the classroom because we wont be here all day." And they are like, "Ah, your so lucky." And I get that a lot from kids and I never really thought about it and they were like. " We wish we could come to the zoo." And I stopped and said "I don't know why you can't? You know. "What are you teachers today?" Of course they are giving me last names and I know everyone by their first names…I swear there are a hundred teachers in that school. So I emailed them and got permission and they boys went with us to the zoo with us. Which gave two more kids one-on-one with teenagers their own age which they really like. They do like that!*

One disadvantage that she had seen from this peer matching was that the individuals with autism would take advantage of the naivety of the reverse integration students.

> *There is a definite clue in there, you know…some of them will take advantage of it because they know that those kids aren't going to order them around or use the strong voice or anything. You have to keep a very close eye on it. My kids will try and get away with all kinds of stuff they are not supposed to like sticking their thumb all the way down their throat and chewing on it you know and we have to go over and go he is not allowed to chew on body parts. Because they do those kind of odd strange things to themselves so ya. But ya there is a definite*

> *connection with kids there own age no matter what the disability for some reason I don't know what that is. It's nice, it's really nice.*

When asked if she thought that any teacher could teach individuals with autism she laughed. It takes a special person with lots of understanding and patience to work with this group of individuals. Flexibility was a necessity or a person would just not survive in this work environment. She shared some of the things that she did in her class and as a teacher to keep herself and her other teaching staff healthy and able to continue in a field that had a very high turn over rate of employees.

> *Well, I think you have to have a sense of humor because if you can't laugh over some of the stuff, you know I mean at one time…this is really bad, don't tell anyone… but we made the weekly "poop award". (Laughing) We crumpled up brown tissue paper and we made a card and we put the biggest poop of the week award and this was for people who had to clean up things and we were awarding it to people. We finally had to trash the paper you know but I mean it was hilarious and sometimes you just have to put you feet up after school and grab the Haggen Dazz and pass the spoons around and sit and chat and go oh my goodness that was the worst day in history. And unfortunately there have been lots of days that I have told my staff: "You know what? It is done go home." And they will say: "But we have to do…" I say: "Leave me a list of what needs to be done and go home." Unfortunately it means that I stay later because they go early but…I was a TA (teachers assistant) and I know what it is like when you've had a rough day and your not paid enough for some of those days and because I am willing to say: "You guys are all going to the bar I will take care of this so you get out of here right now." I think that is why I have staff, the same staff. Any other teacher will tell you that they don't get along with their aids of they say there are problems or their aids think they are smarter than them. I have never had that. I have never had that. The aids that I started my program with are still there except one is injured right now you know. And the ones that have joined me are determined to stay. And I do social things with my aids you know we go to dinner and a movie sometimes and stuff like that. But I know that…it is a lot of pressure working with our kids and you know those days when…Oh and they other thing is no matter what my lesson plans are for the day like they change everyday like one time they changed three times by ten o'clock. Friday was probably one of those days. I had an aid that wasn't coming in suddenly and two kids that weren't coming in so everything gets changed around again and then my other aid who is coming in who is part time on workers comp. phoned in to say that she has a migraine so she is not coming so "oh" we have to change*

> *everything again you know. So and once a student wasn't coming in because he had a seizure but his mother brought him in anyways and he didn't come on the bus so something changes again. But no matter what the plans are for the day I always tell the staff: "No matter what that plan says, no matter what you are supposed to be doing if you have had enough of this kid you come and tell someone now." And the other thing is if they are dealing with a behavior like say they have told this kid has to sit down until they come back, no one else steps in and takes over. That child is totally out of our hands. Even as a teacher I will not step in because... they have to come back and talk to that child and deal with that situation and if they then need to go in the office for twenty minutes and I need to take over whatever they were doing and adjust the schedule again I will always do that and they know that. So no one is going to get to the breaking point and they also have the right to tell me: "You know what? I don't want to be with that kid for the next few days." I say: "Ok." I will then change the schedule again because sometimes you do need to do that. You know there are some kids that are going to do, you know the ones that scream in your ear all day long may be a lot more irritating to you than the ones who tries to punch you in the face every twenty minutes. Like for some people it is that scream that's going to kill them off or you know what ever. We all take turns with all the kids but I give them the right to always say: "I need a break. I can't be with that kid for a while." You know or even in the middle of the afternoon just come back and say: "You know what? I have to do something different." I say: "Ok, go in there and help so and so for the next twenty minutes." You know and that works really well.*

Part of Breanne's secret for building a strong classroom team was to delegate responsibilities and help each individual take on the full responsibility of that role. She met with her staff often and tried to work with each staffs' sensitivities and strengths. Realizing the stresses that working with individuals with autism could have made her an excellent administrator in her own classroom. All of these things made for a better environment for her employees and for the individuals in care.

> *I have given them a lot of responsibility which works really well for me. One of them does all of my scheduling. Then I give them areas of expertise and areas of responsibility. Areas of expertise is like the OT's (Occupational Therapists), speech language, PT (Physiotherapist). If the PT, physiotherapist comes in I don't meet with her she goes straight to that aid which a lot of teacher will not give that out but lets face it I am old and senile anyways right (laughing). So they meet with that aid they train that aid to do what ever physio needs to be done. They do all*

> *that and that aid is in charge to get all that information back to everyone and putting it in the binder. It takes huge amounts off of me to do that. Each of my aids has an area. Each of them goes out and finds their own product for that area that they want to buy then bring them back to me for approval. It always has to come through me, like I have to do the original meeting with the PT and make sure that they are going to meet all of our needs and that kind of stuff. Or they will come to me and say: "I need to see her and also email her parents to come in and get this checked out again or whatever but as far as, you know me meeting with the OT or PT I don't. They do all of that and that is wonderful for me. They then share with the team at the next meeting which we have regular meetings of our own little team not just the school. And then the other thing is that they can take over an area of responsibility. So one staff chose last year that she wanted to do art this year and I get them to...I call it a meeting on paper, I give them this little had out, its like a from one to ten, list these things that you would prefer to do so they would list them all and then which options do you want? You know it is funny because some of them put one for bagpipes and some put ten for bagpipes. You can tell who doesn't mind lots of noise and who loves it and which kids you would like to be working with in this area and so they flow a lot so no one has key kids. It's just like you flow between the kids because you are doing speech and because communication is huge of course there is one for spoken and then there is one for PICS and then there's sign language so there's three in communication. That is sort of and you know also I expect them to find their own courses in that area and then I approve them or I send them to the principal and he approves them after I have approved them. Ya and it builds a team that is very sharp and is really, really good with the kids. They like their jobs because they like that and I know that one of them, you know she takes kids to integration. Well this kid is slouched over all the time and she says: "Well that's it you're going back to classroom." She goes: "My last teacher would be like how dare you be back here you are supposed to be in integration." And I say: "No, he has to earn integration it is not a right it's a privilege and if you see him lean over in his chair and act like an idiot any other kid would be kicked out of class he deserves to get kicked out of class." So he had to come back and take part in the classroom with was watching the girls paint their fingernails which he didn't like (laughing). Because he didn't get his fingernails painted he didn't get to join in he just had to watch them.*

Breanne shared nearing the end of the interview her belief that when dealing with individuals with autism it was necessary to use your own moral structure and belief system in making choices and decisions for them.

> *I think for me and I found this is the golden rule. You know if you had to have this disability, and nobody knows what tomorrow holds how would you want to be*

treated. And if you meet up with these people after you are dead, what do you want them to say to you about the way that you treated them? How hard did you really try to understand their needs or did you just instantly think they must think this because I think this. They must want this because I want this. I have had people express this idea in different ways like if this were my child how hard would I try if they were my own child or my grandchild or because I go to church or because I love Jesus, whatever they all have a reason why they are willing to work this hard for someone. You know I think about my grandpa after he had a stroke and you know how hard it was for him to communicate. Everyone has some sort of way of how it relates to their own value system I think. You have to have that. Because if you don't have that I don't think that you would be able to do it because you would just get frustrated and eventually you would say you know it just isn't worth it. Or I can teach kids who can talk to me.

CHAPTER FIVE

Findings

This study was undertaken to allow for the investigation of the experiences of individuals who have a vested interest in and experience caring for and leaning ways of understanding the needs of individuals with autism. The previous chapter provided detailed narratives from a caregiver, a parent and a teacher of individuals with autism. These narratives were provided to help the reader gain a deeper understanding of how each of these individuals viewed and understood their experiences working with, caring for and teaching those with autism.

The interpretive process begun in Chapter Four has been continued in this current chapter. The focus of which is to display for the reader the main thematic findings of the study. The process of identifying themes was one that was undertaken by study of the rich narrative accounts and the formation of ideas and concepts drawn from the researchers experience and numerous memos and personal notes that were created over the process of the study. As different ideas and concepts arose from meeting with and conversing with those that participated in the study, these ideas were recorded for future review. The ideas and thoughts that were written down were then compared with the thoughts and ideas that flowed from the previous encounters. These combined became the data which was analyzed using the hermeneutic methodology described by Leonard (1994). In this method all data was analyzed through the three interrelated processes of thematic analysis, identification of exemplars and the search for paradigm cases.

The process of uncovering themes that were descriptive of the overall experience of the individuals who participated in this study was one that required patience and the ability to work in a flexible manner with the experiences that were shared. A continual movement back and forth from specific experiences to the whole experience was necessary to understand the ideas expressed. Once an aspect became salient it was then tested across the other accounts to see if it was a common experience. At times the experiences didn't confirm each other and new ideas were then created and tested against the data. As different ideas were entertained and the experiences were read and re-read new ideas began to immerge which enlightened the researcher and often created a new understanding of how ideas that once seemed unsupported were now clearly supporting this new idea. Considering the different backgrounds of the individuals who participated in the study it seemed at first that their experiences were so unique that each one deserved their own study and presentation. Only through this process of questioning, comparing and re-questioning was it possible to view the true value of combining the vast and various experiences of these individuals to gain the greater understanding that was eventually achieved.

The excitement for the researcher was great when ideas began to emerge. There was a temptation to take the first common themes that emerged and begin completing this findings portion of the research project. As this process unfolded new and more compelling ideas would emerge that would cause a return to questioning and begin the process anew.

As in most research, time was a factor that was most precious. Regardless of this it was refreshing and useful to put aside the ideas and experiences for a number of days and even weeks in order to gain new perspectives and to begin again to study and compare with new eyes and a fresh mind. This also had the benefit of allowing the researcher to continue to grow in experience and even incorporate some of the new ideas in personal experiences in the field of caring for individuals with autism. It seemed when working with families who were struggling with many of the issues discussed in this research that as the researcher shared with them the new understanding and wonderings they would be comforted and at times intrigued. At times comfort was not their experience but rather they would share with me another view point related to their experience that I had never contemplated. These experiences fueled a desire to return to the experiences in the research and again question the data and find new common themes.

At times this process gave the researcher the feeling that he was beginning over again every time new ideas or themes would present themselves. Later, it became clear that this was the result of truly experiencing the circular process of inquiry. The loops of the inquiry were frustrating but insightful. The process of breaking free from long held beliefs and ideas was a difficult experience for the researcher. As the questioning began again from this new horizon it was refreshing to accept the changes that were experienced and to begin again with excitement concerning what more there was to be learned.

This research is a continually evolving and growing experience which will continue over time. For the purposes of this study a completion point was chosen. It is the belief of the researcher that this inquiry is one that could continue indefinitely. Perhaps not with the data compiled but the ideas that have come from it continue to beg for further exploration. It is the hope of the researcher that the findings presented will help others to explore and continue to refine the ideas presented. As this process continues it is the belief of the researcher that new unique ways of understanding the inimitable lives and experiences of those who work with individuals with autism will be clarified. More importantly a richer understanding of those who have been diagnoses as having autism will result.

The themes presented are the culmination of many days, weeks, and months of organizing and reorganizing and have been presented in a way to tell the story of the experience of identifying the themes. The themes have arisen from the data that were gathered from the participants. Explanations of each theme are given which give insight into the thoughts of the researcher. The quotes from those that participated in the study are chosen to show how they correlate with the ideas expressed.

Thematic Analysis and Presentation of Exemplars

The experience of coming to understand the needs of individuals with autism is a story of compassion and patience and of individuals who have gone beyond normal expectations because of their dedication to those they love and serve.

The general themes are presented in this section. Contained within each theme are contextual factors that further highlight the importance of and give clarification to each general theme. These contextual factors were not chosen as themes because of their ability to fit within the auspice of a previously identified major theme. At the end of each theme there is a brief discussion on the implications of the general theme in relation to previously held ideas and research.

The themes begin by outlining the participants' experience of working within and adjusting individuals with autism to conform to societies expectations. Taking time to understand the specific wants and desires is a theme that highlights the need for patience and a willingness to adjust personal needs for the needs of the individual with autism. Social needs are discussed in the light of the necessity for these individuals to have a long term caregiver that will be a buffer for them between their reality and the needs of every day life. A theme related to the consequences of trauma experienced by individuals with autism shows the experience of how it has affected future behavior and reaction to new situations. The last theme and certainly not the least important, identified the way that the caring individuals who participated in the study have come to understand the needs of those individuals with autism.

Adjusting to Fit Society's Expectations.

A question that returns again and again to the researcher is why we as a society adjust those with autism as opposed to helping society accept their unique behaviors. The data summarizes many experiences as the narrative accounts are shared by the participants in this study. The following discussion will attempt to show how we in society often make choices for other individuals who are not as able to express themselves as effectively as an average person in society. It is important to take into consideration that their desires may not be the same as society in general and applying society's expectation of conformity may not be in the best interest of the individual and not be in accord with their true desires and wants. The following experiences relayed by the participants in the study showed that often the need to conform to society overrode the need to identify and honor the individual's needs and wants.

One idea that was expressed regularly was the idea that those who care for individuals with autism must take a vested interest in trying to understand the often subtle and difficult to understand desires and needs of these individuals. There seems to be a cost effective way of doing things, a socially appropriate way of doing things, and a respectful honoring way of doing things. Breanne expressed well the idea that was commonly expressed concerning learning the balance between what is socially appropriate and what are the true desires and needs of the individual.

Breanne: *How hard did you really try to understand their needs or did you just instantly think they must think this because I think this. They must want this because I want this.*

She recognized that often the easiest way to proceed is not always the most honoring. A natural response that we generate is to assume that because we would want something another person would want the same thing. This can be due to our focus on the person more than their situation, about which we may know very little. We also know little about how they are interpreting the situation. This is known as the Fundamental Attribution Error (Ross, 1977). When dealing with a person whose social abilities and desires are completely different than the average social person it is presumptuous to make these assumptions. In Donna's experience it can be seen that she makes efforts to value these individuals' desires by helping her staff to be flexible in the types of meals that are prepared for these individuals with autism who live in a group home environment.

Donna: *One thing that my staff has been learning or the staff has been really willing to do is to try and make it so that they would be happy with the food that there is. The things that they really like they know without a question that there would not be a problem when they cook those things right.*

Over time Donna and her staff have become aware of the types of foods that are appreciated and they have made efforts to prepare those foods as opposed to preparing foods that would not be enjoyed. The types of foods that are enjoyed may not be consistent with what an average family would eat such as fruit served with barbeque sauce and mustard or sushi served with ice cream. For these individuals she worked with these tastes were desirous and to restrict them simply because it was odd would not be respectful to them or their desires.

Another area where it is important to realize that events that are normal for the average person can be very traumatic and confusing to an individual with autism was a simple visit to the doctor for a pre-surgery check up. The following experience shared by Donna displays how traumatic it is for an individual with autism to be submitted to a procedure that is common to most people. Proper preparation protocols were not adhered to because it is beyond normal protocol for the hospital and understanding of the unique needs of the individual was not taken into consideration.

Donna: *We had an incident just recently with one young man. He was going to go for his pre-check-up with the doctor before he could go in for surgery because it had been so long she wanted him checked thoroughly over. She told me: "I want to check his heart with the stethoscope and I would like to check his ears." I said "good luck." (Laughing)... And of course the office...I asked them where they were going to put us. I said if it could be bigger, it would be better if it was a larger room because it gives him a little more [comfort] than a tiny room.*

A small room was used because the doctor didn't see the need to use a large room for a quick examination. Once the procedure began to become very upsetting for the individual and then impossible for the doctor to proceed it was then determined that perhaps other arrangements needed to be made to accommodate this individual's needs. Donna again expressed how difficult it is to change expectations for an individual with autism once you have begun to submit them to an event. Donna felt that it is better to follow through with the original plan rather than change mid experience because our comfort level has been adjusted.

Donna: *Of course they wanted to move him then to a bigger room and I said: "no you have already asked him to go into this one." And I think that is one thing that is very particular. If you are asking him or them, an autistic person, to do a real tough thing, you need to follow through with that tough thing.*

Because this experience was so upsetting and difficult for the medical professionals a medical plan was put in place to prevent a similar issue in the future which involved medication to sedate rather than use appropriate planning to prepare an environment that was conducive to this individual's particular needs.

Donna: *This last time at the hospital they actually gave him a drug. They used Ketamine and it just took him down really quick. And because I know him so well you could see that he was really worried as to what was happening to him. He did not comprehend.*

Ketamine is a drug often used in veterinarian clinics primarily for use with horses. This drug has the side effects of muscular skeletal paralysis without any sedation effects. It is difficult to fathom what this experience would have been like especially considering there was no way to express to the individual with autism what was happening or gain any form of consent for the procedure.

At times Donna finds it is necessary to adjust the individual with autism's patterns contrary to their desires due to the fact that many social systems such as government and school systems are not prepared to make the type of individual adjustments that would be necessary to accommodate the unique needs of each individual. She shared an experience where she felt it was necessary to insist that an individual with autism eat breakfast against his will because she new that the school system was not prepared or capable of attending to his dietary needs.

Donna: *If you put him in the school system and say oh well just leave him, he never ate anything that day. Then you have however many children that they have already in the classroom and you're going to have sporadic*

> *breakfast times? That starts to play into some of the key issues, no one is going to accommodate.*

Breanne's experience shows how she is aware that it is sometimes easier to accommodate systems than to accommodate the individual needs of a person with autism.

> *Breanne:* *How we plan an IPP (Individual Progress Plan)... but unfortunately they [individual with autism] don't have much input. They are supposed to but it is difficult right. So we sit down with parents and the child and we try to look at where the parents and the child want them to be in five years in ten years and how... rather than a developmental model where the child has to go through these stages because you are never going to get far that way.*

The desires of the guardians are placed above those of the individual with autism. This is usually done because it is difficult to gain information from the individual that would be helpful in creating a progress plan. By following this process the individual plans are based on the desires of the parents and/or guardians and not particularly on the desires and needs that the individual would potentially indicate if they had the ability to appropriately express them.

Social Pressure to Conform. It was clear from the visits with Brian that there was tremendous pressure to ensure that his son performed in a way that was socially appropriate. All of the training that he received was focused on helping him and his spouse to develop behavioral programs that would "train" their son to be as "normal" as possible. Even at present Brian's focus for his son was to make him as socially integrated as possible. The following experience from Brian depicts the type of social molding and training that was implemented.

> *Brian:* *[regarding making eye contact] you have to train him at the beginning to do it because that's a social norm to look at people when you talk to people. So you have to make them as normal as possible and they can be trained.*

The way that Brian raised his son socially was by comparing him and treating him the same way that he treated his other non-autistic son who was similar in age.

Brian: *So since we had another child close to his age he ate when the other child ate we made sure that he did the same things.*

The focus for Brian's son was to mold and train him to be as normal as possible. In doing this it was impossible to attend to his son's many sensitivities and needs. Even though at times this was uncomfortable for his son the need for social conformity was so great that he would implement programs that were distant from his son's wants and desires in order to accomplish his socialization goals.

Brian: *He likes order in his life and in his world. It's a security blanket. And his schedule has to be the same. It changes...they don't adapt well to changes. It is something that you can train in them though. It's a lot more work to train them to adapt to new environments every day. It could be done but it's going to be a huge amount of trouble. You might as well setup a routine and vary it from time to time and ask him to deal with it.*

This type of social manipulation is also common in school programs. Breanne shared an experience where she worked with a young man with autism extensively to help him follow through with a reading activity.

Breanne: *So finally I said "Ok read. Stop. Make a picture in your mind. Read. Stop. Make a picture in your mind." And if he couldn't tell me what picture was in his mind I wouldn't let him read on. Then he summarized the article perfectly because he was obviously thinking in pictures and he was reading words. He wanted to get it done because once he got his article done he got to look at the sports stats (laughing). Which is really highly motivating [for him].*

As a teacher Breanne finds herself often in this bind of having to continue her school program even though it is obvious that it is far from the individual's needs and wants. This experience is one that is common for most young students as they progress through the educational process. The difference is that the goals a student without autism has may be and aught to be much different than those of an individual with autism. Until these goals are properly identified by coming to understand the particular needs of the individual with autism we may question their appropriateness.

Those who are made responsible to make important decisions for these individuals are pressured to promote sameness in society and cause individuals with autism to conform to what society sees as normal behavior. When we accept autism as simply a deviation from normal the natural response it so train into them behaviors that make them respond, look and communicate in ways that appear normal and socially appropriate. Contrary to this idea when we view autism as a specific set of social behaviors and attributes it become preposterous to think that it is appropriate to change there responses to be that of another social group.

Being Socially Appropriate: A Blockade for Individual Expression. This contextual factor discusses the inherent problems related to adjusting individuals with autism to fit society. The curbing of the actions and reactions of individuals with autism is done in order to not cause society to become uncomfortable. This presents an obstacle to individual freedoms because so much time is spent on managing behaviors as opposed to allowing free expression.

Donna described how there were certain behaviors that were deemed inappropriate by society and thus were programmed out of practice through behavioral modification. She expressed this in an encompassing manner with the following statement from the data.

Donna: *So we guard him from being inappropriate in society only because society won't enjoy it.*

The types of behaviors that Donna was referring to were not behaviors that were violent or immoral but rather behaviors that were common among innocent children. Once these individuals with autism reach the age of majority there were new regulations and new social expectations placed upon them that they lived incognizant of. One young boy who loved to make contact by way of a "butterfly kiss" (fluttering the eye lash on the cheek of another person) was eventually trained to not do this behavior as he became older and larger in stature.

Donna: *He loves to get butterfly kisses and of course it is not always appropriate in the public school to go up to somebody and want them to give you a butterfly kiss, right. He gets pretty close and personal. So we as staff have had to not do butterfly kisses with him anymore when he was little it wasn't so much a big deal. This is the hard thing, right because they don't quite understand or comprehend what has changed. You can't all of a sudden cut out the affection for that young man, right.*

Donna shared that the only reason she restricted this behavior was because of the reaction that she would receive if he were to practice this activity in public.

Donna: *See personally I don't see anything wrong with those butterfly kisses but because we take him out into community and he just walks up to any old man or any old lady and decides that he is going to want a butterfly kiss from them…I mean his cheek is cheek to cheek with theirs right. That is where it becomes socially inappropriate, right. So that is how society views it.*

Brian's experience is one in which he has done everything in his power to help his son conform to social expectations. He feels that he must train his son to act appropriately so that he will not be inappropriate in society.

Brian: *So you have to make them as normal as possible and they can be trained.*

Much of Brian's programming was designed to change behaviors that were not socially appropriate in his son. Some of these behaviors which were programmed out could be seen as social preferences for an individual who was not autistic.

Brian: *even though at first they don't look at you… that's one other sign, they won't have eye contact with you. We don't know why. Probably has a visual…because they would rather see you from the side. I guess their visual is refined, too refined; probably hurts their eyes, so they are always looking at you sideways. So you have to train them early on to have eye contact again with candies, little pieces of candies, then you can begin to hold eye contact. Every time you talk to my son if you notice that he starts not to look at you again you say "Look at me" and then you will notice his eyes go straight to yours. You have to train him at the beginning to do it because that's a social norm to look at people when you talk to people.*

The pressure to conform makes it difficult to allow these individuals to express themselves in ways that are comfortable and preferable to them because these methods do not conform to social norms. Identifying these ways of individual expression become a quest of importance for caregivers and these individuals.

Recognizing the Individual. The need to recognize each person as an individual is not a new concept in our society. There are those who live in our society who often go unheard due to their inability to express their individual needs and desires. Donna describes in her experience a true desire to focus on the individual strengths and weaknesses of each person with autism when making decisions about their futures and care.

Donna: *There has to be a way that society can help these people these individuals keep their identity individualistic to who they are. Without taking them and saying and demanding that they live under the same regulated rules.*

Breanne echoes these sentiments by stating how she uses her "golden rule" to help her know how to work with individuals with autism.

Breanne: *I think for me, and I found this is the golden rule. You know, if you had this disability and nobody knows what tomorrow holds, how would you want to be treated?*

Implications. As is seen in the bulk of the research related to autism a tremendous focus is placed on behavior modification as a way to bring the behaviors of individuals with autism in line with societal expectation. The idea that individuals with autism should be conformed to be like their cohorts in society is distant from the principals of recognizing and accepting individual desires and rights. When individuals with autism are viewed as a class of individuals unto themselves as opposed to a variation of normal, new ways of respecting their identities become apparent. Consideration could be made to develop more guidelines to safeguard the individual rights of individuals with autism as opposed to creating more guidelines and behavioral programs to enforce what is socially appropriate for them to do. The present practice of conforming to societal expectations is distant form the current standards that are in place in the Province of Alberta concerning quality of life for individuals with disabilities which states:

> *Individuals have the right to make decisions in everyday matters, such as what to wear, what and when to eat, how to spend their free time, and so on. Everyone has some way of making their personal likes, dislikes, needs and wishes known, provided others will take the time to listen.*
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> *(The Alberta Association of Rehabilitation Centers, 2003)*

It Takes Time to Understand Autism

A theme that continually emerged from the data is that of the necessity to be patient and allow time to help individuals with autism adjust to new situations and life choices. In each of the stories told there are many references to the experience of giving or spending time to understand or help progress an individual with autism. Most individuals who have not had experience with individuals with autism may not have a clear understanding of the time that it does take to get any form of progress. This issue is also prevalent when funding is determined by governments and politicians who tend not to be people who have extensive experience working with this group of individuals. Donna's words exemplified the typical amount of effort that was common for caregivers, parents and teachers that was required to help progress an individual with autism.

Donna: *One young man just refuses, we try, we try hand-over-hand coaxing all the time and we go through a routine and we have worked out a specific routine just personally for him in regards to, you know, how to go through a day time. And we work on that continually. We've continually worked on that in nine years. We see little bits of improvement where he will now actually take the deodorant out of the drawer and he will put it on like I can verbally say "put it on" and he will put it on. Not that he will get it in the right spot but he will get it on. If he is close I leave it, no problem but if he is getting it to close to other parts that doesn't need it then I will move his hand out of the way. But I mean that is a good step.*

Brian's experience as well shows the numberless hours that he dedicated to his son's treatment over years to gain small outcomes.

Brian: *since he was so far gone we had to cut the Smarties into little 8ths, that was a big chore right there. ...(laughing)... cutting those Smarties in 8ths, and to stop him from hitting we would have to sit with him and hold his hands and extend the time of not hitting by rewarding him with little Smarties and that is how we got him to stop hitting himself. And that's pretty well it for 2 or 3 years, those interventions are what did it.*

Breanne speaks of the frustrations that she felt when she wasn't given sufficient time to learn how to appropriately help an individual with autism. She makes reference to a young lady that she had an opportunity to teach.

Breanne: *She has never been in a program long enough to... for people to genuinely get good at understanding her. It would have been nice to have her for three years and then we could have really seen if it clicked in for her.*

A key to understanding individuals with autism was expressed by Donna in her experience of how she had come to understand specific needs. As these individuals became integrated into the lives of those that cared for them the caregivers were able to sense their needs and begin to make choices for them based on their experiences with them.

Donna: *I think the key thing for us has been... is that we have a home where they have been together now for nine years. And most of the key staff or the key working people that are with them have been there almost the same length of time. And these children have been integrated basically into the homes and the functioning of these staff people. They have really allowed them to become part of their life. And I think because they have done that then they can actually perceive some of these things with these children before they happen.*

Over time caregivers can begin to sense and react in a timely manner to avoid uncomfortable situations with these individuals as they become perceptive of their desires and needs.

Donna: *So I would say that the more you know them the easier it is perceive or discern what they going to do and how they are going to behave, right.*

Brian was also very adamant that he could not help a family with an individual with autism unless he knew the individual and family well enough to make recommendations based on the families and individuals specific needs. He felt that it took more than just a simple answer to get progress. When asked what he would tell a family who was struggling with raising an individual with autism he stated that there was no advice that he could give unless he knew the exact situation they were experiencing.

Brian: *I would have to know them.*

Because there is such a demand on time it is sometimes difficult to ensure that the individual with autism is being treated in a way that is best for them and not only in a way that is best for the system that is responsible for them. One of Donna's greatest fears was that one day some of the individuals in her care would be transitioned out to another placement and the information that had been gained over the last 10 years would not be taken advantage of. Due to the dynamics of various programs, she believed that regression could happen if they did not take the necessary time to complete a proper and carefully planned transition.

Donna: *you take this young man this older one that I was talking about and remove him to another home where no one knew him, meds would be the first thing that would be upped to the degree that he would not, no longer function. Because he is very capable of being abusive right to the degree that he could really hurt someone or somebody. But without them having any idea how to deal with him or be aware of what his triggers are they would really throw him into a tizzy. Because they would want him to eat this and he wouldn't eat this. He would probably go hungry for I don't know how long, because they have no idea how to deal with his food or how we get him to eat. He would not brush his teeth; he would not bath for them he would poop on them. He would be a mess, he would be a mess. And that is what they are dealing with. One great big huge psychotic mess, because that is what it would look like to this other staff.*

From a teacher's perspective, Breanne also shared a concern about continuity for individuals with autism. Often changes that are out of their control limit the ability of caregivers and teachers to develop a time based program to create an understanding of the specific needs and desires of the individual. With numerous transitions individuals with autism can be delayed in their progress and it can become frustrating for caregivers, teachers and parents.

Breanne: *We had a girl this year and she started out as a 13 years old with no communication at all; none. So we went through everything that they tried which was basically everything. The drink place was catching on and then they moved her to a different program....she had been in you know in 8 years of school she had been in about 10 schools and this year alone she has been in three. Because after setting her up in the one school that she moved to and giving that teacher lots of information about her, two months later I get a call from a different teacher who is actually a friend of mine saying "this new girl just moved in and I need help! What does she do and how does she communicate?"*

Family dynamics played a major role in the longevity of an individual with autism in a particular program. Transitions often happened because of changing family composition and financial upheaval. Due to the stresses and time commitment required by parents to care for these individuals strain can be placed on the basic family unit both emotionally and financially.

Brian: *My wife and I, spent 16 hours a day and we had workers. We had a worker everyday, 5 days a week, 4 hours everyday and that was our break. Other than that we had to do [it].*

At the same time in his life Brian was required to work two jobs in order to maintain the house hold in Ottawa.

Brian: *In Ottawa you need two jobs to live.*

There were also other children in the home that needed the attention of parents. When asked if he spent every free moment working with his son with autism he stated that he had to find time for his other children but most of his time was spent helping his son progress and achieve desired goals. Brian shared how this demand on a family could be destructive to the integrity of the family relationship, especially for parents. In his account Brian used the phrase "there lives are on hold" to express the type of time commitment that is placed upon families. Considering the longsuffering necessary and the potential for frustration he gave advice to parents on how to defend against marital breakups while working with and raising a child with autism.

Brian: *Maybe a counselor could get a commitment from the parents and talk to them on a regular basis because they will get discouraged and they will need to know where to vent and put there frustration because there will be a lot of frustration. And their lives are on hold until their problem is alleviated.*

The Dangers of Frustration. In our society time is a very precious commodity and individuals with autism, as shown in the narrative accounts, have a particular need for more time than other individuals. One of the dangers that presents itself is when frustration due to the demands on time and patience begins to play a role in the choices that are made for these individuals. Burnout in schools, the workplace and home are a reality that must be addressed for those that care for individuals with autism.

Breanne: *Everyone has some sort of way of how it relates to their own value system I think. You have to have that. Because if you don't have that I don't think that you would be able to do it because you would just get frustrated and eventually you would say you know it just isn't worth it. Or I can teach kids who can talk to me.*

When caregivers and teachers burnout they then put the individual with autism at a disadvantage because of the many hours, months and years that it has taken for them to become aware of the individuals unique needs and abilities. The process of learning this individuals manner of expression must then begin over again with a new person which leaves the individual with autism wanting.

Breanne: *So when you look at the burnout, people who should have been there for all of junior high haven't been you know or that little girl who gets moved every year or three times this year ya. Where does that put her? There's not going to be anyone there who is going to be able to say "you know she really likes…this kind of music." You know?*

When considering the detrimental effects that burnout and frustration have on caregivers and the amount of stress placed on the family unit which provides care for their child with autism can be staggering. Many families are unable to continue under the stressful, time demanding environments that are forced upon them due to the nature of raising an autistic individual. One method that has been used to deal with this frustration is to use practices that may become abusive. These practices are used because they are effective in getting immediate outcomes. An example that Donna shared in her story was of a child who habitually took food out of garbage cans and ate it. The guardian was incensed by the practice and threatened to use corporal punishment to curb this behavior. Donna stated that this reaction was not uncommon and that it was difficult for her to endure when she knew that these practices were being used with individuals with autism.

Donna: *So that just made me really uncomfortable because I know personally dealing with him that you don't have to be mean or abusive, right. That disturbs me completely, because I believe that there are other ways to deal with it, right. You can be kind and still deal with it.*

Breanne expressed her concerns about the way that individuals with autism were treated due to the fact that they could not express themselves in a way to protect their individual rights.

Breanne: *I think that there is a lot of abuse that is going on that is not noticed or cared about. Maybe it is noticed but on one is going to make much effort to stop it for a non-verbal person.*

Some families choose to place their children in residential settings so that the care of their children can be performed by individuals who are paid to deal with the often frustrating demands. Donna who provides care for individuals with autism expressed in her experience that if there was more help and training provided for parents they may be able to maintain their children in their own home.

Donna: *If you had someone to come in who had the patience, knowledge and capability of showing the parents how you could deal with the individual in a non-abusive manner I think that there could be a lot of happy support in that sense.*

Donna sees home as the ideal placement for individuals with autism because of her belief that it is best to have an invested guardian who is aware of the individual's needs through first hand experience.

Donna: *If families are capable of functioning with their autistic children it is best to be care for by them. That may be more of a key thing for them, because they would know their children from birth to what ever age.*

Implications. Looking carefully at how we evaluate the time that is given to provide quality of life and care to individuals with autism could lead to greater understanding of their particular needs for transitions. From this theme it can be implied that the passing of time is a necessary component in coming to learn the needs and desires of individuals with autism. If proper allowances for time are not respected, the potential for frustration with and abuse of individuals with autism could increase. This increase would be remorseful especially considering that abuse among the non-verbal population is an appalling problem in our society (Konstantareas, 1998). Proper supports for families could be formulated with a priority to prevent abuse and to help keep family units intact. Consideration of the demands on families could to be undertaken so that families could have the proper funding and supports to allow them to maintain healthy households and potentially keep their children with them as long as is practical. Since family members are those that typically would understand and have spent the most time with these individuals with autism they may be the best guides as to determining their needs and wants. It would then not be necessary to integrate them into another workers life to learn their desires and needs. This is especially imperative since teachers and caregivers can be much more transient due to the realities of fiscal management and burnout.

Social Needs: Guardians.

In coming to understand the social needs of individuals with autism it is important to have the understanding that their social needs are not the same as the social needs of all people. One area that is uniquely different is in the need for a guardian who can make decisions concerning safety and welfare for the entirety of their lives. This need causes particular dilemmas due to the inherent problems of maintaining a child with a developmental disability in a family unit for parents and for siblings. Donna, in describing this need for long term care expressed that though there was progression over time this progression would not be sufficient for the individuals that she worked with to become independent.

Donna: *Safety is still a concern even until now. And he will still be the same as he is now as he will be when he is 45. I do not see a great change for him. Just anything that we can keep that he is capable of now is a positive.*

Donna: *They are never going to progress to the point that they are fine on their own.*

As an educator, Breanne echoed the need for someone who would be caring enough to make decisions for these individuals after they had reached the age of majority. She expressed the desire that the caregiver was someone who would have a vested interest in the life of the individual with autism so that the choices made for them would be in their best benefit and not simply the most economical or convenient.

Breanne: *You hope that there is someone involved who knows and cares enough to make sure that the decisions are for the benefit of that child and not for the caregivers.*

Breanne: *Then what happens to that poor kid who is actually sitting twitling his sock in the corner because he is easy and hasn't bit anyone you know and he is just going to go deeper into himself maybe and not having the care that he needs to become the best that he can be. And if there is no parent involvement it is easy for an agency or a group home to go with that model I think and the government too. The government wants the easiest way out as well for their paycheck, the biggest bang for the buck as well or what ever.*

When asked about his son's future, Brian felt that if something traumatic happened to him and his wife he could rely on the government to care for his son.

Brian: *and there's the government of Alberta where we know of their programs, group homes and how they work and...and he wouldn't be by himself. He will always be with other people with his type of problems. They are not always the best because my wife works for them in group homes but it is better than no environment.*

After discussing further he shared that the care that his son would receive would not be the same as the care that he would receive in the home environment. Government guardianship is seen as truly a last choice option.

Brian: *There is no way a government could mimic what we offer him as a family.*

It was difficult to discuss with Brian the process that he expected to happen with his son after he was no longer able to care for him. He expressed in a joking way his expectation that his other sons who do not have autism would simply accept the responsibility of caring for their brother.

Brian: *He has brothers.*

Brian: *His brothers have to be nice to him, like I said he is our cook.*

This is a common concern for families who have children with autism. There will come a time when they are no longer capable of the care requirements of their children and will be required to access the public system to provide guardianship in the future. Lobato (1990) discusses some of the benefits and risks of siblings taking on responsibility for their disabled siblings. Though it is becoming more common there are many issues that must be addressed before this type of caring situation can be successful.

Caring for Guardians. It is odd discussing the needs of another individual when considering the needs of individuals with autism but it is appropriate when you consider the importance of maintaining caregiver contact and participation with their children. According to Fishman, Wolf, Ellison, & Freeman, (2000) the impact of a child with a developmental disability such as autism has greater detrimental effects on parents and siblings than other disabilities. The narrative accounts in this study express the need to care for the caregiver in order to create an opportunity for them to continue to participate in their child's life over time. Donna shared some of the difficulties that she had seen in her experience of working with individuals with autism and their families.

Donna: *We realize that there has to be someone who cares about and loves this individual to determine what is best for them, yet at the same time we can see that families can be overwhelmed and overrun by the demands to do that thus causing them to live in a way that they would rather not live, right, the families, the parents.*

Donna: *I can see how in a family situation that just gets so frustrating.*

Brian shared in his experience what it was like socially to have a son with autism and how it affected him and his family when they began dealing with the behaviors their son began exhibiting.

Brian: *He had black eyes. It was fun going public with our son in Germany, it was lucky we didn't get beat up by the people. They don't hold to child abuse over there. It wasn't abuse but they didn't have any way to know that.*

In order to protect his son from self injury Brian purchased a hockey helmet to be worn in public.

Brian: *It was fun going around with a kid in a hockey helmet.*

Though he uses the term "fun" to describe his social experience of going into public with a hockey helmet on his son he implies some of the difficulties common to many families who have to make unique social adjustments to accommodate their child's disability.

Caring for an individual is also an experience of unpredictability. For many guardians this can be an aspect of care that over time becomes overwhelming. By discussing her reaction to a violent episode, Breanne highlighted this constant feeling of being on guard when dealing with individuals with autism.

Breanne: *The guy went flying and I would have told you that he liked that guy but not right then he didn't. Get between me and my burger I guess. And he was like "Oh Mrs. B. remember we played fish come play fish with me. Come go for a walk around the school with me." You got the feeling that he liked you but there was no...*

Brian also experienced this type of unpredictability in his life by describing how things always happened at the most inconvenient time for him and his family.

Brian: *We were in Germany at the time; of course everything always happens when you are away from home.*

Every time a new difficulty was encountered with his son he expressed that he felt like his life was on hold while he was developing a way to alleviate or manage the problem at hand.

Brian: *because there will be a lot of frustration and their lives are on hold until their problem is alleviated.*

According to Donna one of the ways to support families who care for an individual with autism is to put in place enough respite that they can get appropriate breaks to help them to be able to care for their child over time.

Donna: *They would have to have respite of some sort where that individual was removed from the home at some point right and put into a spot where they could be taken care of and the parents and the family would have a break.*

Brian indicates that more responsibility should be placed on governments to provide for families so that they could continue to provide care for individuals with autism.

Brian: *And if there is no help from the province they have no choice if both people have to work they can't work and come home and do 12 hours of therapy at home. So it depends on the government.*

Implications. This theme is one that has far reaching implications for the individual with autism. Since it is necessary to have an individual who is willing to maintain a close relationship with them over time who can make decisions about safety and living arrangements; more needs to be done to promote healthy lifestyles for guardians. Since families appear to be the best guardians for their children with autism it might be wise for governments and policies to focus time and resources on creating ways to help families manage the many stresses that will be placed upon them due to the nature of Autism. From personal experience the researcher has seen a priority by governments to focus on crisis management rather than future prevention of crisis. Early family intervention may be one of the keys to helping decrease crisis in the future. Focus has also been on behavioral programming for the individual with autism in order to help them become functional in society. From the experiences shared and from research findings the amount of progress that individuals with autism will achieve tends to be limited and accompanied by a very lengthy and time intensive process. The idea of focusing on the integrity of the living arrangement may be a more appropriate place to spend time and resources.

Trauma: A Basis for Behavior.

This theme was unexpected by the researcher at the beginning of the inquiry. It was believed that trauma would play a significant role in the lives of these individuals but primarily in the way that their behaviors would cause those around them to be traumatized. As the data were studied and compared to the field notes and experiences of the researcher it became clear that trauma plays a significant role in the individual with autism's current behaviors. Trauma also gave insight into ways in which they could be best helped and cared for by guardians, caregivers and families. Trauma is defined as:

> *Trauma is an emotional wound or shock that creates substantial, lasting damage to the psychological development of a person, often leading to neurosis, or an event or situation that causes great distress and disruption. The experience of trauma is a subjective one thus events that may or may not be traumatic to one person could be to another and have a lasting effect on them.*
>
> (*The American Heritage Dictionary of the English Language, 2000)*

Because of the subjective nature of what could be traumatic to an individual, it is important to take into consideration that, events that to an average person have no significance, to an individual with autism could be absolutely terrifying. Breanne described the differences that she was aware of between what some individuals with autism found terrifying because they would be processed in a different way, and what non-autistic individuals see as benign.

Breanne: *They would process it differently. They may see a car but not understand that it is hard. Or even if they touch it they may not understand what that means as far as if it hit something going at a certain speed; Whereas, if there is a loud noise from...maybe not even a loud noise like the noise from an air conditioner that might be terrifying.*

Brian's training on behavioral modification has caused him to see a more limited view of his son's experience of traumatic events. He sees the need to socialize his son as more important than the potential negative and traumatic experiences that he may experience due to the process of being behaviorally managed.

Brian: *Autistic people do not like to be touched. Their senses are heightened, auditorally and visually and sometimes tactile and if one is more heightened than the other for example tactile, for them they will just close in when you touch them or when they wear their cloths. So it depends on each child. I don't know if there is a way to desensitize a person with that one but there is a way with sound. You expose the child to a loud sound for a long time, you probably effect his hearing but that has and effect of...they say for some autistic, some sounds [sound] like jet aircraft. The only way to do that is to desensitize the part that is causing the most problem.*

From the experiences shared in the narratives it is clear that trauma is a common occurrence for individuals with autism. This trauma appears from the narrative to have an indelible effect on future behavior and choices. Donna shared a number of experiences that she has seen that would result in tremendous trauma for any individual regardless of whether they were an individual with autism or not.

Donna: *It was four years ago, so he would have been about 14 or 15 years old and it literally took five of the hospital staff to hold that young man down on the floor to give him the mask...the anesthetic enough to put him out to put him on the bed and put him to sleep, which would just be terribly traumatic. Well traumatic! I mean he does not forget a hospital. Even to this day if you take him to a hospital you can be guaranteed that it will be one of those things where he will have to be forced to go.*

It is hard to imagine what that experience would have been like for an individual who didn't understand the process the medical professionals were performing on him. The memory of this experience seemed to be one that effected this young person's actions even at present.

Donna: *Even to this day if you take him to a hospital you can be guaranteed that it will be one of those things where he will have to be forced to go.*

Donna tries to describe what she feels this young man is experiencing in her own words to try and give others a deeper understanding of what it would have been like to be taken into a medical establishment and held to the floor by five men and to have a gas mask forced upon you.

Donna: *"What are they going to do to me now?"... "Now what is going to happen to me?"*

This young man's last visit to the doctor was so traumatic that after he had been forced into the hospital he became so upset that he suffered a seizure.

Donna: *It was so traumatic that he actually had a seizure at the hospital.*

At another visit to the hospital, Donna recounts how they tried to avoid a violent outburst by administering a drug to the individual with autism to sedate him before he was examined. The experience of feeling the drug take effect was viewed by Donna as just another experience that could be traumatic to any individual.

Donna: *This last time at the hospital they actually gave him a drug. They used Ketamine. And it just took him down really quick. And because I know him so well you could see that he was really worried as to what was happening to him. He did not comprehend.*

Donna explained how one bad experience was all that was necessary to change future behavior in an individual with autism for a long time. An activity as simple as cutting hair or trimming fingernails could become a recurring traumatic event for these individuals. Donna described the amount of effort it took to complete nail cutting for an individual with autism who had had a previously negative experience with nail cutting.

Donna: *It was a year and a half ago almost a year to July I believe this July that... because he used to hand us his hands and let us trim them even though he hated it. You would just keep repeating "hand me your hand, now the next one now the next one." But what he tends to do is jerk away. And one of the staff cut his fingernail and it left it hanging and he got to it before she could get to it and he ripped it. Because he ripped it, he ripped it right down to where it was hurting and bleeding and since that day he has been a fight to get his nails trimmed, right, a fight. I have literally had to put it in as a restrictive procedure so that I put him in a corner and I'm almost sitting on top of him, bracing him against the wall while protecting his arms as best as I can, hold his hands and trim them. And one staff sits and sings to him while that's happening. Or watch the other hand so that it doesn't hurt me. Well the last probably five times, so I do it about once every two weeks I've been trying now to make sure that I cut them about every two weeks. The last five times that I have done it, I've done this for a long time but it has been just this last five times, where he is starting to trust again.*

For Donna it was important to be aware of the various traumatic backgrounds of the individuals that she worked with so that she could be aware of their current sensitivities and try to avoid having to inflict future experiences that could be traumatic again to the individual with autism.

> *Donna:* *The key too is to look at the different traumatic backgrounds of these people. Exactly, where they have come from how they have been treated. And then go from there as to how you deal with them and realize that you may have a few more difficulties with trust issues with them. (pp. 17)*

Implications. Trauma for any individual is a great concern due to the long lasting effects that it can have on emotional and physical wellbeing of individuals (Davis & McKearney, 2003). These traumatic experiences are compounded for individuals with autism because there are limited ways to help them overcome the experience of trauma, except through, as in the above described experiences, a lengthy and trust enhanced time period. There are also implications as to creating and maintaining a record of experiences that have been experienced by the individuals with autism that could be causally related to their current behavior. This could help parents, caregivers and teachers be aware of activities that could be perceived as traumatic by the individual and thus make some allowances to adjust the environment to help alleviate the distress for them.

Avoidance of trauma is an area that could be further studied concerning individuals with autism. Perhaps as shown in the narrative accounts of preparing to prevent trauma, a better way could be found to prepare and communicate ideas and procedures to individuals who do not have the ability to express themselves or fully understand a procedure that is going to be administered to them.

Expression of Needs

At the outset of this research the researcher desired to gain a greater understanding of how we understand the needs of individuals with autism. Who better to consult than those in whom the needs reside? A problem that arose was that there was not a convenient or simple way to access the information from the individuals. The researcher has made every effort to apply questions to the data, created by gaining narrative accounts of individuals who have a vested interest in and much experience with individuals with autism. The hope was to in some way come to a better understanding or a more sophisticated way of understanding what these needs could be. The needs themselves can not be accurately attributed directly to individuals with autism since they are but the perceptions of those who work with them. It is for this purpose though that this research has been conducted to help those that presently and will continue to work with individuals with autism gain insight into some of the issues facing this group of individuals.

The data had to be exposed to many different lines of questioning which looked at expression in many different ways. Verbal expression is the most relied upon method of communication in our society. Many efforts have been made to teach verbal communication to individuals with autism and there have been some successes. Other forms of communication such as PICS (Picture and Image Communication System) and sign language are also taught on a regular basis but each of these is limited in effectiveness of communication. In general verbal communication methods of gaining insight into these individuals' needs and desires tend to be less than effective. As will be shown through the narrative accounts, clear messages are being sent to caregivers, teachers, and parents concerning the individuals with autisms needs. Learning to accept these types of communication that will be presented may hold keys to new forms of communication. Time spent communicating may be done in a more productive manner. Donna described the experience of learning to feel what the individual was feeling and trying to understand how and why they were reacting to a particular situation. When she did this she felt that she was better able respond to the individual in a connected manner.

Donna: *I was speaking to someone the other day that if you start to determine how you would feel in their bodies, you know, when you work with them. How would you feel with what you are asking them to do or having them participate in if you were in their body or in their situation how would that make you feel. And if you start looking at how you would feel and you treat them that way it is amazing what transcribes with them what transforms between the two of you.*

By following this introspective practice Donna was able to be sensitive to the immediate needs of the individual. With her experience she was then able to determine how quickly to proceed with a procedure that needed to be accomplished such as trimming fingernails or going to the doctor's office for a check-up. This very respectful form of management is one that requires the caregiver to proceed at a pace that may not be conducive to society or to the caregiver but it shows respect and concern for the individuals feelings and needs. Breanne recommended a similar approach as she advised to be patient with what you request of these individuals.

Breanne: *Don't expect things to happen quickly that they have to process because their processes are different than ours and so that could take them a while to come back with a response.*

Breanne: *Use both an auditory and a visual method at the same time and try to communicate with that person and be prepared for lots of wait time.*

Body language can be a good source of information concerning the needs of individuals with autism but it could not be relied on all the time to be accurate. Donna talked about an experience that she had when feeding two different individuals with autism. One of them would eat whatever food was placed in front of him because he had been trained to do so by his previous caregivers. Another individual was rather picky and would only eat food in a way that he liked it prepared.

Donna: *For one of the other boys you could feed him anything you want everyday and he would eat it anyways. Whereas this one other boy you can't it has to be certain foods that he will accept or want or with dips.*

After Donna has worked with this individual for a time she began to recognize that he would make certain sounds to indicate that he was not happy with something. These sounds were often not related to the activity at hand but through her experience working with this young man she began to see his vocalizations as an expression of this young mans wants.

Donna: *There are times when you put something down in front of him to eat in the morning that early and he will be unhappy and he will either hit himself or…he'll just slap at himself, you know angry… "ouf"…and he will make an "ouf" sound like a I don't know how do you say that in words…a vocal … not a word of any kind but a vocal acknowledgment that I am not happy about this like "ouf."*

The difficulty with these forms of communication is that they are not all easily linked to the activity at hand. This individual who was previously discussed could be taking the garbage out and making the dissatisfied sound and it wouldn't be because he was taking the garbage out. It could very well be due to the fact that his shoes are bothering him or he is not happy with the food that will be served for breakfast. In order to come to understand his expressions Donna has had to take a special interest in his life. As she has she was better able to sense the specific things that were bothering him.

Donna: *If they are verbal and they can reply back...you may get some sense. If they are non-verbal then it's just a basic of discerning and reading their outward appearance and the body language that they display.*

Donna: *You need to show that kind of interest in their life they discern that from you, right as a worker.*

As implied by this statement as individuals with autism become more comfortable with the person that is caring for and them they begin to express their desires more readily. These expressions may not be desirable as Donna describes in her dealings with a young man who has fun doing behaviors that socially we find repulsive and unhealthy.

Donna: *You could wake up to one having picked his nose and there is blood everywhere because he does it just when it gets dry he doesn't do it as an abusive tendency, right. But the one young man he can poop his pants in the middle of the night just out of shear funny business, right that is a goofy thing for him. BM (Bowel Movement)...Feces is a real happy thing for him; I guess, you know, he just loves that, so he uses that. You know it is interesting thing you know as I have calculated that over a period of time, he doesn't necessarily use it to particularly irritate anybody. He just...he just likes it and does it and it's getting him to realize that he can not do that kind of thing.*

These behaviors need to be seen as the individual's expressions. The tendency for most caregivers is to assume that this expression is simply a negative behavior and an expression of dissatisfaction with others and their environment. Though these behaviors can indicate unhappiness for some individuals with autism it shows that Donna was very in tune with the feelings and desires of the individuals that she cared for.

Verbal Communication: A Poor Method of Assessing Needs. A difficulty that arises with verbal communication and individuals with autism is that their verbal responses are not always indicative of their desires. If you were to ask an autistic individual if they wanted toast or pizza they will often respond with the first option given them and they would say toast. If you asked them again and reversed the choices they would most likely respond with pizza the second time around.

Donna: *He will repeat most of the time the language that he says back to you is a repetitive of what you have said to him.*

Due to this echolalic tendency and the practice of training response behaviors into individuals with autism, verbal communication of needs is a poor method of knowing what they truly desire. Breanne experienced this type of verbal responding regularly as a teacher and had learned to be aware when it was happening.

Breanne: *Like I said that young man who was reading the paper, he could read that and not verbalize what it meant and so if he was saying I would like to go to Disney Land, does he have any clue what Disney Land is or did he see it on TV last night or did he hear someone else in the hallway say that or they just think that that will make you go away so that he can read the stats page. Where as in reality he may what to go and see the New York Yankees or something.*

Donna found in her work that it could be difficult to watch individuals who you care about not have the ability to express to others the things that they would like. With one young man that she worked with she found that he would not express to others when he was hungry. This young man would just continue through with the day until food was made available to him. He may have had difficulty in other areas because he was hungry but it would be very difficult to assess what the problem was unless you had known that he hadn't eaten.

Donna: *There are things that he will request but he would probably not go up to a teacher and say "I am hungry; I didn't have breakfast I need something to eat." He would not do that he would just go ahead with whatever the* *school day was and do whatever until they said ok its lunchtime go get your bags or come and make your sandwiches.*

Donna: *They would never ask for a meal, they have never asked for a meal.*

Learning to decipher the communication is something that can only be achieved through experience with the individual's way of expressing his desires. The one young man that Donna worked with when hungry would request specific foods such as cookies but she had come to know that he was expressing to her that he was hungry and would like to eat something.

Donna: *He would go to someone and say "I want a cookie." He won't say "I am hungry," he would probably ask for something, you know and there are only a couple of things that he ever really asks for.*

Brian's experience working with his son had similar parallels to the difficulties of verbal communication. When he began working with his son at a pace of about 16 hours a day his son was capable of very little communication.

Brian: *He couldn't dress himself, he couldn't speak, he could point to the milk in the refrigerator that was as far as he could go.*

After a couple of years of programming and behavioral management Brian was able to teach his son to speak and do a number of other practical activities. Brian expressed that even though he taught his son how to make a choice his son often didn't have the ability to recognize that he could make a choice and still had to be given the response to the choice.

Brian: *He chooses. Helping them make choices first, then you can give them the tools. You have to notice you have a choice and that's the hard part.*

Many individuals with autism have been exposed to this same form of behavioral training which preprograms their responses to specific situations and questions. Brian feels that once his son learned these behavioral responses that eventually the ability to respond appropriately became something that his son became good at.

Brian: *You can teach them a behavior but you must also teach them to do what they want and what they like then these behaviors become something that they want to show.*

Brian has noticed that his son had over time become subtle in expressing himself by manipulating his father and family to ask him the correct questions so that he could respond in a way that he desired.

Brian: *That is because he trains us. He trains us to ask him what he wants us to ask him. They...some of them can manipulate over time it's not a bad thing, because manipulation is also part of society.*

This subtle form of communication is more indicative of his desires than the words that he actually speaks.

Violence as an Expression of Needs. Movie portrayals often present as the typical individual with autism an eccentric person who is afraid to go outside and who has amazing memory or mathematical abilities. Though these individuals do exist the general public does not have an informed awareness of the realities and social consequences of autism. Violence is a reality that many caregivers, parents and teachers must deal with on a regular and sometimes daily basis. Violence as a form of communication of needs is a lower echelon communication style but it is often regarded as an expression of negative behavior as opposed to a form of expression. As questions were posed to the data it became clear that violence resulted in a restriction of opportunities as opposed to being viewed as a rudimentary form of expression of needs. The experiences of those who participated in this study show an exceptional patience in dealing with violent behavior and give insight into some areas that could be explored to gain a greater understanding of how individuals express their needs.

Breanne, as a teacher is exposed to violence on a regular basis due to the population that she teaches. Unpredictability is the greatest obstacle to finding ways to address the needs of individuals with autism. Violence is not used consistently to express needs and thus when it does happen there tends to be greater consequences.

> Breanne: *a very, very big kid who threw one of the aids, who was very big man, across the food court at a mall and broke his back after I had been told that no none of them are violent you know but they told him to put his burger away because it was time to go swimming and he wanted to eat it and that was it. The guy went flying and I would have told you that he liked that guy but not right then he didn't. Get between me and my burger I guess.*

Breanne's advice to others is paramount when you consider the unpredictability of these individuals.

> Breanne: *I would say go slow, protect yourself.*

An unexpected consequence to violence that presented itself in the narrative accounts was the fact that those individuals who did use violence as a form of communicating their needs often got more attention from their caregivers. In some instances they draw away resources from other individuals with autism because of the necessary adjustment that caregivers have to make to protect themselves and others.

> Breanne: *You hope that there is someone involved who knows and cares enough to make sure that the decisions are for the benefit of that child and not for the caregivers. Because it is really easy to go, lets group these two kids together in a home or what ever because this one is hard and this one is easy so the easy one will make up for all of the time that you spend with this one.*

Violence does not always achieve the desired results for individuals with autism. Sometimes they become very restricted because of their actions and actually lose out on opportunities to learn with others or to express themselves in other ways. Brian was told that because of his son's self abusive manner it would be better to institutionalize him and leave him there.

Brian: *The Psychiatrist in Germany told us that David was so bad off that they would be better to put him in an institution and leave him there. I don't think he had ever seen a kid at 2 years and a half hit himself, abusing himself as hard as he can. That was kind of a shock.*

Breanne described a harness that is used to restrict the behavior of individuals who ride a school bus to school. These are used if the individual has a history of acting out in a violent manner. These devices appear to be very archaic and tend to cause further behavior problems because of their restrictive nature. The harness is an unfortunate consequence of violent expressions of needs.

Breanne: *A harness has straps over the shoulder with clips and two sets of straps around the body and they also have clips that hook into a special harness system seat on the bus. And there's also a place where the seat belts go through but not always. Once you have all of that harness hooked up you are not going anywhere. Even if the bus crashes you are stuck there because it is screwed in tight. So ya, (sigh). It would hurt.*

Donna has found that as the individuals that she works with become more connected to their caregivers the violent behavior begins to decrease. A decrease in violent actions can be regarded as an increase in the understanding between the individual with autism and the caregivers. Violence will still be a regular occurrence but not as often as it was when they were first beginning to work with this individual.

Donna: *He does not physically hit you all of the time. He might every once in a while whop you one but he does not bite anymore he does not hit anymore like he use to and he is learning to actually listen to what you say as you*

> *explain it and make a choice in some degree. But he still may choose not to, you know in that process.*

Breanne's experience was one in which she was not able to work with individuals long enough to get the type of decrease with violent behavior that she thought was possible. Concerning a young lady who she had begun a particular form of communication program in which her gross body movements were identified and systematized as communication, her hope was that over time when this young lady was able to express herself more fully her violent behavior would decrease.

> *Breanne:* *How far it went from there I don't know but that is different for her and at least she could kind of start to tell us because she has never been able to do that before and she could be quite violent.*

A social consequence of using violence as a form of communication is that individuals who are taxing on their respective systems tend to be moved regularly thus limiting their exposure to individuals who can take a genuine interest in them and begin to understand their form of expression of needs.

> *Breanne:* *Especially the ones who are very high maintenance because they beat up their caregivers or they have worn their parents out you know or what ever and so they haven't lived with people on a continual basis or interacted with the same person.*

Danger to Others. Because individuals with autism can be a risk to others there are often restrictions and restraints placed upon them to keep others safe. All participants in the study felt remorse about the restrictions that had to be implemented in order to maintain a safe environment for themselves and others. Brian found that as his son grew older and bigger there were more demands on his time and his wife's time. Before that age his other sons were able to help out with the care of their brother but he soon became too large and dangerous so they no longer could watch him.

Brian: *They did baby-sit for our son when say he was 11 or 12 because we couldn't leave him alone at that age, but after that no.*

Donna had found it necessary to restrain one young man with autism on a regular basis in order to keep his fingernails trimmed. He unintentionally hurt himself and others with them and absolutely refused to allow them to be trimmed peacefully.

Donna: *We have a really problem with his finger nails. Those are one of those things that you've asked that have to be done. I have no question, I have scars on my arms actually that I will probably always have because his finger nails are like a dangerous weapon. Not that he meant to hurt me, all he did was grab me, but he squose and because he had long nails that's what injured me, right. And he will injure himself there are scares all on the back of his…he just has that tendency when he has anything that is upsetting him his hands will fly to his head and he will scratch his head and scratch the back of his neck and if he has long nails he will draw blood. There is no question unless staff can get to him and say "Hands down." So that is one thing that has to happen…so hands down and his nails have to be trimmed.*

If this young mans fingernails were not trimmed on a regular basis he could become a serious danger to himself or others. Donna felt that if this maintenance was not done on a regular basis this young man with autism would be dealt with in a much harsher manner in society if he were to have an outburst and use violence as a form of expression.

Donna: *His nails would be five feet tall and they would have five men or more holding him down.*

Danger to Self. Another sub-theme shared by each of the participants in this study was the danger that individuals with autism pose to themselves. When considering self violence as an expression of needs it is difficult to understand how this type of behavior is reinforced. For most individuals with autism if they are not protected from themselves they would seriously injure themselves and even kill themselves in a very short period of time.

Breanne: *Some of them are so violent towards others and themselves, well mostly themselves. I have seen autistic kids who are blind because they have made themselves blind because they have caused so much brain damage to themselves.*

Because of the risk that they place themselves in it is often required to restrict some of their freedoms in order to keep them from injuring themselves. This balance between what was for their safety and what was socially inappropriate was a difficult balance for caregivers to identify. It was also complicated because each individual case was different and guardians had their own opinion as to what was and was not appropriate. In the example shared by Brian concerning his son's self violent actions it was obvious that he needs to be protected.

Brian: *We had to wrap David's hands with bandages and gauze so that he wouldn't damage his eyes further, he had black eyes.*

Brian: *And to stop him from hitting we would have to sit with him and hold his hands and extend the time of not hitting by rewarding him with little Smarties and that is how we got him to stop hitting himself.*

Donna struggles with identifying this balance for one young individual with autism that she cares for. It is more difficult to determine the amount of restriction to place on an individual when their actions are not violent but still present a potential risk to their safety.

Donna: *He walks down the road and he picks up gum, pills, and whatever is laying around and pop them in thinking whatever, candy or whatever it is something to eat. So for his safety issues allowing him to pick up stuff and just pop it in his mouth we have not allowed him to do that. Where as some say that that is a personal right for them but it isn't a personal right as far as this young mans safety goes, because he can not differentiate between medication and candy. Or something like a poison berry on a tree just walking through a park or a strawberry off of a vine which would be normal for them to eat.*

Breanne again emphasizes the need to have a guardian who can make the decisions necessary to protect them from themselves and others in the community that could take advantage of them because of their innocence and disability.

Breanne: *[They would] be with someone to protect them from the world, [which] doesn't understand them.*

Breanne: *Dangers from other people and dangers from not understanding dangers. Walking out in front of traffic, being terrified of things that aren't dangerous and running into areas where there could be dangers that they don't understand. And being taken advantage of by unscrupulous people who could twist their disability to their advantage in many different ways, financially, sexually, whatever, violence wise but mostly it is the total different understanding of what could be dangerous to them and what could cause them to put themselves in danger.*

<u>Anxiety as an Expression of Need.</u> Anxiety was a common theme that was expressed related to dealing with individuals with autism. Each of the individuals who participated in the study gave numerous examples of how they have had to deal with problems related to anxiety and some of the techniques that they used to manage it. Anxiety was correlated with the experience of trauma and was usually the primary factor that lead up to violent outbursts towards self and others. Anxiety, like violent behavior was seen as a negative side effect of autism. Medication was often administered to manage anxiety in an effort to decrease violent outbursts and increase compliance to caregivers, teachers and parents. From the accounts shared it appeared that anxiety was a reliable from of expression that those that care for individuals with autism could recognize and use as a guide to understanding the individual's needs.

Donna: *Even when he was drugged he did not comprehend and understand he does not like to be out of control at all, right. He likes to be in control and that is really hard for him to be out of control. He has to have control.*

Donna described this need to be in control that this young man had. Having control of ones experiences and obligations is a dear opportunity that is very valued in our society. Donna's experiences showed how she had learned to respect this desire to be in control in helping one individual participate and integrate into social situations.

Donna: *First of all they would not right away associate with anybody who is there. They would remove themselves from that position until they feel comfortable. And it is interesting is to how well they feel trust and secure with the people they are with. Right?*

She also shared how she had allowed this young man to socially integrate into her own family by allowing him to have control over the interaction, using anxiety as a guide to his participation.

Donna: *Not to long ago it was Christmas time that was quite interesting to me. We were…he came and visited with us that night and he decided to stay out in the dinning room part of our kitchen but it is open to the family room area so you can see each other and he just sat on the chair tapping you know like he likes to do all of a sudden Shawn decided he wanted to join us. He hops up and comes down and squishes into the middle of the sofa where everybody is and sits and starts doing his singing "ahhhha, ahhha," That's what he did and he chose to participate in that group with us.*

Donna found that these experiences could not be contrived. If he would participate he must choose to on his own. If he ever felt that he was being coaxed or forced to participate she notices that anxiety was the immediate reaction and he would refuse to participate in any way. Brian found that his son found great comfort in a world that he was able to manage. Brian had made efforts to move his son out of this comfort zone for his social benefit but found it to be a lot of hard work.

Brian: *He really likes to have order in his life and in his world. It's like a security blanket and his schedule has to be the same. It changes…they don't adapt well to changes. It is something that you can train in them thought. Its' a*

> *lot more work to train them to adapt to new environment every day. It could be done but it's going to be a huge amount of trouble.*

Breanne's experience described a similar theme when working with individuals with autism in a school setting. Until they became comfortable with their programming they could often be violent. She shared what she believed would be most useful in helping one young lady with autism become comfortable with her surroundings.

Breanne: *It would have been nice to have her for three years and then we could have really seen if it clicked for her.*

Breanne: *Overall consistency, definite consistency.*

One of Donna's fears is that the individuals that she had been working with for the last 10 years would be transitioned out of her care because they reached the age of majority. Due to government protocols and restrictions they would be forced to begin a new life in a new home with a whole set of new caregivers. She feared terribly what could happen to him.

Donna: *To all of a sudden [place them] in a whole new environment with people who do not have the same kind of awareness or discernment to their behaviors, their tendencies, their wants, their dislikes and I think that you put them in a position that they regress. And they will regress to the degree that could put them in a real serious problem.*

Donna: *He would not brush his teeth; he would not bath for them he would poop on them. He would be a mess, he would be a mess. And that is what they are dealing with. One great big huge psychotic mess, because that is what it would look like to this other staff. "He is a psychotic basket case what are we going to do with him?"*

<u>Reliance on Others for Assurance.</u> Caregivers play a very important role for individuals with autism in that they are often used as references to determine the

appropriate reaction to a situation. This places a lot of pressure on the caregiver to be confident and in control of themselves when dealing with these individuals. Brian found that in his home his son often used him as a sounding board concerning how to react to particular situations.

Brian: *Our son likes to report other people getting into trouble. And he doesn't like it when his brothers do it to him. Sometimes he will do that to check your reaction. He is waiting for you to get angry or ...so he can react to something.*

During the interview with Brian his son approached us with a concern and it was interesting to watch how Brian dealt with the situation in a calm and reassuring manner which immediately decreased his son's anxiety and helped him to continue with his daily activities.

Breanne has noticed a similar phenomenon while working with these individuals in the school system. Part of her program was to do what she calls reverse integration. Students who do not have disabilities are brought in to participate in the classes and outings of the students with autism. She found that the experience was enjoyable for both her students and the reverse integration students but she did notice certain behaviors arose during these outings.

Breanne: *Yes, but there is a definite clue in there that you know...some of them will take advantage of it because they know that those kids aren't going to order them around or use the strong voice or anything. You have to keep a very close eye on it.*

Breanne: *My kids will try and get away with all kinds of stuff they are not supposed to like sticking their thumb all the way down their throat and chewing on it, you know, and we have to go over and go "he's not allowed to chew on body parts."*

Managing Anxiety. Anxiety tends to be a precursor to most violent outbursts that are expressed by individuals with autism. As their anxiety increases it signals to caregivers and those around them that they are becoming uncomfortable with their surroundings or a particular situation. If there isn't a change or an adjustment to their surroundings there could be negative consequences for the individual or the people and property around them. Psychotropic medication is a common method of managing this anxiety reaction but there are consequences to using these medications over time. Those who participated in this study showed an amazing ability to sense and prepare to deal with anxiety. The methods they employed show a genuine understanding of the individual with autism's particular sensitivities and needs.

Donna stated that the doctor who worked with one of the young men that she worked with was surprised when he was informed that medication was no longer necessary to manage behavior.

Donna: *We have [been] good working on getting his medication down and he will be done at the end of this week, all of it. He will have no medication just a vitamin every day and his doctor said: "Really?" He was just excited to see that he wouldn't' need any medication. He has been fine.*

Donna attributes these successes to building relationships with these individuals with autism that help them as caregivers begin to slowly integrate them through a process of trusting and experiencing. Donna's experience described how painstakingly she worked to help a young man that she worked with prepare for a doctors visit he would have in a couple of weeks.

Donna: *He knows it is a clinic and he is already weary but you know we have been singing and priming him for this and we are going to go and visit the office and that it is OK and their not going to do anything to you we are just going to visit. Well he walked in and he wasn't super happy and I had him sit down on the chair and just sit there for a bit and he calmed down*

> *and he could see that the other guys and all of us were sitting there and so he was perfectly happy.*

Once he was calm she then proceeded further into the doctor's office to help him adjust to being there even more.

Donna: *Just so that he would move a little further than the front area. So I took him in back there and he actually let me wash my hands in the sink because that is all I wanted to do was wash my hands. He stood outside the door but I washed my hands. I wasn't making him go in anywhere.*

A plan was developed for a successful visit to the doctors the following week but when they arrived the requested large room was not available and they were given a small room for the medical examination.

Donna: *Well it was the next week that I had to take him right, and they didn't have a bigger room available they had a smaller room. And his guardian was with me and myself we walked in and he walked in perfectly fine, they were prepared but walked in right back to the tiny little room and as soon as he realized that he was going to have to go in there he was not a happy camper. Of course they wanted to move him then to a bigger room and I said no you have already asked him to go into this one. And I think that is one thing that is very particular. If you are asking him or them an autistic person to do a real tough thing you need to follow through with that tough thing. Because otherwise you, if you let up at all they do not comprehend or understand and it becomes a worse fight.*

In managing anxiety it is clear to see that Donna tried to keep her understanding of the situation linked to that of the individual with autism. She was constantly trying to understand his experience and made appropriate adjustments to manage his anxiety.

Donna: *to have moved him from the smaller room to a larger room then would have even been, to me a more traumatic thing for him, right. Because then it puts him into even more concern. "What are they going to do to me now?" Right, they have moved me from where they forced me to try and go into to a bigger room, now what is going to happen to me?*

Donna: *If you sing to him you can almost get Shawn to do anything.*

Donna: *What we do is I sit him at the Kitchen table I put the clippers on the table I put too suckers or two kinds of candy on the table and then I say were going to cut nails Shawn. Now hand me your hand and as soon as we have this hand done you can have one of these suckers or candies. And he likes them but he does not like food to the degree that you can use it for him to do anything, because he will choose otherwise. And this is one thing that he really hates.*

<u>Emotional Needs: A Different Kind of Expression.</u> Coming to understand the emotional needs of individuals with autism remains a mystery. There doesn't seem to be the same social or emotional connections to others that are common and necessary to most individuals. After posing numerous questions to the data concerning emotional needs a different kind of emotional expression began to come into view.

Breanne has found new ways to connect to individuals with autism that she recognized as an emotional expression from them. She compared her experience of being welcomed back by non-autistic students and then the type of reception that she received when she worked with individuals with autism again.

Breanne: *Sometimes you would go back to classes and normal kids will, even grade 11 will, give you a hug or be like cool your back you know but there wasn't that kind of a reaction in a autistic room but there was a "I know what you do" routineness "I like that kind of thing" more, you know. "You fit well with what I like to do and how I do things."*

Brian also shared this same type of experience of recognizing unique behaviors as expressions of emotional connection.

Brian: *You don't need the physical hug to know, just a smile or sometimes they will just come and sit near you. As long as you have taught them what they want to do then you know by certain actions that it is voluntary and they are showing emotion...especially when he can sit anywhere else in the living room.*

Breanne's experience really emphasized the need to be aware of the different ways that a person could interact with an individual with autism. By understanding the uniqueness of each individual, ways of participating with them on their own terms could emerge.

Breanne: *I think that autistic kids are, I couldn't say cuddly but they almost are on their own terms. You go over and cuddle them they are going to scratch you, but they come to you and all of a sudden they want that, you know and there was an autistic boy that I worked with a number of years ago and if you got into his space oh my goodness you would bleed. But he had the weirdest thing because you could tickle his aura around him and he would giggle.*

Donna expressed that through integration into the homes of those that cared for these individuals with autism small expressions of connection could happen as these individuals were able to participate on their own terms and through choice.

Donna: *He may choose to sit. If we are going to sing a song, you know, but he may choose but he definitely has his individual knowledge of what he would like to participate in and what he does not want to.*

Donna: *If we sit as a family and sing, every evening if I am working late we will come home and join them for scriptures and prayers and sing, we always sing a hymn. He loves that, he likes to participate in that.*

Donna felt that this emotional connection was possible for autistic individuals to create. She was overcome with emotion when she discussed how difficult and limiting it would be for this particular young man with autism if he were required to leave this environment where he had created these kinds of attachments.

Donna: *He would judge his trust level on the familiar things that he has had before. I have often thought what would happen if we were all of a sudden just determined out of his life. It would be very (tearing) sad for him… (Quiet weeping for 10 seconds)…I believe that these individuals are capable of love and trust.*

Implications. When considering the needs of individuals who can not verbally or through other conventional forms of communication express themselves, new and imaginative ways to identify different methods that communication of these needs can be accessed is recommended. Conventional forms of communication training still tend to be the focus in educational programs. Though individuals with autism are at times able to use these methods to communicate they don't seem to be a reliable form of genuine expression as shown in the interpretive analysis. From the accounts it appears that this communication is more of an expression of practiced and socially trained responses. These responses may have no correlation with the actual desires or needs of the individual.

Recognizing violence as a form of communication seems unorthodox due to the effects that it has on others and the individual with autism. The implication is not to allow behaviors to continue without management but rather to first recognize behavior as an expression of needs then regard it as something to be adjusted. So often behavioral programs are implemented simply because the violence is unacceptable without the least inquiry as to what is instigating the behavior. Due to the risks to self and others there are often social consequences related to violent behavior. More inquiry could to be done regarding finding the balance between protection and expression for these individuals. As anxiety is managed for these individuals there seems to be a decrease in the amount of communication that happens in a violent way.

The caregivers describe the ways that they have become aware of unique forms of communication when it comes to emotional expression. Each account is filled with examples of a special but unique form on an emotional exspression. Helping guardians recognize these could give a sense of connectedness that is often seen as non-existent in autistic individuals.

Summary of Common Themes

The themes presented in this chapter provide insight into the experiences of a dedicated parent, caregiver and teacher to individuals with autism. Each of these participants had varied backgrounds and even different contexts in which they experienced individuals with autism. Though their contexts were different there was a connection in the ideas that they had and the experiences that they shared. These experiences have been classified into themes and these themes will now be reviewed.

The process of coming to understand the needs of individuals with autism began by first realizing that there was tremendous pressure on caregivers to socialize all aspects of the individual with autism's life. This was done in spite of concern for their individual feelings or needs. This stemmed from early practices in autism management that were still in use today. Brian, a parent of an autistic individual, still held very strongly to the idea that these individuals needed to be conformed to be as "normal" as possible. This regulation of behavior was seen as an obstacle for communication of the individual's needs and desires. Implications of this theme included a recommendation to look for new ways of respecting individual identity in autism and possibly creating guidelines specifically for autism that would enshrine individual rights. These rights would become the focus rather than behavior management to conform to societal standards of "normal."

The theme of taking time to understand autism was reiterated time and again in the narrative accounts. From the stories shared and emphasis on the amount of time it took to truly understand the specific and unique needs of each individual was astounding.

Progress was slow and could take years to achieve the smallest progress with no guarantee that the progress would maintain over time. Frustration could become a concern in that it could lead to burnout and abuse to individuals with autism. An implication from this theme was that efforts needed to be made to fortify primary caregivers to avoid the dangers of frustration and burnout. Social awareness of the demands that an autistic individual places on the family, needs to be considered. By doing so families can be better supported in their efforts to provide the type of care that would benefit the individual with autism and the family over time.

Social needs for individuals with autism are very different than that of an average individual in society. Due to the reality that these individuals would need a primary caregiver for the entirety of their lives, social planning for the caregivers needs to be undertaken. As discussed in the previous theme the idea that long term stable placements were most favorable for individuals with autism, this theme focused on the role that these caregivers played long term in the life of an individual with autism. Managing safety and personal directives are primary roles that these individuals manage. Implications discussed focus on the need to place a greater emphasis on family intervention instead of crisis intervention. Autism is a disorder that is commonly diagnosed at 18 months of age therefore it is not unreasonable to place expectations on governments to implement strategies to assist families in making healthy, sustainable environment over time for these individuals. Ways to accomplish this could be through promoting realistic lifestyles and expectations for guardians. When it is impractical for families to supply the needed supports, long term placements need to be established for these individuals which focus on limited transitions and low turn over in caregivers.

Trauma has long lasting effects of all individuals who suffer from it. Individuals with autism seemed to be more susceptible to trauma due to the inability to clearly express to these individuals what was happening to them. They were also less able to express their fears and concerns to caregivers. Things that may not be traumatic to an average person may be crushing to an individual with autism. According to those interviewed trauma played a role in the future choices and reactions to new social situations for individuals with autism. Implications from trauma include the need to be aware that individuals with autism may react to benign situations and suffer trauma if their unique needs are not attended to.

The last theme but most encompassing was the insights gained into the expression of needs by individuals with autism. A focus was still placed on teaching forms of communication which trained the individual with autism to participate verbally with others who are non-autistic. The inherent problem was that the responses given by these individuals may not be representative of their desires. These communication behaviors may simply have been a reiteration of previously learned socially appropriate responses. As a form of communication, violence seems to be a clearer way of expression than verbal processes. The dangers involved out weight the benefits of this type of communication for the individuals with autism and those that care for them. A precursor to violence was anxiety and learning to understand and manage anxiety could give excellent cues to caregivers concerning ways to understand specific needs of these individuals. From the experience that was gained over time caregivers were eventually able to distinguish a unique type of communication of needs and wants. Emotional needs are expressed in ways that to the untrained eye are non-existent. These types of communications give insight into the realities of latent emotional needs of individuals with autism. Implications include the need to be aware of the echolalic nature of responses that have been trained in to these individuals through communication techniques. Anxiety needs to be further studied as a form of communication that can not only accurately express when trauma may be happening but also as an effective way of managing violent outbursts. Again the implication that was common in most of the themes discussed was the need to maintain long term contact with caregivers so that they could eventually, through patience and experience come to recognize the subtle aspects of expression that give insight into the individual with autism's feelings, needs and desires.

Presentation of Paradigm Cases

The preceding vignettes were used to illustrate themes that were identified through thematic analysis. Paradigm cases are a holistic account of one individual's experience which assists the reader in understanding "how an individual's actions and understanding emerge from his or her situational context" (Leonard, 1994, p. 59). The paradigm cases provide a summary of each of the participant's experiences with working with and coming to understand the needs of individuals with autism.

The three paradigm cases presented in the following section are but specific examples of an individual's experience and should not be considered as representative of all people who work with individuals with autism. As expressed in the findings, autism has many presentations and learning to understand each individual will be a completely unique process and experience. These cases are presented to help the reader understand the particular background and situational factors that have made their experience with autism unique and fruitful for study. Accordingly, generalizations to other cases must be done with caution. Rather than making generalizations it may be more helpful to use the experiences contained in these paradigm cases to help the reader formulate their own process of learning to become connected and a participant in the life of an individual with autism.

Donna

At the time of the interview Donna was in her early 40's and happily married to her husband of 24 years. She and her husband were the parents of 4 strapping young men. She had a confidence about her that was uncommon in most people and exuded a sense of compassion and understanding to all those that came in contact with her. She was formally trained as a nurse and spent most of her early career working in the palliative care wing of the hospital. She found herself well suited to this kind of caring because of her indomitable belief in the value of the individual. Her religious beliefs were such that she had a strong connection to individuals who she believed would be passing over to the other side. She looked forward to the day when she would again reunite with them and rekindle the friendships that she had developed with them when in the next life. Donna was a driven and inspiring woman who was a pleasure to meet and build a friendship with. In conversation with her she shared detailed information about topics that she was well versed in with passion and a desire to inspire the best in others. Autism and working with individuals with autism was one of these areas that she was very passionate about.

Approximately 10 years ago, Donna began working in a group home environment after being away from the work environment for a number of years to attend to raising her sons while they were school age. The group home she began working in had children of different cultural backgrounds but who all were diagnosed with autism as their primary disability. Due to her caring nature she immediately became attached to these individuals that she worked with and began integrating them into her life and the life of her family. She would have them participate in family outings, church functions, and trips to the mall or school. Though this at times was challenging due to the level of behavior that was experienced she felt that it was important for these individuals to experience real life. She equally desired that her sons had an opportunity to be comfortable with uniqueness and disability.

Working with individuals with autism was a new experience for Donna. She had never been schooled in the particulars of autism so she immediately began learning through experience with them. The basis for her understanding came from her moral belief that these individuals were pure and innocent and would serve a special purpose in the next life. She viewed it an honor to participate in their lives and make it as comfortable and respectful as possible. Her desire to understand and serve developed into feelings of compassion which have guided her to this day.

Behavior was one aspect that Donna specialized in dealing with. She would view each violent outburst as an expression of something that was missing or something that was wanted. She would determine if the thing desired was appropriate for the individuals based on the ability to make the desired object safe for the individual and for others. Behaviors which were odd and socially uncomfortable she would often accept as an expression of something needed. Those expressions that were dangerous to self and others she would redirect or manage the environment to control these. Donna was patient through the many bites, hair pulls, punches, slaps and kicks that she received. She noticed that over the years the amount of these violent outbursts had decreased dramatically due to the fact that she felt that there was a level of respect that had developed between her and the individuals that she worked with. Donna was wise in that she always planned ahead for social events and always had an exit plan when she was participating in public with these individuals. Though she had seen great decreases in violent outbursts over the years she still was always cognizant that unexpected situations could cause an anxiety reaction which could lead to a dangerous situation.

Because of the positive outcomes that she had seen over the years her greatest fear was always that some higher authority, social worker, social services, or government would one day create a directive that would move the individuals in her care to another agency or placement because of cost management or governmental politicking. Due to the abnormally high ratio of funding that is required to care for individuals with autism Donna found that when behaviors decreased due to the stability of the placement there was a tendency for authorities to seek for less expensive placements such as foster care or a return to home with families again. Each of these attempts was disastrous requiring that the individual be returned to Donna's care in order to regain lost progress. At the time of the interview Donna was in the process of dealing with a change in funders due to the chronological age of one of the individuals in her care. During the interview it was clear that she was very concerned about the possible outcomes for this young man. Frustration was evident as she expressed her concerns and the lack of true concern for the individual that was obvious to her.

Donna was not a proponent of the old ways of dealing with disability. She feels that individuals with disability should be accepted by society as special and unique and that society should make allowances for these special individuals. She understands that society can at times be uncomfortable with the way that these individuals express themselves but she feels that as more and more people become involved in their lives they will gain a greater understanding and appreciation for them.

Family involvement and patience were the two things that Donna saw as most beneficial in working with these individuals. Donna has a unique way of viewing integration in that for her integration for individuals with autism looked very different than for other disabilities. Socializing at a dance was often limited to walking the hallways and never interacting with another person. For the particular individual she was discussing this was his desired level of social interaction. She never would have forced the individual to participate in the normal social way at a dance because it would not be respectful to the individual's wants and could present a dangerous atmosphere if this was forced upon him.

Donna was truly a unique and caring treasure for those who she cared for and for the community at large. There is much to be learned from her practices and experiences. She would continue to play a significant role in the community as an advocate for individuals with autism and would always be willing to share her understanding and experience with any who desired to know more about autism and these unique individuals she had grown to love and respect.

Brian

Brian at the time of the interview was in his fifties and was happily married to his wife of nearly 30 years. Brian and his wife had three sons the oldest of which was diagnosed with autism at 18 months of age while they were posted in the military to a Canadian installation in Germany. While on a temporary course in Canada they noticed that their son began to exhibit self injurious behavior. He would take his first and hit himself in the face thousands of times a day. Once back in Germany they began seeking medical referrals to get help with their son's behaviors.

The experience of diagnosis was very difficult for this family in that there was very little information about autism at the time and being in a foreign country they had to rely on medical professionals from various countries which also had military installations in Germany. They were eventually referred to the United States military psychiatrist who was rather surprised by the amount of self abuse that their son was causing to himself and did not give them much hope as to their son's future. The doctor recommended that they institutionalize their son and not spend another day focusing on his special needs. There would be no hope of improvement and the demands on the family would be just too great especially for a military family.

Brian's reaction to the doctor's recommendations was symbolic of his personality. He would never place his son in an institution but rather he would find a way to correct his son's problem and prove the doctor wrong. He knew that for the era it would have been acceptable to place his son in an institution but his strong faith drove him to look for another way to proceed with providing for his son within the family unit.

Immediately, Brian began gaining as much information as he could about autism which was very limited at the time. He would use the techniques that he found to help his son curb his self abusive tendencies. With a son with autism, Brian noticed that because of his son's actions people began to question him as a parent. Due to the damage that had happened to his son's face because of the self hitting behavior, people would question whether the boy had been abused by his parents. Brian stated that this was quite a concern because in Germany people did not take kindly to child abuse and would deal with this type of problem in a very social way by beating up the abusive parent. He found that if he placed large amounts of gauze on his son's hands it served two purposes. One, it would cushion the blows that his son would inflict and decrease the amount of bruising and damage that happened. Secondly, it became obvious to people in society that he was taking measures to protect his son who now had an obvious sign on his hands that there was something wrong with him. A hockey helmet was later ordered with a face guard on it which served as a negative stimulus for his son when he attempted to hit his face. He would hit the bars of his helmet and found this painful.

An opportunity to be posted back to Canada arrived and they were given choice as to where they wanted to move back to. They chose to move back to Ottawa because there was much family close by who could help them with their particular parenting needs. Once back in Canada they were offered an 80 hour course which taught them how to effectively manage behavior based on a simple reward system. They would first gather basis line data, then apply a treatment and then assess the effectiveness of the treatment based on the change from the base line data. As a reward they would use Smarties that they would sit down and cut into little 8ths and then each section would be used to reinforce an appropriate behavior. Using the many little pieces of Smarties as a reward they were able to eventually get their son to stop hitting himself in the face. It took many years at approximately 12 to 16 hours a day of therapy to get this outcome. Once this was achieved Brian saw no limits to what was possible for his son to do with this intensive training.

The time commitment for the family was staggering and Brian found himself working two jobs in order to support his household in the expensive city of Ottawa. More children came along and it became necessary to find other ways to support their son in his training. Brian became an expert at obtaining support from government agencies and from his community. Supports were still limited but he made available everything that they could find for their son. Brian played a considerable role in his sons behavioral planning but now they had four hours a day five days a week that they could call on other workers to continue with behavioral programming. With these supports in place it became Brian's goal to train into his son every social skill and behavior that he felt would help his son be normal in society.

Training was intensive and often very disruptive for his son. He remarked that at times the programming was so intense that it would be very disruptive to his son's emotional state. These upsetting times were seen as necessary in accomplishing the more important social goals that he had outlined for his son. These difficult experiences were seen as necessary for his son's social integration goals. Brian's programming was directly in line with the current ideas surrounding autism of the day. Through intensive programming and social training it was believed that autistic individuals could be taught to react just like their cohorts in society and even become indistinguishable from them.

At the time of the interview Brian's views on social programming had changed dramatically. He had come to the realization that his son was not going to ever become indistinguishable from other young men his age. He had in later years begun to focus more on what would make his son happy and comfortable while still participating in society. Brian still relied heavily on the social system that governments and communities provided and he was an active advocate for his son and for others who had difficulty accessing the proper supports to integrate all individuals with disabilities into society. Brian believed that the early work that they did as a family with their son may have been painful and disruptive for him but he felt that it had been a benefit to the government because it would cost less to support his son over his lifetime. A teacher's aid was required all through school and he still had a worker that took his son to work and worked with him on a daily basis. His son's work was as a janitor for an oil well company. Brain wasn't sure if his son enjoyed his work but saw it as a benefit to his son and others.

Brian planned to keep his son in his home indefinitely because he was aware of much of the group care and didn't feel that they could even mimic the type of environment that his son enjoyed at home. He felt that if the day ever came that he and his wife could no longer provide direct support for their son that their other sons would take over that responsibility. If this were to fail he knew that there are safe guards in the governmental programs that would ensure that his son would have a place to live and a guardian appointed him. Brian actively helps other families access the different programs that are available to them and their children. He was very cautious about how he approached each family. He would not give advice to them unless he had a very good understanding of their particular situation. He saw that different individuals with autism had different blockades to helping them progress socially. He recognized the importance of developing and sticking to goals that the guardian determined for their children. Brian felt that attending to the guardians needs was the only way that they could remain healthy enough to provide the type of care that their child would require. He felt that parents would know best for their children because they had a strong connection with them. This connection was one that Brian saw as developing over time and difficult to see unless you lived with and loved the individual that you cared for.

Patience and hard work were the keys to Brian's successes with his son with autism. Developing behavioral plans was the key to helping his son become socially acceptable and able to play a role in society with limited expenses to government agencies. Brain felt that he couldn't have been any more intense and wouldn't have changed the way that he raised his son. He now recognizes that his son's needs do not always fit with society's expectation and thus the need for effective social programming to help him act in a way that society will appreciate and respect.

Breanne

At the time of the interview Breanne was 53 years old and had been happily married to her husband of 31 years. She was the mother of one son and three daughters who were all grown and in various stages of moving out of home. She was a grandmother and just loved spending time with her grandchildren and telling stories about them. Breanne was a very talkative and open person to converse with. She shared anecdote after anecdote to describe many of her vast experiences in working with people with disabilities and in particular individuals with autism. She has always had a caring and forgiving heart with a great sensitivity to others difficulties and weaknesses. Over the years she and her husband had taken many people into their home who were having difficulty in their lives and just needed a place to stay. She had always made it a practice to share anything that she had had with those that were in need from a dinner to the clothes on her back. This was a focus that she had in her home when raising her children that they all had opportunities to give to those that were in need. Many exciting stories of dropping off food and treats and running away as a family were shared. Breanne's sense of humor was lively and sharp. She always looked at the things that happened to her and her family as adventures rather than hardships. Even the most difficult aspects of her life are met with a smile and a chuckle. Her personality was one that could be characterized as unflappable. She would walk into the most difficult situation imaginable and immediately begin to apply her amazing skills with people to deal with the crisis and seem in complete control throughout the experience.

About fifteen years ago she had begun working with individuals in care who had various disabilities. She spent weekends helping these individuals have meaningful community activities and often integrated them into her family and friends. Because of he natural gift in working with these individuals she began working in schools as an aid. This immediately changed her outlook on career goals and she determined to become a special needs teacher. Once she had completed her university education she began first by being a substitute teacher for the public school system. She worked with many different special needs organizations and schools around the city of Edmonton. This gave her a very broad outlook concerning the different kinds of programs that were available to individuals with autism. She also became very versed in the different political aspects of working in this field and with this special population. Eventually she was offered a full-time teaching position and was happily employed from that point on to the time that we met.

Breanne has proven to be an organizational genius as she has developed an amazing program with consistent staffing over the years. She discussed a method of delegation that was well received by her support staff and showed a particular understanding of caregiver's needs in working with this population. Burnout is an area of great concern for Breanne and many of the practices that she implemented were developed to decrease the demands and suit the sensitivities of the many individuals who work in her classroom. Due to the nature of behaviors that she and her colleagues were required to work with the staffing ratio in her classroom was very high, at times it was as high as one staff member for each individual with autism. She had to plan daily to manage the different influxes caused by illness in workers, students in the program and planned activities.

Breanne was truly an outside the box thinker when it came to working with individuals with autism. All of her spare time was devoted to finding new ways of communicating with individuals that she taught. She searched through magazines on a regular basis to find the newest piece of equipment that she could add to her teaching environment in order to inspire and foster participation from her students. The type of environment she created was one where the individual chose to participate at their level of comfort and readiness.

Being an out of the box thinker has made her very aware of many of the differences between autistic students and non-autistic ones. She accepted that the way that individuals with autism express themselves is very linked to their perception of the world they are participating in. She was also aware that many times, we being non-autistic could not experience their perception of the world and needed to be exceptionally considerate and understanding of these differences. She approached each new conundrum presented by a new student with an open mind using her experience to see if she could come to understand even slightly what the individual was experiencing.

A difficulty that had been burdensome in her work with individuals with autism was that she had no way of determining how long an individual would be staying in her program. The length of time that an individual with autism would remain in a program was dependent on so many factors. Funding was always a factor. Programs would be created and then decreased due to school changes and chronological age of her students. Parents also had the prerogative to move their children to other programs or these families would relocate to another area of the city or province requiring another transfer to a new program for their children. She found these transitions to be difficult on the students and on her ability to understand the individual's particular needs and style of communicating these needs. She felt that the more years that an individual could be worked with in succession the better. It allowed for future planning and the development of an understanding between the teacher and the student. This understanding though impossible to describe helped Breanne plan and create a program that would be well accepted and enjoyed by her students with autism.

The connection that Breanne developed with her students was above what was expected in her job description. Her love and care for these individuals helped her develop a model of social integration where she felt that it was society's responsibility to be open and accepting of differences as opposed to adjusting individuals with autism to make society comfortable. Though she was open about participating socially without hesitation she also maintained a respect for the potential conflicts that could arise due to the particular anxieties that seemed common among her students with autism.

Participation in society was always highly staffed and was planned in such a way as to always have an exit plan if an emergent situation were to arise. Breanne had seen many instances of negative behavior in her students with autism but had always seen it as a way of communicating their needs to her or other guardians. She has always focused on finding non-violent ways of dealing with these behaviors while trying to understand their cause. The most common program that she implemented is one were she tries new things with a student on a daily basis until she found a technique that calms the behavior or adds clarity to the expression. Often these techniques were based on theory as to why the student is reacting in this manner. It could be at times a "hit and miss" process but her patience had proven valuable many times over.

She had changed the view of many non-autistic students by giving them the opportunity to experience outings and activities with individuals with autism. She found that this gave them a better understanding of the needs of this particular group of individuals and also helped them become more comfortable around them. She was an advocator for the rights of individuals with autism to live in an abuse free environment where they are seen as equals in rights and freedoms. Protection for individuals with autism from others was seen as necessary because of these individual's innocence and the many unscrupulous people in our society. Breanne shared that these unscrupulous people could take advantage of her student's innocence and inability to express the abuse that happened in a verbal or comprehendible manner. She has never been afraid to express her concerns when she sees an individual with autism being neglected and is not afraid of repercussions of speaking her mind to administrators and guardians when she feels that they are unaware or unsympathetic of her student's needs or feelings.

Though she was open in confronting those that didn't consider properly the needs of her students with autism she was very sensitive to the struggles of parents and family members who care for them. She would make adjustments in her lesson plans daily and often more times than that to accommodate parents who were overwhelmed, running behind or simply worn out because of the demands of care for their children. She was grateful for guardians who continued to play a role in the lives of her students. Though often surviving day to day she felt that many of these situations were better than the government provided guardians that she has worked with. Those that are in care she longs to see them accepted into programs that will take a particular interest in them and provide a stable environment to develop and thrive in. Breanne actively advocated for individuals with autism who go into care. She feared that some choices for placement in out of home care was done on a purely financial or staffing organization basis.

Breanne was a shining example of teacher who had a true desire to understand the needs and desires of those individuals with autism that she worked with. Her understandings were vast and her capacity to love and care commendable. She had done much for her community and for individuals with autism in general by her example and teaching methods.

Summary of Paradigm Cases

These paradigm cases showed a variety of personal contexts in which people that were experienced working with individuals with autism have come to a greater understanding their needs. Each of these experiences was presented as a unique experience of a particular individual and should not be considered as representative of all parents, teachers or caregivers who work with individuals with autism. These individuals who have participated have shared their experiences in a way that was meaningful to them and to the researcher. They have been presented by the researcher in a method that was intended to give the reader a greater sense of their experiences and how they have come to their understanding of the needs of individuals with autism that they work with. Due to the exploratory nature of this study it became necessary to limit the number of participants that could participate in this study. Further investigation into the experiences of other caregivers, parents and teachers could add even further understanding with more paradigm cases.

A short Summary statement of each paradigm case will now be presented. These summaries are intended to highlight some of the key contextual factors that played a role in their experience of coming to know the needs of the individuals with autism that they worked with.

Donna was a nurse who had particular abilities working with very difficult populations of people. Her abilities in this area eventually lead her to begin working in group homes for children with autism. She found great success in integrating these individuals into her own family and the families of her other workers. Through this process she began to truly love and care for these individuals. Her feelings for them were driven by a belief that individuals with autism are innocent and are were deserving of a special measure of respect and caring here on earth. Violent outbursts were common place for Donna in dealing with these individuals but found that through proper preparation and management of anxious events decreased these behaviors dramatically. One of Donna's greatest fears was that due to government politics and the demands of other social powers, the youth that she had worked with and became connected to would be swiftly taken from her care and put in jeopardy in another placement. They would be in jeopardy because a new placement would not be prepared or aware of the individual's particular needs and sensitivities. She feels strongly that society needs to become more aware of individuals with autism and that trust filled environments can be created that will foster social participation at the individual with autism's pace. Donna is a true treasure to those who have autism and especially those in her care.

Brian was a father of three sons the oldest of which was diagnosed with autism while they were posted in Germany for the Canadian Armed Forces. His son's self abusive tendencies caused some social concerns for his parents and other in the community and they as a family were recommended to institutionalize their son and continue on with their lives. For Brian this just wasn't an option so he began learning about autism. Information about autism was very limited at the time but eventually he and his wife were posted back to Canada where they were given state of the art training on behavioral methods that they could apply with their son. Brian would spend as many as 16 hours a day to train appropriate social behaviors into his son and stop negative behaviors if they arose. The responsibilities of family and extra care for their son were staggering at times for this family. Brian's social views changed over the years as he began to accept his son's limitations in becoming unrecognizably autistic. He became an advocate in his community and looks at each situation and individual as a specific case and helps them access programs in the community and those that are available through the government. Brian sees a great responsibility on family to take care of their own and relies heavily on his non-autistic sons to continue to care for their brother when he can not one day. Brian's patience and many hours of determined intensive effort are certainly characteristic of his character and the work with his son with autism.

Breanne was a caring and accepting individual long before she began working with individuals with autism. Later in her career she began working in schools as an aid for individuals with autism and determined to go back to university and become a special needs teacher. After substitute teaching for a number of years she became a full-time teacher for individuals with autism. Breanne could be viewed as an organizational genius who is unflappable in her abilities to deal with crisis and unique situations. She was very aware of her needs and the needs of her aids in the classroom and made regular adjustments to avoid burnout and fatigue. Breanne was an "out of the box" thinker when it came to dealing with behavior and understanding the needs of her students with autism. She created a classroom where her students could experience growth based on their comfort levels. She saw time with students as necessary to developing an understanding that would allow her to plan and create programs that individuals with autism would appreciate and need. She was often frustrated due to the short times that she was given with particular students due to the realities of parental movement and government down and upsizing classrooms. Breanne enjoyed participating in society with individuals with autism and felt society needs to become more understanding of differences. She was aware of the risks of violence in her students and always prepared plans to deal with its potential. Her practices were experimental in trying to find non-violent ways of managing negative behavior. Breanne was very open to discuss the dangers of abuse that her students face and was always open to discuss her understanding of her student's needs with others. With this openness, she would confront others to advocate but she also expressed a great understanding of the stresses felt by families who cared for their children with disabilities at home. Breanne's efforts as an educator could be classed as above normal and indicative of her loving and giving nature.

CHAPTER SIX

Discussion

The findings of this study have contributed by creating a deeper understanding of how individuals who parent, work with and teach individuals with autism understand their needs. These findings add a truly individual focused approach to understanding the desires and needs of these individuals. This individual approach is one that is recommended by Billington (2006) and honors the individual nature and worth of the individual with autism through this process.

The researcher, through this research process has come to a greater appreciation for those individuals who care for these individuals with unique needs and unique ways of expressing these needs. It is hoped that the ideas and descriptions contained herein will be of use to caregivers, parents and teachers in the future and also to all those who have an interest or preoccupation with individuals with autism.

This chapter will present the major findings from the study and will discuss some of the implications that arose from the process of analysis. Due to the nature of qualitative research findings, they are not scrutinized in the same way that a study in the positivist tradition would be. For the reader's benefit an explanation of the evaluation of interpretive inquires is outlined and then this study is evaluated based on these criteria. The limitations of this study are presented along with future research directions in the field of autism and fostering the individual perspective. The last section is a compilation of final reflections that the researcher experienced as this study came to a close.

Main Research Findings

Narratives were created for each of the individuals who participated in this study. These narratives were created from each individual's sharing of their stories of working and living with individuals with autism. Though each of these experiences was unique there were many commonalities that were found among them. As these narratives were analyzed new perspectives were achieved and richer insights were developed in relation to the needs of individuals with autism. These insights or uncoverings were organized into common themes that permeated each of the narratives. These uncoverings enrich our understanding of the needs of individuals with autism and provide ideas for further investigation and potential implications for policies and practice. These findings will now be presented in summary form.

The first finding that emerged from the study was one that was expected by the researcher. The theme was entitled "adjusting to fit society's expectations." The prevailing practices in the treatment and training of individuals with autism remains focused on the management of behavior that is abnormal according to society's standards or seen as impeding individuals with autism from functioning in ways that are viewed as the social norm (Firth, 1989; Morton-Cooper, 2004; Schreibman, 2005; Scott, Clark, & Brady, 2000). This theme enlightened the researcher as to how much social pressure that is placed on parents, caregivers and teachers to have individuals with autism conform their appearance and behavior to be in accordance with generally accepted social practices. Even when the views of the participating caregivers expressed a focus on the individual, it seemed impossible to evade the social pressures to conform that were built into the systems in which they worked and lived. This practice of training or behaviorally programming these social behaviors was seen as a hindrance to the expression of the desires and individually focused needs of the individual with autism. Trying to satisfy the needs of society often required the caregivers to disregard the focus on the individual's desires. Learning this balance was an area that still presents as an area of concern for these individuals who participated in the study. Though this theme was expected it was exciting and refreshing to view it in the light of another's experience.

The next theme was entitled "it takes time to understand autism." This theme was common in all of the narratives. Time and again it was expressed how much time was necessary to achieve desired progress with individuals with autism. Years are needed to help parents, caregivers and teachers to gain greater insight into the individual uniqueness of each individual with autism. Techniques that work with one individual may not work at all for another. It was found that social experiences happened in the lives of these individuals as they were given the time and space necessary for them to become integrated into families and the lives of workers. These situations can not be contrived but allowed to happen respecting the individual's pace. A problem with recognizing the individual's pace in social integration was presented in that social agencies and governments are fiscally responsible for the care of individuals with autism. There was a concern expressed by the participants in this study that transitions could happen due to government adjustments that could cause considerable concerns for the individual with autism.

Due to the amount of time that is required to allow these individuals desires and social expressions to unfold, great strains are placed on those that care for them. The dangers of this extraordinary time commitment were found to cause stress and frustration on those that care for individuals with autism and especially on the family unit. The risk of burnout is great and so is the risk of abuse for individuals with autism.

The next theme that presented itself was entitled “social needs: guardians.” Social needs for individuals with autism seem to be very different than the social needs of other individuals in society. A social need identified through analysis was the need for individuals with autism to have someone who will care for them for their entire life. The identification and fostering of a guardian who could be stable and involved over time was a common theme expressed in the narratives.

As discussed in the previous theme there are tremendous stresses placed on caregivers to make decisions for individuals with autism and the longer these caregivers have to come to understand the particular needs of a particular individual the greater the chance that they will make choices that will be individually focused and tailored to the style and desires of the individual with autism. A special kind of involvement is discussed where the guardian has a special investment to the individual with autism. If the investment doesn’t come by nature of a family responsibility to care for one’s own than fostering a non-family guardian who has this type of investment could be identified as a social need.

Creating or fostering an already invested relationship becomes a need for the individual with autism. Caring for others seems a unique way of caring for individuals with autism but with their particular need for a long term guardian, the stability and support of others becomes a need that individuals with autism have.

The next theme was entitled “Trauma: A basis for behavior.” This theme emerged from the stories told of the pains suffered by individuals with autism as they were exposed to traumatic events in their lives. Some of the events were due to the nature of their perception of the world and others were due to the inability or lack of effort to gain consent and understanding from the individual with autism for medical and social procedures. Trauma has long lasting effects on individuals who suffer from it. The early experience of trauma is theorized by Barrows (2004) to be a potential precipitating factor in the development of autism in individuals who are already genetically predisposed to it. Once trauma has been experienced it is often necessary to debrief the experience with another person in order to begin the process of healing. The narratives revealed that individuals with autism are traumatized regularly and there seems to be limited ways to give them an opportunity to express their experience of what has happened to them. The full expression of the feelings associated with the traumatic event is essential to a healthy resolution of the trauma (Schwarz, 2002). These traumatic events were seen to have lasting consequences on individuals with autism in how they approached the world and how they reacted emotionally and physically to situations which paralleled their trauma experiences.

The final theme was entitled "expression of needs." The last common theme but certainly the greatest was the findings related to how individuals express their needs and how we understand and make sense of these expressions. Current practices focus on the introduction of communication patterns that are socially acceptable and easily understood by the non-autistic individual (Ganz, & Simpson, 2004; Lovaas & Simmons, 1969; Tincani, 2004). The findings from the analysis of the narratives questions the validity of the expressions that are produced through these trained communicative methods that are often taught or "trained" into individuals with autism. Insights were deepened in relation to the ways that individuals do express their needs and desires. These expressions tend to be from a less sophisticated method of communication which can be problematic for the individual with autism and the parents, caregivers and teachers that live and work with them. Anxiety and violence were seen as forms of expression that were representative of individual desires of individuals with autism.

The stories told by the participants in this study gave greater insight into a type of understanding between individuals that only happens when they have spent sufficient time together. There is an understanding that begins to happen were subtle behaviors begin to be seen as expressions of emotion, desires and feelings. These types of experiences reported by these caregivers implies a type of emotional connection which is theoretically opposed in the diagnosis of autism (American Psychiatric Association, 2000) and has implications in regards to what we do and could come to understand about the needs and desires of the individual with autism.

Recommendations

The implications of each of the themes will now be reviewed and presented as recommendations that have arisen from this study. These recommendations are presented as new ways of looking at the experience of individuals with autism and how a caregiver, a parent and a teacher comes to understand and make sense of the needs of individuals with autism. These recommendations also include the expressions and ideas of the researcher who has played an integral role in the process of interpreting the ideas and experiences of the participants. These ideas are not presented as actions that must be taken but rather as ideas that may help another in their process of gaining a deeper appreciation for and insight into the lives of individuals with autism and those that love, live and work with them.

Considering the current practices in the diagnosis and treatment of individuals with autism it is obvious that we are still distant from the ideas presented by those who would have a greater focus looking at the needs of individuals with autism from an individual focus (Billington, 2006; Hall, 2001; Sainsbury, 2000). Learning new ways of respecting the individual and the democratic rights of individuals with autism could commence a new era in autism research. Rather than focusing on efforts to conform individuals with autism to participate in a society that they perceive and react to differently than others, greater focus could be placed on creating new ways for each individual to participate in a way that suits them and their wants and desires. For most people in North American society the idea of not wanting to participate socially and emotionally with others seems extraordinary but accepting that this may be the case for individuals with autism may be the next step in accepting their individual desires. Rather than viewing autism as a negative variation of "normal" autism could begin to be seen as a culture of individuals who function differently on many different levels. The pressures that are placed upon parents could be greatly alleviated by this new focus and impediments to greater insight into individual expression could be mitigated. The ideas expressed in the common theme of adjusting autism to fit society's expectations cries for imaginative ways of learning to respect the individual identities and experiences of individual with autism.

Helping society become aware of the dramatically different amount of time that is necessary for individuals with autism to adjust to new situations is paramount. This could also allow others that care for them to become enlightened as to how they express individual needs and desires. This in turn could allow for greater quality of experience for individuals with autism. When time frames are imposed on caregivers, parents, and teachers the opportunity for frustration and potential abuse of the individuals could increase. If governments, policy and programs were to take this into consideration practices could be put in place to help families be supported in a realistic manner allowing the family unit to stay intact and able to care for the individual with autism. These individuals could be seen as the ones most suited to care for individuals with autism simply because of the amount of time that they would have spent with them coming to understand their individual capacities and ways of expression. A familial guardian would be preferable considering the difficulties of long-term integration into a caregiver or teacher's life and the realities of fiscal management of programs and burnout.

Viewing a guardian as a social need for individuals with autism has implications due to the pervasive nature of this condition. Individuals with autism perceive the world in a way that could put them at risk (Beitman, & Nair, 2004; Schreibman, 2005). The implications from the analysis point to family members as the best possible guardians for individuals with autism. A shift from crisis management of families to early family prevention is recommended. Creating new ways to support families of individuals with autism may be the key to decreasing crisis and trauma in the future for these individuals and their families. The time intensive and frustrating process of behavioral programming to create independence may not be the most effective expenditure of resources. A more appropriate place to focus these resources may be in maintaining the integrity and longevity of guardian arrangements for the future. Though there are no guarantees that changes will not happen when considering the diversity of guardians and family compositions minimizing these transitions for individuals with autism could be fundamental to their future wellbeing.

Trauma as a basis of behavior formulated a number of implications in relation to its effects on individuals with autism. Due to the inherent difficulties in communication styles it is very difficult to explain procedures and activities to them that may be for the individual with autism's benefit. These procedures could then be perceived as traumatic events and cause implications toward reactive behavior in the future. Producing some form of record of traumatic events for and individual with autism could be helpful in helping others that will work, teach and live with them understand some of their particular sensitivities that could have been created through the experience of traumatic events.

Health care is an area where traumatic types of procedures may be common. The following recommendations are put forward to potentially alleviate some experiences of trauma for individuals with autism. First, it is recommended that health care providers become aware of the sensitivities of the individuals that they provide care for so that they could take preventative measures to manage the environment for individuals with autism. It is hoped that this will create an atmosphere where trauma is less likely. Secondly, new inventive ways could be developed to help describe procedures, in a non-verbal way, which would be done for individuals with autism. An example of this could be to have a guardian introduce the idea of a stethoscope over a longer period of time so that when the doctor needed to perform an evaluation the individual would already be accepting of this procedure and have it not contribute to the already anxious situation of visiting the doctor. The idea of using medication to restrain individuals with autism during events that are traumatic seems to be distant from the individually focused perspective.

Individuals with autism are able to express their needs. Their expressions tend to be subtle but they can also be overt and dangerous. Not only dangerous to themselves but also to those around them. A finding of this study was that individuals with autism who are trained to use specific communication methods may not be expressing their genuine desires but rather rehearsing back socially appropriate, trained responses. Looking at other forms of natural expression is recommended to gaining greater insight into the needs and desires of these individuals.

Violence is a rudimentary form of communicating needs. An inherent problem with the use of violence as an expression it that others perceive the experience of violence in various ways and their experience may not be that of the individual with autism. A recommendation is given to regard the fundamental purpose of violent behaviors rather than immediately creating a program to extinguish the negative behavior without first making efforts to understand the expressions behind the event. More research could be undertaken to clarify the balance between protection of the individual and others and this form of expression for individuals with autism,

Anxiety was seen to be a predictor to violence. As anxiety was effectively managed there was reported a decrease in the use of violence as a method of the communication of the individual with autism's needs. More research into the expressions behind the anxiety experience may give clues to how these individuals perceive their world and their experience of trying to have their needs met in it.

The analysis of the narratives created new understandings as to how individuals with autism express emotion to those that care for them. The idea that individuals with autism do not bond with their parents or their deficits in social behavior are so pervasive that they can not express emotions to caregivers (Kanner, 1943, Schreibman, 2006) seems to be unfounded. There seems to be a type of connection that is developed between caregivers, parents and teachers that is difficult to explain in terms of usual attachment. The narrative experiences expressed give a sense that these connections are happening just at a different pace and perhaps in a different form than would be expected in usual attachment experiences. Helping parents, caregivers and teachers become aware of these types of subtle expressions may help them create and foster a sense of emotional connectedness with the individuals with autism that they live with, care for or teach.

Evaluating the Interpretive Account

Traditionally evaluation of research has been conducted under the positivist tradition which relies heavily on research being theory driven, hypothesis testing or hypotheses producing generalizable results. It is important to understand that qualitative research cannot be held to the same ideas about validity and reliability that are central in quantitative, experimental designs. "The word qualitative implies an emphasis on processes and meaning that are not rigorously examined, or measured, in terms of quantity, amount, intensity, or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry" (Denzin & Lincoln, 1994). An interpretive inquiry does not make claims of generalizability or objectivity that would be expected in the positivist tradition. Rather, in qualitative research the quality of the study depends upon whether the research has fully addressed the research problem or concern. Reliability, in positivist terminology refers to the consistency, stability, and dependability of a test or testing procedure. The consistency of the test or testing procedure is established when data yield the same results after being subjected more than once to a particular testing procedure. A different approach is taken in the qualitative research perspective. An interview with a participant is an example of a one time, unrepeatable occurrence that is not open to the positivist dictate of repeatability and thus, reliability; each participant will have an individual account of their experience. In fact, multiple perspectives will emanate from the participants in the interviews. These perspectives provide a wide range of views, beliefs, thoughts and understanding for each participant regarding the phenomena being studied.

Authenticity. In judging the goodness or quality of an inquiry, the authenticity of the research and the researcher are important considerations. Authenticity is the quality or condition of being authentic, trustworthy, or genuine. Knowledge accumulates through the process of inquiry when there is the formation of more informed and sophisticated constructions through the hermeneutical and dialectical processes (Guba & Lincoln, 1994). Authenticity is achieved when we as researchers and individuals begin to enlarge our own personal constructions, come to understand better another's construction and are then motivated to action because of our new informed and sophisticated understanding.

In the evaluation of an interpretive inquiry the reader plays a fundamental role in the validation process. Benner (1985) suggested that the reader should evaluate an interpretive work by keeping in mind the following five criteria of internal validity. First, the inquiry should help us to understand the lives of the participants in the study and we should better comprehend the complex patterns of human experience. Second, the themes should maintain the integrity of the original data that were collected from the participants. Third, the interpretations should be internally consistent. Fourth, there should be included data to support the findings that were concluded. This is usually done by including excerpts from the interviews. Fifth, the reported conclusions should be consistent with the reader's own experience.

To be ontologically authentic as a researcher, an important consideration in qualitative research is that the initial question of the study has been advanced and the researcher has gained new insight and understanding. Ellis (1998) has outlined:

> "To evaluate an account, one should ask whether the concerns which motivated the inquiry have been advanced. To judge whether an answer has been uncovered by an interpretive account, use the following six questions to direct attention to considerations we value:
>
> 1. Is it plausible, Convincing?
> 2. Does it fit with other material we know?
> 3. Does it have the power to change practice?
> 4 Has the researcher's understanding been transformed?
> 5 Has a solution been uncovered?
> 6 Have new possibilities been opened up for the researcher, research participants and the structure of the context?" (p. 30).

The current study will now be evaluated by the researcher in light of the two models of evaluation that have been presented to evaluate an interpretive inquiry study.

This evaluation was performed by the researcher. These criteria need to be applied by the reader as well in order to evaluate for themselves the validity of the study.

The study is first evaluated using the five points recommended by Benner (1985). The patterns of human experience truly are complex in relation to the individual with autism. The researcher believes that the ideas presented and the rich descriptions of the participants stories will give the reader greater insight into the experience of caregivers, parents and teachers who strive to understand and make sense of the needs of individuals with autism.

The themes that were presented were developed from the narratives that have been included with this research study. By including these narratives the researcher has made available the original "data" so that those who are reading and evaluating this study can see from whence these themes have arisen. Though the experience of the narrative may be different for another person, it is still visible to see how the researcher drew upon this data to create the presented ideas and themes. This ability to return to the data allows the readers to assess the internal consistency of the interpretations. This ability enhances the credibility of the findings. The findings section was constructed using various samples of data referred to as exemplars. These were used to give concrete examples of the ideas that were presented. These excerpts allow the reader to experience examples from the data that supported the themes that were developed through the interpretive process.

The last criterion is that the conclusions should be consistent with the reader's own experience. The researcher can not give an evaluation of this for the reader. The reader must play an active role in this process of evaluation and critically scrutinize the results of this interpretive inquiry. It is hoped that by doing this their experience will be consistent with that of the conclusions reached by the researcher. It is also hoped that through this scrutiny new and imaginative ways of viewing this research may be realized.

The study will now be evaluated using the six questions suggested by Ellis (1998). The researcher has found the findings to be plausible and convincing in the way that they presented the ideas of those who work with and care for individuals with autism. The findings that were presented do fit with some of the current ideas concerning autism, especially those ideas that relate to giving voice to individuals with autism by becoming individually focused when working with these individuals. Numerous implications were drawn from the themes and findings that were described in this study and these implications have the power to change the way that we currently view and treat individuals with autism. They have been presented in such a way as to help others gain a greater understanding of what it is like to work with and care for an individual with autism. The narratives were drawn from commanding individuals in the field of autism who are credible in their experiences of working with individuals with autism. Their views and expressions will resonate with others who share the same passions about understanding the unique and particular needs of individuals with autism.

Question five; has a solution been uncovered, was covered in the recommendation section that proceeded this evaluation. Question six; have new possibilities been opened up for the research to research, will be discussed in the section entitled future research directions. Question four; has the researcher's understanding been transformed, is the question that was of the greatest importance to the researcher. Due to the extent that the researcher works with individuals with autism and their families it was imperative that this type of growth of insight happen. At the beginning of the study it was a real process to allow the type of self exploration what would lead to the challenging of my pre-understandings. Accepting the inadequacies of my perceptions was a humbling experience which at first was uncomfortable but now is emancipatory in nature. Lather (1986) stated: "Emancipatory knowledge increases awareness of the contradictions hidden or distorted by everyday understanding, and in doing so it directs attention to the possibilities for social transformation inherent in the present configuration of social processes." (p. 32). The hope of the researcher is to continue to accept the "growing pains" that come with greater insight and acceptance of other's world views. In relation to autism the researcher has gained a greater understanding of the subtle ways that communication can happen with individuals with autism. A true appreciation for the amount of time that is required to allow these individual's feelings and desires to be respected will change the way that the researcher approaches these individuals in the future and the way that he will advocate for them. The researcher is confident that this evaluative question has been answered in the affirmative and relishes in the anticipation of what new understandings and uncoverings will come in the future.

Limitations of the Study

This section is devoted for the researcher to share some of the limitation that were discovered and experienced in the process of this study. The limitations presented are not flaws in the design or errors in interpretation but rather points to be considered when reviewing this study. These points could also be used in the formulation of other studies in the future that could address some of the limitations included in a new and imaginative way.

The first limitation that will be discussed is one that was most painful for the researcher. Due to the ethical restraints placed on this research process it became impossible to have individuals with autism themselves participate in this study. Due to the positivist tradition that still maintains an authoritative posture over the process of research, individuals who can not participate in a study in conventional ways (i.e. verbal or written responses) are not considered to be participants in the research but rather "subjects" to be studied. As subjects of a study the ethical ramifications were difficult to assuage. The researcher is in agreement that as "subjects" it would be unethical to proceed with research on individuals with autism. Only as participants would it be possible to recognize their individual values and subtle expression that would give greater understanding and insight into their lives and world views.

There was considerable confusion in the literature concerning the autism spectrum of disorders and the classification of individuals within that paradigm. The researcher was confident of the particular population to be studied but it was difficult to express properly to the reader the distinction between individuals who have classic autism, aspergers syndrome, or simply fall in the autism spectrum. The diagnostic process is still under reform and there are still substantial differences in what is viewed as "autism" depending on the criteria that are used. As criteria are better defined focus can be placed on individuals who have specific presentations and can be more appropriately chosen to participate in studies that will further our understanding of autism.

The participants in this study were selected using a non-random purposeful sample intended to identify individuals who could give a rich experience of working with and understanding of individuals with autism. A larger sample of caregivers, parents, and teachers could be desirable to give a deeper understanding of the particular experiences of each of these different groups of individuals. It was interesting to see the similarities between different groups of individuals who work with individuals with autism but it may also be interesting to see the similarities within their particular group.

Future Research Directions

This study provided the researcher with some new insights into the field of autism and particularly in working from an individually focused perspective with these individuals. This section will present some of the future research directions to be explored by the researcher and those who will read and be inspired by this study.

The issue of trauma and the individual with autism is one that could be studied to a greater extent. Considering the effect that trauma has on all individuals and the unpredictable perceptions of individuals with autism; a greater understanding of these issues is warranted. Further research is needed to illuminate this complex and life altering issue for these individuals.

The idea of an emotional connection between caregivers, parents and teachers is discussed in the research findings of this study. This idea is novel and one that deserves emphasis in future research. The idea of emotional connections that develop over time has implications in the diagnosis of autism and the basic theoretical basis that it is founded upon. Research is warranted to study this phenomenon and gain greater understanding of this type of social connection in autism research.

As was seen in this research the social and emotional pressures that are placed on biological caregivers differ from those experienced by non-biological caregivers such as teachers and group home workers. An area of future research could be to identify these differences and come to understand the effect that they have in the experience of their understanding of what individuals with autism want and need.

The last area of future research direction is in the area of social perceptions of autism and how they can be adjusted by teaching the individual based approach to understanding autism. Many of the ideas currently found in research present a very clinical approach to dealing with and understanding autism. Even the individuals who participated in this study began the interviews with the researcher by first describing a medical explanation of autism. Only after the conversation progressed was there a more interpersonal expression of autism expressed. This medical presentation is still very prevalent in the field of autism. Further research would be required to gain a better understanding of why this is so in the field of autism and how it could be adjusted to incorporate the individually focused approach.

Reflections of the Researcher-Practitioner

My greatest desire was to truly gain a richer understanding of how we understand the needs of individuals with autism. In my work with these individuals I see examples of expression of need on a regular basis that would not be apparent to someone who only interacts with people with autism in a limited capacity. Due to the nature of the dual relationship that I was forced to balance as a scientific researcher and a service provider I was not able to invite the people with autism that I work with to participate in this study because of the ethical implications.

I was truly impressed with the quality of individuals who did participate in the study. At the outset I didn't realize the learning that would happen for me and the relationships that would develop between me and the participants in this study. The experience was one of learning through stories and experiences that I will cherish for a lifetime. The nature of the interview is paradoxical in that the interview is conducted in private and is between two people yet the words, ideas and stories are then used for a very public purpose for many to read in a much broader forum. Efforts were made to give the readers of this research sufficient background and reference to help them understand the nature of the data that were gathered through this medium of the interview. In future conversations with those that participated in this study it has been comforting as a researcher to know that they feel that they have contributed in some way to further the communities understanding of this unique experience we call autism.

As a counselor this research has changed the way that I look at individuals with autism. I have become conditioned to look first at what the individual may need and then I implement ideas and theories of practice to help them progress. As a counselor I have realized the need to have this focus with all people that I work with not just those that are considered autistic. I have come to a greater respect for the individual perspective and how dear a treasure that it is to those of us who can express our desires and needs. Another change that I have seen as a counselor is the amount of time that I allow myself to come to understand another. Many times I have come to see more clearly what a person truly desires when I wait for greater understanding to happen through the process of listening and experiencing what another is telling me. I hope that I can continue to have this focus in all that I do as a counselor, service provider and scientific researcher.

Final Reflections

At the completion of this study I felt it wise to share some of the experiences that have changed the way that I view individuals with autism. I am also appreciative of the experience that I have been offered to gain greater understanding into the needs and desires of these unique individuals.

During the process of this study there were some experiences that had a profound effect on the researcher. The one that was most salient was when Donna was asked about the effects of transitions in a young man's life that she worked with and she immediately began to well up and then began sobbing in the interview. It was then that I realized the amount of time and emotional energy that these individuals had invested in the lives of individuals with autism. This developed into a curiosity as to what it is about this population that engenders such a reaction from others. My views of autism are now colored by this experience and I am constantly wondering how these connections develop and what role they play in the caregiving experience.

Listening to the stories shared with me in the interviews I have been renewed in my love for what can be shared through this medium of conversation and how people share their heart and soul through the experiences that they recall and tell to others. I have cherished the opportunity that has been given me to step into the lives and experiences of these extraordinary individuals that I have come to know as friends and colleges in the field of autism.

My last thought is related to what I need to do next. The emancipatory nature of the knowledge that I have acquired motivates me to do something about the ideas that I have uncovered and the broadened perspectives that I now have. The interpretive inquiry is a practice that I will continue to observe in my everyday life in order to continually challenge the perceptions that I have come to understand. I hope that over time I will be able to broaden even further my perceptions and become a more understanding and accepting individual. I hope to play a significant role in the lives of individuals with autism and those that care for, live with and teach them.

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APPENDIX A

INFORMATION AND CONSENT FORM FOR PERSONAL CARE ATTENDANT

My name is Kevin Hatch. I am presently completing a Doctoral dissertation in Counselling Psychology in the Department of Educational Psychology at the University of Alberta. I am interested in learning more about how we come to understand the needs of individuals with autism. The title of the study that I intend to complete is: How do we come to understand the needs of individuals with autism?

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education and Extension Research Ethics Board (EE REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EE REB at (780) 492-3751.

The purpose of the study is to explore and develop a more sophisticated understanding of how we come to understand and make sense of the needs of individuals with autism. It is my hope that through this collaborative enterprise a number of benefits will be realized. First of all, by collaborating with individuals who have great experience, greater understanding can be reached concerning the process of understanding the needs of individuals with autism. Second, I hope to improve my personal understandings and insights so that I can benefit the community in which I play a role as a therapist. Lastly, I hope that this research will serve to help others who care for individuals with autism to gain a richer understanding of what is it like to participate in the lives of these individuals.

It is important for you to know that you are not obligated in any way to participate in this research. If you choose not to participate your decision will be respected. If you chose to participate you may, at anytime, withdraw from this research study without penalty or prejudice. If during the research process you feel uncomfortable with proceeding you may contact any of the undersigned individuals to end your participation immediately.

In order to gather the information required for this study I will be conducting a number of audio-recorded collaborative interview sessions with people who have great experience working and caring for individuals with autism. I am requesting one formal interview of approximately 45 minutes in length and up to 3 follow up interviews of 10 minutes in length to clarify ideas and thoughts expressed in the initial interview. Each interview will happen at a mutually agreed upon time and place.

This is to Certify that I, ________________________________ have been informed about, and agree to the following:

1. I have been advised about the nature and purpose of the study.

2. My participation in the study is voluntary and I may withdraw at any time.

3. Any information shared with Kevin Hatch will be held confidence. Quotations and or summaries of what I say will only appear in the final thesis with my consent. The use of pseudonyms will ensure my anonymity.

5. The study findings may be published in an article or presented to a larger audience in the future.

6. The interviews will be digitally recorded and then transcribed. Audio-recordings, transcriptions, and any notes will be safeguarded and destroyed after the required time period has passed.

7. Interviews will be conducted at times and locations that are mutually convenient for myself and the researcher.

8. In the event that I should need to speak to someone about my thoughts and feelings resulting from the interviews, the researcher will work with me to access appropriate professional assistance.

9. If at any time I have questions or concerns about my participation in this research, I may contact the following individuals:

Research Supervisor:	**Dr. Derek Truscott** Phone 780-492-1161
Researcher:	**Kevin Hatch** Phone 780-414-1091

My Signature indicates that I have read and understand the content of this form.

Signature of Participant ________________________________

Date: ________________________________

APPENDIX B

INFORMATION AND CONSENT FORM FOR PARENTS

My name is Kevin Hatch. I am presently completing a Doctoral dissertation in Counselling Psychology in the Department of Educational Psychology at the University of Alberta. I am interested in learning more about how we come to understand the needs of individuals with autism. The title of the study that I intend to complete is: How do we come to understand the needs of individuals with autism?

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education and Extension Research Ethics Board (EE REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EE REB at (780) 492-3751.

The purpose of the study is to explore and develop a more sophisticated understanding of how we come to understand and make sense of the needs of individuals with autism. It is my hope that through this collaborative enterprise a number of benefits will be realized. First of all, by collaborating with individuals who have great experience, greater understanding can be reached concerning the process of understanding the needs of individuals with autism. Second, I hope to improve my personal understandings and insights so that I can benefit the community in which I play a role as a therapist. Lastly, I hope that this research will serve to help others who care for individuals with autism to gain a richer understanding of what is it like to participate in the lives of these individuals.

It is important for you to know that you are not obligated in any way to participate in this research. If you choose not to participate your decision will be respected. If you chose to participate you may, at anytime, withdraw from this research study without penalty or prejudice. If during the research process you feel uncomfortable with proceeding you may contact any of the undersigned individuals to end your participation immediately.

In order to gather the information required for this study I will be conducting a number of audio-recorded collaborative interview sessions with people who have great experience working and caring for individuals with autism. I am requesting one formal interview of approximately 45 minutes in length and up to 3 follow up interviews of 10 minutes in length to clarify ideas and thoughts expressed in the initial interview. Each interview will happen at a mutually agreed upon time and place.

This is to Certify that I, ________________________________ have been informed about, and agree to the following:

1. I have been advised about the nature and purpose of the study.
2. My participation in the study is voluntary and I may withdraw at any time.
3. Any information shared with Kevin Hatch will be held confidence. Quotations and or summaries of what I say will only appear in the final thesis with my consent. The use of pseudonyms will ensure my anonymity.
5. The study findings may be published in an article or presented to a larger audience in the future.
6. The interviews will be digitally recorded and then transcribed. Audio-recordings, transcriptions, and any notes will be safeguarded and destroyed after the required time period has passed.
7. Interviews will be conducted at times and locations that are mutually convenient for myself and the researcher.
8. In the event that I should need to speak to someone about my thoughts and feelings resulting from the interviews, the researcher will work with me to access appropriate professional assistance.
9. If at any time I have questions or concerns about my participation in this research, I may contact the following individuals:

Research Supervisor:	**Dr. Derek Truscott** Phone 780-492-1161
Researcher:	**Kevin Hatch** Phone 780-414-1091

My Signature indicates that I have read and understand the content of this form.

Signature of Participant ________________________________

Date: ________________________________

APPENDIX C

INFORMATION AND CONSENT FORM FOR TEACHERS

My name is Kevin Hatch. I am presently completing a Doctoral dissertation in Counselling Psychology in the Department of Educational Psychology at the University of Alberta. I am interested in learning more about how we come to understand the needs of individuals with autism. The title of the study that I intend to complete is: How do we come to understand the needs of individuals with autism?

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by the Faculties of Education and Extension Research Ethics Board (EE REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EE REB at (780) 492-3751.

The purpose of the study is to explore and develop a more sophisticated understanding of how we come to understand and make sense of the needs of individuals with autism. It is my hope that through this collaborative enterprise a number of benefits will be realized. First of all, by collaborating with individuals who have great experience, greater understanding can be reached concerning the process of understanding the needs of individuals with autism. Second, I hope to improve my personal understandings and insights so that I can benefit the community in which I play a role as a therapist. Lastly, I hope that this research will serve to help others who care for individuals with autism to gain a richer understanding of what is it like to participate in the lives of these individuals.

It is important for you to know that you are not obligated in any way to participate in this research. If you choose not to participate your decision will be respected. If you chose to participate you may, at anytime, withdraw from this research study without penalty or prejudice. If during the research process you feel uncomfortable with proceeding you may contact any of the undersigned individuals to end your participation immediately.

In order to gather the information required for this study I will be conducting a number of audio-recorded collaborative interview sessions with people who have great experience working and caring for individuals with autism. I am requesting one formal interview of approximately 45 minutes in length and up to 3 follow up interviews of 10 minutes in length to clarify ideas and thoughts expressed in the initial interview. Each interview will happen at a mutually agreed upon time and place.

This is to Certify that I, ________________________________ have been informed about, and agree to the following:

1. I have been advised about the nature and purpose of the study.

2. My participation in the study is voluntary and I may withdraw at any time.

3. Any information shared with Kevin Hatch will be held confidence. Quotations and or summaries of what I say will only appear in the final thesis with my consent. The use of pseudonyms will ensure my anonymity.

5. The study findings may be published in an article or presented to a larger audience in the future.

6. The interviews will be digitally recorded and then transcribed. Audio-recordings, transcriptions, and any notes will be safeguarded and destroyed after the required time period has passed.

7. Interviews will be conducted at times and locations that are mutually convenient for myself and the researcher.

8. In the event that I should need to speak to someone about my thoughts and feelings resulting from the interviews, the researcher will work with me to access appropriate professional assistance.

9. If at any time I have questions or concerns about my participation in this research, I may contact the following individuals:

Research Supervisor:	**Dr. Derek Truscott** Phone 780-492-1161
Researcher:	**Kevin Hatch** Phone 780-414-1091

My Signature indicates that I have read and understand the content of this form.

Signature of Participant ________________________________

Date: ________________________________

Appendix D

Confidentiality Agreement

Project title: How do we understand the needs of individuals with autism?

I, ____ the transcriber have been hired to transcribe audio recordings of interviews and field notes relating to the above mentioned research project.

I agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format with anyone other than the researcher.
2. Keep all research information in any form or format secure while it is in my possession.
3. Return all research information in any form or format to the researcher when I have completed the research tasks.
4. After consulting with the researcher, erase or destroy all research information in any form or format regarding this research project that in not returnable to the researcher.

____________________	____________________	____________________
(transcriber's name)	(signature)	(date)
____________________	____________________	____________________
(researcher's name)	(signature)	(date)