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Karen S. Hurlbutt

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ADULTS WITH AUTISM SPEAK OUT:  
PERCEPTIONS OF THEIR LIFE EXPERIENCES

by

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A Dissertation  
Submitted to the Graduate Faculty  
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This dissertation, submitted by Karen S. Hurlbutt in partial fulfillment of the requirements for the Degree of Doctor of Philosophy from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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This dissertation meets the standards for appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

Harvey Knell  
Dean of the Graduate School  
7-27-00

PERMISSION

Title            Adults with Autism Speak Out: Perceptions of Their Life Experiences

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Date 7-24-00

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This last introduction was no exception and maybe even the most difficult. How do I say thank you to so very many people who supported and encouraged me? I will attempt now to do so.

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You and I have done a lot these past three years and have experienced some pretty neat things together. What should we try next? I think you are the greatest! Thanks, Amanda!

## ABSTRACT

The purpose of this study was to investigate and describe the perceptions of three high functioning adults with autism about their life experiences. After a review of the literature, I determined that there is a lack of information regarding adults with autism, especially those at the high end of the spectrum. There is a great deal of information regarding the educational needs of individuals with autism; however, there are few studies available which address the unique needs of the adults. I wondered "What can we learn about adults with autism that we did not know before? What can they tell us about their life experiences?"

The participants in this study were three high functioning adults with autism who lived in different cities across the United States. I met, visited, and corresponded with them over a nine-month period of time, beginning at a national conference on autism in July 1999 and ending in April 2000.

Qualitative research methods were used to study the perceptions of the life experiences of high functioning adults with autism. These methods included initial visits and interviews, follow-up interviews, and the reading of published and unpublished material written by the participants.

Through analysis of the data, an overall main assertion, three themes, and several sub-assertions were developed. Each theme and assertion was

documented and supported with verbatim data and related literature. These themes and assertions are summarized as follows.

High functioning adults with autism want to be considered *experts* in the field of autism, have opinions on, and want to be consulted on issues related to autism.

They see, and believe in, the value of others learning about autism directly from *the sources* themselves. They are proud to have autism and do not desire to be a neurotypical, whom they see as narrow-minded and biased.

Over time, with experience and education, high functioning adults with autism have developed opinions on a wide variety of topics related to autism. They believe that group living is dehumanizing, issues of employment are a big problem, behaviors need to be addressed individually and positively, and the use of gentle and supportive techniques is the best way to teach social skills.

Recommendations to parents and professionals involved in working with individuals with autism were provided.

## CHAPTER I

### INTRODUCTION

The purpose of this study was to investigate and describe the perceptions of three high functioning adults with autism about their life experiences. This study was intended to gain insight into how adults with autism perceive what their experiences have been, including their backgrounds and current life situations, their thoughts on having autism, and about autism in general.

In Chapter I, I will discuss the reason for the study. I will also include information on definitions and characteristics of autism and Asperger's syndrome/High Functioning Autism, including a discussion on the debate over Asperger's syndrome being considered a subcategory of autism. I will also discuss the need for and significance of the study and will conclude with the organization of the study.

#### Reason for the Study

My first classroom teaching position was with a class of primary-aged children with autism. I was intrigued by the behaviors, characteristics, strengths, and needs of these young children. I had the fortunate experience of being guided by both a veteran teacher and a speech therapist who taught me a great deal about autism. I later moved to the state in which I currently reside and even though there is not a large population of individuals with autism, I have remained

interested in this field for the past several years. In my present job as a Developmental Disabilities Case Manager, I work with individuals with developmental disabilities, including students who graduate from special education services and transition to adult services. Some of these individuals also have autism and I became curious about the lives of individuals with autism as they continued into adulthood. I wondered what services were available around the country and what the lives of these adults were like.

Through reading current literature and talking with professors with knowledge of autism, I discovered there is current interest in learning more about both the high end of the autism spectrum and about adults with autism, particularly those at the high end. I became more interested in and excited about learning more about the lives of high functioning adults with autism and began exploring this area as much as possible. The following section includes information about autism which provides the reader with a background of facts and characteristics.

### Historical Background

The term autism was first used by Leo Kanner in 1943 when he described a group of children with whom he was working as having "early infantile autism." He later selected five diagnostic criteria from his descriptions which he believed were central to this syndrome. These included a lack of affect, an obsessive desire for sameness, a fascination for objects, mutism, and good cognitive potential (Wing, 1991).

Only a year after Kanner described his group of children in the United States, Hans Asperger also identified a group of children with whom he worked as being autistic (Frith, 1991). The paper Asperger wrote at that time has been basically ignored until recently, even though the one Kanner wrote has become very well-known. Both men, independent of each other, described the same type of child and agreed on many of the same characteristics. These included impairments in language, nonverbal communication, imaginative play, stereotypical movements, clumsiness, and odd responses to sensory stimuli (Wing, 1991).

According to Lorna Wing (1991), individuals that Asperger described, and who would now be labeled as having Asperger's syndrome, tend to have and use good language skills at a young age, exhibit inappropriate social skills, have poor gross motor coordination, and mostly test in the mildly retarded, normal, or superior range of intellectual functioning. The individuals in Kanner's group covered a wider range of intellectual abilities, including those in the severely mentally retarded range, and had delayed or deviant language skills, as well as social impairments.

Attwood (1998) identified the core features of Asperger's syndrome to be a "lack of social skills, limited ability to have a reciprocal conversation, and an intense interest in a particular subject" (p. 13). According to Attwood (1998), in 1983, Burgoine and Wing suggested the following characteristics be the main clinical features of Asperger's syndrome:

- \* lack of empathy
-

- \* naive, inappropriate, one-sided interactions
- \* little or no ability to form friendships
- \* pedantic, repetitive speech
- \* poor, non-verbal communication
- \* intense absorption in certain subjects
- \* clumsy and ill-coordinated movements and odd postures. (p. 15)

Attwood (1998) was careful to note that "lack of empathy" should be interpreted to mean that individuals with Asperger's syndrome "can be confused by the emotions of others or have difficulty expressing their own feelings", not that they do not have the ability to care about others (p. 56). He also discussed the difficulties individuals with Asperger's syndrome experience with reading others' body language and picking up on social cues. This can result in embarrassing situations for parents and others who are with the individual, who may be confused as to what happened to cause disapproval. They may not be able to understand why doing or saying things which are true, may be offensive or annoying to others.

Sometimes, an individual with Asperger's syndrome may develop an intense interest in a specific topic and may talk incessantly about it. These interests can dominate the individual's free time and conversation which may be another irritation to others. An individual with Asperger's syndrome may also misinterpret another person's interest in him/her as being romantic or sexual as opposed to casual or platonic. They may not realize there are various levels of



relationships and may inadvertently set themselves up for abuse or exploitation, as well as legal troubles (Attwood, 1998; Howlin, 1997; Mesibov, 1992).

Currently, there exists a controversy over whether autism and Asperger's syndrome should be separate and distinct diagnostic categories or if Asperger's syndrome should be considered a subcategory of autism. According to the current Diagnostic Statistical Manual (DSM-IV) (1994) classifications, Asperger's is a separate and distinct syndrome from autistic disorder or autism. This, however, is a source of disagreement among professionals. Lorna Wing (1981) was one of the first of current specialists in the field who suggested that Asperger's syndrome be considered a part of the autism spectrum. Attwood (1998) stated that Asperger's syndrome is "now considered as a subgroup within the autistic spectrum, and the prevailing view is that it is a variant of autism and pervasive developmental disorder" (p. 16).

Attwood (1998) also stated that the use of the term "high functioning autism" is most popular in the United States and has generally been used for people who had been diagnosed in their early childhood as having autism, particularly those with characteristics of classic autism (p. 150). He also stated that this term continues to be used for a variety of reasons, among them a "lack of knowledge and training in the diagnosis of Asperger's syndrome" and the use of the term autism may better access services needed by the individual (p. 150). I have chosen to include Asperger's syndrome, also referred to as high functioning autism in this paper, as a subcategory of autism for this research project.

Since Kanner's first description of autism in 1943, much more information has become available regarding the needs of individuals with autism, especially those at the lower end of the spectrum. In contrast, Asperger's first writings about high functioning individuals were largely ignored until more recently.

By the 1970's, researchers in the field of autism were reminded of the existence of this high functioning group whose behaviors and needs were different from those with classic symptoms of autism. In the 1980s, a need to better define criteria for the whole spectrum of autism became apparent.

#### Characteristics

Autism is a lifelong developmental disability which affects an individual's communication skills, social skills, interpersonal relationships, and behavior. It typically appears during the first three years of life, is four times more prevalent in males than females, and is present in all racial, ethnic, and socio-economic groups. It affects nearly one-million people in the United States in some form (Autism Society of America, 1997; Autism Society of North Carolina, 1993).

Autism is a developmental disorder, with core features of impairments in communication, socialization, and imagination, with manifestations of behavior, which present in a variety of forms, stages, and ability levels (Frith, 1991).

#### Communication

In the communication area, impairments include being completely nonverbal to being echolalic (echoes of phrases previously heard), to having an age-appropriate vocabulary yet being unable to use speech functionally. In most cases, the development of language is delayed while in other cases, it never

develops at all (Frith, 1991). Problems include poor comprehension, literal interpretation of what was said, poorly modulated speech, unusual vocabulary, semantic problems, echolalic speech, difficulty dealing with abstract concepts, a lack of understanding and using social rules, and the failure to understand that what they say has an impact on others (Howlin, 1997). The development of language may be related to general intellectual ability (Frith, 1991). It is estimated that 75% to 80% of people with autism also have a diagnosis of mental retardation (Howlin, 1997).

### Socialization

In the social area, people with autism often fail to understand or respond appropriately to others' feelings or emotions, exhibit the lack of ability to share emotions or experiences, and demonstrate poor integration of social, economic, and communicative behaviors within an interpersonal context (Howlin, 1997).

They may have difficulty understanding social rules and may misinterpret social situations and their role in them, including why other people do what they do and how they should respond. They may have difficulty establishing eye contact, smiling, laughing, and showing affection, but may be able to do any one or all of these in varying degrees. Children with autism typically show a lack of spontaneous or imaginative play and may behave as if others around them did not exist (Frith, 1991).

Overall, people with autism have difficulty understanding the social rules necessary for successful relationships and experiences in life. They may not pick up on subtle cues and body language from others (Stoddart, 1998) and

seem to not understand and know how to respond to feelings, emotions, and opinions of others (Matson, 1994; Mesibov & Stephens, 1990).

In today's society, people learn social rules by observing and learning from them in their attempt to fit in and have successful experiences. People with autism often lack this ability to observe and learn from others (Siegel, 1996) and lack the insight and motivation to know that they should engage in reciprocal social interactions (Cohen, 1998; Matson, 1994; Siegel, 1996), including understanding why others feel or respond the way they do and how they should respond in turn (Howlin, 1997).

#### Imagination

In children with autism, imaginative pretend play is absent, delayed, or repetitive (Wing, 1991). These children may become fixated on simple activities or routines or may persevere on objects or topics (Frith, 1991). Individuals with autism may demonstrate stereotypical play (spinning, twirling, lining up) with some objects while ignoring others, may collect objects, or, as adults, may collect large amounts of information about one particular topic (Wing, 1991). Individuals with autism often do not interact with others while exhibiting these behaviors and may even use others only as "mechanical aids" (Wing, 1991), p. 112).

#### Manifestations of Behavior

Manifestations of behavior are exhibited in a variety of ways. Individuals with autism may also have sensory impairments. They may show unusual

reactions to being touched or feeling pain. They may appear to be deaf at times, but become extremely upset over sounds at other times. They may demonstrate insensitivity to sounds, smells, tastes, and touch, but may overreact to any of these as well (Attwood, 1998; Grandin, 1992; Siegel, 1996).

People with autism often exhibit obsessional and ritualistic behaviors. They may perform repetitive body movements such as rocking, spinning, finger flicking, hand flapping, and pacing, and may show distress over changes in routine, patterns, order, or schedule (Autism Society of North Carolina, 1998).

Their strict adherence to rules makes it difficult for them to adjust to changes and different situations. Once a rule has been learned, individuals with autism often have difficulty understanding that rules may need to be broken; they may adhere to the rule without flexibility, no matter what the social situation may be (Howlin, 1997).

See Appendix A for the current definition of Autistic Disorder according to the Diagnostic Statistical Manual (DSM-IV), and Appendix B for the definition of Asperger's syndrome according to the Diagnostic Statistical Manual.

#### Need for the Study

Limited research has been conducted on how adults with autism adapt to community living (Van Bourgondien & Elgar, 1990). There is a great deal of information available regarding the educational needs of students with autism, but there have been few studies completed which follow them into adulthood and address other needs (Hart, 1993). People with autism can continue learning well

into adulthood with encouragement and support systems; however, there are no federal mandates for the provision of services for adults as there are for children in the public school systems.

Most of the research that has been completed has focused on children. Very little research has focused on adults and their needs and how their quality of life can be enhanced (Howlin, 1997). What little research has been done has shown there to be a lack of specially trained staff and services needed to provide the help and support adults with autism require (Howlin, 1997; Wehman, Gibson, Brooke, & Unger, 1998).

In regard to adults with autism, Wing (1991) stated that "there is a lack of understanding of the wide range of severity and the widely differing manifestations of the basic impairments" (p. 117). Because the group of high functioning individuals with autism was ignored for so long, there is little information available to parents, family members, professionals, and the individuals themselves.

Howlin (1997) stressed the need for more research to be completed with adults with autism, especially "those who are more able" (p. 2). Much needs to be learned about how the social, communication, and behavioral deficits impact the lives of those with autism and what can be expected in adulthood.

Attwood (1998) believed that the high end of the autistic continuum is an area that is just beginning to be explored. There is a need to research how much progress can be made along the continuum, as little is known about the

prognosis or long-term outcomes for adults with Asperger's syndrome or high functioning autism. Myles and Simpson (1998) believed there to be an "enormous lack of understanding" (p. vii) regarding Asperger's syndrome which is a direct result of a lack of available information.

#### Significance of the Study

I believe that one of the best ways to learn more about the lives of high functioning adults with autism is to talk to and observe them, and read what they have written. There have not been many studies carried out with this population and what studies have been completed tend to suggest tentative success in the future for these individuals.

Lord and Venter (1991) stated that while some findings suggest that improved services (such as supported employment) have made a difference for these individuals, there remains a great number of unanswered questions regarding academics, adaptive skills, communication, and predictors for future success. Wing (1991) stated that some individuals with autism who are high functioning and have only social impairments and a desire to "compensate for their problems" can become "markedly successful as adults" (p. 118).

Holmes (1998) suggested that as more services become available to adults with autism, the needs of the individuals are "being discovered in more detail" (p. 218). He feels that even though autism is a lifelong disorder, there is no certainty as to the effect it will have on any individual. Because of the lack of sufficient follow-up research, there is a need to determine how these adults with

autism are doing, how they feel autism has impacted their lives, and what they think is important for parents and professionals to know about being an adult with autism. Cohen (1998) identified a need to continue to study adults with autism which could lead to improved life experiences for them.

I felt there was much more to learn about autism, particularly the higher end of the spectrum. I was interested, as Cohen (1998) suggested, in "switching the lenses and looking at the world from the perspective" of those with autism (p.183). As a way of increasing the knowledge base of the unique needs and behaviors of this population, I investigated and described the perceptions of the lives of three adults with high functioning autism.

#### Delimitations

The purpose of this qualitative study was to investigate and describe the perceptions of three high functioning adults with autism about their life experiences. I intended to define the perceptions on the basis of the adults' own understanding of their experiences and life events.

1. Because I confined this study to three adults diagnosed with high functioning autism only, this study did not account for or differentiate among such experiences on the basis of sex, age, ethnicity, socio-economic status, nationality, or religion.
2. The information I received from the participants was based only on their own perceptions that specifically dealt with their individual life experiences.



I did not solicit or use commentary or narrative from the participants' family members, peers, employers, or agency representatives.

3. I selected participants from the high end of the spectrum (upper fourth) who have been diagnosed as having high functioning autism; however, using current diagnostic material, may be considered to have Asperger's syndrome.

#### Organization of the Study

Chapter I of this study included an introduction to the study, with background information, the reason for the study, and characteristics of autism and Asperger's syndrome. Also addressed were discussions of the need for and significance of the study, as well as delimitations. It concluded with an organization of the study.

The methodology chapter (Chapter II), includes information on the qualitative methods used to gather and analyze the data. A detailed discussion of the exact procedures used is also included. The section on data analysis contains a description of the process of coding data and identifying themes, patterns, and assertions.

In Chapter III, vignettes of each participant provides the reader with rich descriptions of the participants as individuals. Also included with each vignette is a description of the initial face-to-face visits and interviews. Chapter IV includes a statement of the overarching theme of the study and several assertions and subassertions. Each theme and assertion is supported by verbatim narrative taken from the data and a discussion of related literature. The study is concluded

in Chapter V with a summary, conclusions, limitations, recommendations, and my personal reflections.

## CHAPTER II

### METHODOLOGY

The purpose of this study was to investigate and describe the perceptions of three high functioning adults with autism about their life experiences. This study was intended to gain insight into the adults' perceptions, including their thoughts on their backgrounds, current life situations, having autism, and about autism in general.

In Chapter II, I will discuss background information on the use of qualitative research techniques, including the model used for this study. This is followed by a discussion of reliability and validity. The next section includes a detailed description of the data collection procedures used, followed by a description of the process of data analysis, including the identification of codes, patterns, themes, and assertions.

In order to develop a base of background information and further develop an understanding of the lives of adults with autism, I researched related literature in several main areas. The first area included definitions and background information about autism. The second area included information about treatment options and educational issues. The third area included information about adults with autism, programming options, identifying and addressing the unique needs of adults, and the need for additional follow-up studies.

### Qualitative Research Techniques

This study incorporated qualitative research techniques. Qualitative research is helpful for theory development and can help "bridge the gap between practice and theory in special education" (Stainback and Stainback, 1984, p. 404). Through the review of related literature, it was determined that there is a lack of sufficient information regarding the lives of adults with autism (Frith, 1991; Howlin, 1997; Myles & Simpson, 1998; Wing, 1991). The use of qualitative research methods is a way to learn more about a phenomenon where little is known or to gain new views on a topic which has been researched before (Strauss & Corbin, 1990).

Because of the lack of sufficient research regarding the lives of adults with autism, I believed that perhaps we, as professionals, did not know enough about these adults. What can adults with autism tell us about their life experiences? What can we learn about adults with autism that we did not know before?

In order to thoroughly describe the perceptions of adults with autism about their life experiences, it was necessary to conduct this research through the use of qualitative research methods. As defined by Maykut and Morehouse (1994), qualitative research "generally examines people's words and actions in narrative or descriptive ways more closely representing the situation as experienced by the participants" (p. 2). I was best able to obtain information about adults with autism and their perceptions of their life experiences by asking them about their experiences and listening to them talk about them. As defined by Creswell (1998), a phenomenological study "describes the meaning of the lived

experiences for several individuals about a concept or the phenomenon" (p. 51). The open-ended interview format I used was designed to "reveal what is important to understand about the phenomenon being studied" (Maykut & Morehouse, 1994, p. 81).

Maykut and Morehouse (1994) suggested that the researcher ask him or herself "Is this understanding of the participants' world helpful to others? In what ways?" (p. 29). I gathered information that will be useful to professionals who work with adults with autism. Through qualitative research, I gathered information that addressed the meaning life has for adults with autism.

#### Research Design

First, a model I used for the design of my research will be described, then the methodology will be described. I used the eight characteristics of qualitative research as described by Maykut and Morehouse (1994) as the basis for the design of my research. These included an early and descriptive focus, emergent design, a purposive sample, data collection in the natural setting, emphasis on 'human-as-instrument', qualitative methods of data collection, early and ongoing data analysis, and a case study approach to reporting research outcomes.

#### Early and Descriptive Focus

This research study was designed to discover information about the phenomenon of how adults with autism describe their life experiences. The results are not expected to be generalized but rather to provide more of an understanding of life experiences from their perspective. As previously

mentioned, there is very little follow-up research regarding the lives of adults with autism, which is the focus of this study. The stated purpose of this study was, at this point in the design, broad and general.

### Emergent Design

An emergent design is one in which the initial focus is refined and narrowed through an ongoing process of data collection and analysis (Maykut & Morehouse, 1994). While meeting with the participants, interviewing, and interacting with them, and then doing follow-up interviews, I conducted an ongoing analysis of the data to refine and narrow it throughout the investigation.

### A Purposive Sample

In qualitative research, participants are carefully selected for inclusion, based on the possibility that each participant will expand the variability of the sample (Maykut & Morehouse, 1994). The participants in this study were selected not as a random sample, but rather as participants who "represent the range of experience on the phenomenon in which we are interested" (Maykut & Morehouse, 1994, p. 57). The sample included one female and two males.

### Data Collection in the Natural Setting

The natural setting is where the phenomenon under research is most likely to occur. As there is not a population of adults with autism who are able to share their life experiences with me in the area in which I live, I needed to go to them. The setting of a national autism conference was a place where I could meet and socialize with adults with autism and begin the process of data collection.

### Emphasis on 'human-as-instrument'

The researcher of a qualitative research study is both a collector and analyzer of that data. The data were collected from interviews, field notes, and samples of published and unpublished personal writings of the participants. The data collector was human and data were received from human participants.

### Qualitative Methods of Data Collection

The most common forms of data collection include participant observation, in-depth interviews, group interviews, and the collection of relevant documents. I used initial visits, in-depth and follow-up interviews, and the reading of various writing samples by the participants as methods of data collection.

Maykut & Morehouse (1994, p.79) consider interviews to be a "conversation with a purpose." By first establishing rapport with the participants, I was able to have such conversations with them during the interview sessions. While the participants talked about their life experiences, I made some comments and asked for clarification or elaboration when necessary.

### Early and Ongoing Inductive Data Analysis

Analysis of data needs to begin when one set of data has been collected. The researcher begins to analyze this data and identifies important pieces of information, concepts, or individuals that can help broaden or refine the focus of inquiry. After the initial set of interviews and observations, I analyzed those results and identified any "leads" that began to emerge. These leads were more

thoroughly investigated and analyzed using a coding procedure described in the "Data Analysis" section of this paper.

#### A Case Study Approach to Reporting Research Outcomes

A rich narrative was written which presents the results of the qualitative research study. A researcher needs to write about what has been seen and heard and to make sense of the data. The journey from the identification of the initial focus of inquiry to the assertions derived from the data analysis are described in detail in the Procedures and Data Collection section.

#### Verification

##### Validity

Kvale (1996) defined validity as pertaining to "the degree that a method investigates what it is intended to investigate, to the extent to which our observations indeed reflect the phenomena or variables of interest to us" (p. 238). Miles & Huberman (1994) suggested that in order to make field research valid, the researcher needs to "link the meanings and interpretations of our informants, our own interpretation of those meanings, and our confirmatory, theory-connected operations" (p. 262).

A researcher needs to increase his or her own confidence as well as the confidence of the reader, in what was found. Creswell (1998) and Miles & Huberman (1994) identified several methods a researcher can use to confirm findings. Creswell (1998) recommended using at least two verification strategies in any given study. Some of the strategies recommended include checking for representativeness, checking for researcher effects, weighting the evidence,



looking for negative evidence (Miles & Huberman, 1994), peer review or debriefing, including a rich, thick description for transferability (Creswell, 1998), and member checks and triangulation (Creswell, 1998; Miles & Huberman, 1994).

Following are the strategies I used in this study based on the recommendations of the aforementioned authors:

1. Member checks or getting feedback from participants: This strategy involved taking the data, analyses, and conclusions back to the participants so they could read, review, react to, and comment on the information. The participants needed to check for accuracy. I utilized this strategy at different points in the process. As mentioned earlier, I asked the participants for clarification when necessary and I also made comments and asked their opinions of the accuracy of my understanding during several data collection sessions. If I was wrong, they told me. If I was correct, they told me. I was careful to not ask for feedback on any emerging patterns during the data collection sessions, because, as Miles & Huberman (1994) warned, I may have changed the participants' perspectives. Up to this point, I only asked for clarification.

Next, I asked for feedback regarding the information in the vignettes (Chapter III). There were, in fact, corrections to be made, including a couple of typos, the number of years ago an incident occurred, and the wrong example used to illustrate a point. I obtained feedback from the participants at one last point. I reviewed my assertions with them and asked for their opinions.

Responses included *That's exactly right!*, *That's the message I was trying to get across*, *I believe that would be accurate*, and *I'm so proud of you for doing this!*

I also obtained additional information from the participants by reading several articles, stories, and editorials they have written. This provided me with additional information to help me learn more about them and also gave me another source of data.

## 2. Peer review or debriefing:

In this strategy, a peer serves as a "devil's advocate" (Creswell, 1998, p. 202) and provides an external check of the research process by asking questions about the whole process. I debriefed with three different colleagues on a number of occasions to review my data, asked for input and direction, and double checked my interpretations.

## Reliability

Reliability is the consistency of the data. Bogdan & Lutfiyya (1998) suggested that a qualitative researcher's check of reliability includes demonstrating a "fit between what is recorded as data and what actually occurs in the setting under study" (p. 232). In qualitative research, there is more emphasis on validity than reliability, although attempts must be made to "try to make the research situation the same for all respondents" (Bogdan & Lutfiyya, 1998, p. 231).

I attempted to increase reliability by creating as much similarity as possible, using the following methods:

1. I explained the procedures and my intentions in the same way to all three participants;
2. I initially interviewed all three participants in the same setting (the hotel) and asked the same questions;
3. I audio taped and reviewed all of the interviews;
4. I asked the same questions during follow-up interviews; and
5. I gave the same information regarding progress of the study to all three participants.

#### Procedures and Data Collection

Two months before I started the process of data collection, I submitted a Human Subjects Review Form for New Projects to the Institutional Review Board (IRB) for their review and approval. The purpose of this board is to protect human subjects by weighing the costs of risks of the research against possible benefits to that particular field. Included with the review form, I also submitted three letters of support from administrative staff at three different providers of services for individuals with autism. I had contacted agencies from three different parts of the country and explained my proposed research to the administrative staff. One was the President and Executive Director of an agency, the second was the Director of Outreach services at another agency, and the third was the Division Director of Transition and Adult services at another agency. I also met all three of these individuals at the national conference two months later and spent time with them discussing the agencies they represented and current issues for adults with autism. Their initial support was very valuable

to me and was one of many motivating factors for me throughout the research process.

The Autism Society of America hosts a national conference every year and this was the site of the initial data collection. At the start of the conference, I met with the coordinator of the conference to talk about this study. She verbally expressed her support and suggested that I introduce myself to parents, representatives from agencies, and adults with autism and ask if they would be interested in participating.

On the first day of the conference during breakfast, I was approached by one adult with autism, who saw my name tag with my hometown (Fargo) and recognized it as the name of a movie. We introduced ourselves and talked about why we were both at the conference. I told her that I would need to meet and interview some adults with autism and she volunteered to participate. She said *I have autism; I would love to be interviewed by you!* We selected a time to meet and she also introduced me to several other adults with autism, two of whom volunteered to participate after I explained the proposal for this study.

As we visited, we talked about where we live and our roles at and reasons for attending the conference. I explained my purpose in wanting to do this research. Each participant readily and enthusiastically agreed to participate in this study. We first set up a schedule for interviewing and each participant signed a consent form (See Appendix C). Each interviewee was assured in writing of his or her right to cease participation in the project at any time or to

have any information shared with me removed from the records. I met with each participant for approximately two hours during the initial visit.

I first met with Joe, early in the morning of the second day of the conference. We met in the hotel lobby and drank coffee, which I bought for him. It was a busy place with many conference attendees coming and going. However, no one interrupted us as we visited. I next met with Xenia, shortly before lunch on the second day of the conference. We went outside and sat on benches in the area across the street from the conference. It was warm and sunny and much quieter and more private than staying inside. Also, Xenia has a difficult time being in small areas where sounds bounce off the walls. It was easier for her to concentrate outside. Afterwards, we bought a hot dog from the hot dog vendor near the hotel. I met with the third participant, Eugene, in the afternoon. We met in one of the rooms at the hotel where we could talk quietly and privately. I bought a pop for him as well.

I first established rapport with the participants and obtained background information about them, such as where they lived, where they went to school, what their work situation was, and what they liked to do in their leisure time. After the initial visits of establishing rapport, I began the interviews. Maykut and Morehouse (1994) recommended that interview questions be open-ended and designed to identify what the participants felt was important for the researcher to understand. I started by asking two questions. These were "Please tell me about your life" and "How has having autism affected your life?"

Maykut & Morehouse (1994) suggested that a qualitative study does have a focus but it needs to be broad and open-ended at first which allows for important meanings to be discovered. Other questions were asked in response to participants' responses or for clarification.

Each initial interview lasted approximately two hours and was audio taped. The tapes were kept on my person or locked in the hotel room. These were later transcribed by only me. During the interviews, my role was to listen to what they had to tell me about their lives and concerns and to hear them express their views and opinions of their lives (Kvale, 1996). All participants were informed of the need for possible follow-up questions which were conducted over the phone and/or through the use of e-mail. The interview questions and responses were written down verbatim during the discussions.

Throughout the conference, I met again with the participants at different sessions and activities. Each of the participants attended several sessions and panels and participated in activities for adults with autism. One participant was a speaker at a couple of the sessions as well. The others have been speakers at other conferences and will be speakers again but were not at this one.

Over the course of the next nine months following the conference, I corresponded regularly with the participants by phone and e-mail. Each participant also sent me copies of various articles, stories, and essays they have written over the years.

All communication with the participants was documented verbatim and I asked for clarification and accuracy of my understanding on a number of issues and occasions. Data were collected during all interview sessions and reviewed afterwards for accuracy.

During the initial and subsequent interview sessions, participants were asked to elaborate on a subject or topic being addressed. After each initial interview, I returned to my hotel room and read through the notes I had taken during the interviews. While their thoughts and comments were still fresh in my mind, I was able to organize the notes and include additional comments and notes to myself. When I returned home after the conference, I listened to each interview in its entirety from the cassette tapes and added additional verbatim comments to my original notes. The initial interviews were the basis for all future interactions.

From each interview, which I recorded verbatim, I made notes and listed topics or questions I wanted to pursue further or needed clarified. This procedure allowed me to become thoroughly absorbed in my interactions with the participants and accurately document their thoughts and feelings. If I needed clarification or elaboration, I asked for it. If I did not understand, I asked for examples. This regular review and reflection of the data reduced the chances of reaching any conclusions too early in the research process.

As a part of the data collection process, I also read several articles, stories, and editorials written by the participants. I highlighted information and

also took notes from these writings. During the nine-month data collection period, I kept all notes and data in separate files, one file for each participant. I numbered each page of notes and data in the order I received it. At the end of the nine-month period, I read through each set of notes and data several times before beginning the coding procedure.

Data were analyzed using qualitative data analysis methods. As suggested by Maykut and Morehouse (1994), the data were analyzed early on and as an ongoing research activity. As I read through the data, I documented recurring ideas and thoughts and identified any patterns which emerged.

As I reviewed the data, comparisons were made and data were analyzed using an open coding procedure. The process of coding includes looking at data to see what goes together and what does not. Miles & Huberman (1994) identified the importance of coding to include the researcher "trying to understand a phenomenon better" by clustering together the data and sorting them into categories (p. 249).

As I tried to understand the phenomenon of the perceptions of the lives of adults with autism, I inductively formed categories and sorted the data into those categories. Strauss and Corbin (1990) suggested three possible ways to code data. These include coding line by line, sentence (or paragraph) by sentence (or paragraph), or coding the entire document. I looked at all data as it became available and then looked at the entire document and asked "What seems to be going on here?" According to Emerson, Fretz, and Shaw (1995), the researcher



begins to "entertain a wide variety of ideas and insights about what is going on in the data" (p. 155).

Throughout the whole data collection and analysis processes, I noted several thoughts, ideas, and patterns, which seemed significant to me, although some issues did not prove to be significant. I followed up on any issues needing clarification. I documented the participants' opinions of various treatment methods and available support service options. I pursued their understanding of the social rules in our society and their perception of their ability to follow them. The service delivery system was an issue that did not end up being significant. Opportunities presented themselves to discuss their ideas about individuals all along the autism spectrum.

As I went through this process, I identified patterns and codes by isolating thoughts, counting the number of times the thoughts occurred, and how many times they consistently happened in a specific way. I identified thoughts I believed to be important or significant, which Miles & Huberman (1994) suggested is how judgements are made, i.e., by counting and making comparisons. Actually counting occurrences can help the researcher see what is in the data, can verify a hypothesis, and can test for possible bias.

At the beginning of the coding procedure, I coded by paragraph and/or main idea. As I read the field notes, I wrote down a word or phrase which identified the main idea of the paragraph. I started by reading data from each participant separately at first, and wrote down main ideas for each one. When finished, I had identified approximately 150 "main ideas." Next, I coded each of

those main ideas by clustering similar points into one code. This procedure resulted in the identification of 29 codes. After all the data were coded, the next step involved identifying concepts. Concepts were grouped or categorized and then named according to the characteristics of the grouped concepts.

Sometimes, the categories are named from a "pool of concepts" (Strauss and Corbin, 1990, p. 67) obtained from the literature review or they can just be names that seem most logical to the data and make the most sense to the researcher. I named my categories in a way that seemed logical to me and was related to the data.

By reviewing the data while working with the coding scheme, patterns began to emerge in a past, present, and future format. There were issues identified at each stage, including 1) the past - looking back on their lives, experiences growing up, family issues, school experiences, and peers; 2) the present - what their lives are like now, what their beliefs and practices are, how they feel about their experiences; and 3) the future - what their goals are, what they would like to see happen, and what they feel needs to be addressed. Grouping the codes and data this way allowed me to look at the whole picture of what the participants had told me. They had described so many parts of their lives and I was able to understand their views of their lives.

Miles & Huberman (1994) suggested that even though participants would agree with the facts and patterns the researcher saw, they are not able to put them together as the researcher did. The researcher is able to see the patterns because he/she sees things happening and hears similar things from other

participants. The researcher should be able to see the whole picture as he or she has access to all the data. I had access to data from all three participants so I was able to continue "reducing the bulk of the data" and finding patterns in the data (Miles & Huberman, 1994, p. 256).

After further analysis, I was able to collapse the codes into seven categories. Some of the codes were assigned to more than one category while some were clustered together into one specific category only. The seven categories included codes relating to families and experiences growing up, religion, employment, formal and informal social rules, advocacy, specific information on autism, and participants' personal feelings on many subjects.

Eventually, four patterns emerged after the coding and categorizing process. These four patterns were equally supported by all three participants throughout the nine-month period of data collection. They are identified with these names: "Past and Current Philosophies and Treatments", "Neurotypicals", "Spread the Word", and "Family". With the identification of these patterns, an overall assertion regarding the perceptions adults with autism have about their life experiences was made. This assertion and three themes are discussed in detail in Chapter IV and support my overall assertion that "high functioning adults with autism would like to be considered experts in the field of autism, have opinions about, and want to be consulted on issues that affect their lives."

## CHAPTER III

### PARTICIPANT VIGNETTES

Chapter III contains vignettes from each of the three participants in this study. Even though I obtained permission from each of them to include this information, I consider these vignettes to be a very private glimpse into their lives.

As previously mentioned, in this study, I considered the term high functioning autism to be the same as Asperger's. High functioning autism is the term the participants used when pressed to describe themselves, which is consistent with their diagnoses. I believe each participant would "fit into" the definition of Asperger's syndrome; however, I have used the term high functioning autism because this is how the participants referred to themselves. Interestingly, the participants scoffed at the labels we use. Just because someone may be "more involved or less involved" does not mean to them that they should have different labels. They consider themselves to have autism, that is all.

The rest of this chapter contains a vignette on each participant, Xenia Katz, Eugene Thomas, and Joe Bower. The names used in this study are pseudonyms, selected by the participants, and used to protect anonymity. Each vignette was reviewed and approved by each of the participants. I am very

grateful to Xenia, Eugene, and Joe for sharing their life stories with me and allowing them to be summarized here. They have been very gracious indeed.

#### Xenia Katz

Friendly, talkative, open-minded, compassionate, and committed to the cause of autism are words that describe Xenia, a 35-year-old woman with a diagnosis of high functioning autism. She is from a large family (seventh of eight children) and was brought up in the Midwest. She currently lives alone in an apartment in a large city in the interior west section of the United States with her cat, Vivir, with whom she likes to snuggle. She works at a job doing data entry work and likes it very much. She was married for three years but got divorced three years ago.

By the time Xenia was a year old, her parents knew something was different about her; something was wrong. She did not reach for toys and did not appear to react to the noise and commotion in the large household. She was tested at about 2 ½ to 3 years of age and her parents were told she had an IQ of 48. Xenia started talking at age four and, as she puts it, *I haven't stopped since!* She credits her family with helping her to start talking and learning how to play games, both of which helped her develop social skills. She is grateful that she did start talking because she knows she would have been institutionalized if she had not been talking by age five.

Xenia's years of growing up were hard ones as she notes, *I was made fun of for eight years straight from third grade to tenth grade.* She tried hard to fit in and be like the other girls, even though she never truly was successful at this.

As she says, *It's hard to stifle what you like because you're trying to fit in*, and her interests were not the same as her peers. While they were interested in music, sports, rock singers, and the opposite sex, she was interested in and fixated on numbers (she used to impress people with her knowledge of multiplication tables), Indians and rocks, and her biggest fixation, South America. She used to jump rope with tunes she made up using the names of various countries in South America, *Venezuela, Colombia, Ecuador, Peru, Chile, and Argentina*. Her fixation on other countries started at a young age and continues today. Even her love letters to 5th grade boys reflected this fixation, *Dear Greg, Africa, Asia, Europe. Love, Xenia*. She found out that other kids did not want to talk about the Soviet Union, Communism, and South America.

Because of a miscommunication between her mother and the doctor when she was ten years old, she did not know she had been diagnosed as having autism. She was nineteen years old and in college (where she *felt normal for the first time because I met so many people from other countries*) when she finally found out she had autism. Things finally started to make sense to her about why she was the way she was and why she was unable to *fit in*. Xenia graduated from college with a degree in Political Science. She feels she is typical of many high functioning adults with autism, in that she has struggled with finding satisfying and meaningful employment. She has been a telemarketer (which helped her learn how to do public speaking!), a direct care staff person at a group home (but the low pay and working the early morning

shift were too much for her), and a janitor at a veterinary clinic (which was *boring, boring, boring*). She believes that unemployment and underemployment of adults with autism is a *very big problem* which needs to be addressed.

Xenia is involved in an Orthodox church and is deeply religious. She attends church regularly and enjoys socializing at the brunches afterwards. She also participates in a Social Skills group for people with autism. Even though she is generally happy, she also takes medication for depression. She is sensitive to certain noises and sounds (high-pitched, static, babies crying, kids' songs, and being in small places where sounds bounce off the walls). She is a visual learner and thinker and often takes things literally, especially when asked a literal question (*too short a sentence, not enough information*). She admits she cannot worry about paying attention to all of the informal rules of society and wondering what others think of her all the time, as she would become overwhelmed and want to *curl up and go away*.

Xenia's fixation on countries and cities is a prominent theme in her life. She has maps and flags of different countries, bus schedules from different cities, and can remember where people are from before she remembers their names! She gave an example of this fixation: *When you go shopping for clothes, you probably look at the size or price tag. I look at what country it is from*. Our conversations were often sprinkled with thoughts, comments, and facts about other countries and cities.

Xenia's goal is to learn as much as she can about autism and share as much as possible with others (preferably in different countries and languages). She believes that others need to hear about autism, *especially the high end of the spectrum* directly from those individuals themselves, and she is proud to be a part of this. She plans on continuing to travel to, participate in, and speak at conferences on autism, and publish more articles about autism than she already has. This includes being published in journals and newsletters in India, England, Israel, Australia, and Canada, to name a few.

Xenia is finally proud of who she is and does not want to be any different. She finds many *neurotypicals* (i.e., people without autism) to be *narrow-minded, biased, and unpredictable* and she is not interested in being *conventional -- it bores me to death!* Over time, her family has also learned more about autism and this has resulted in them understanding her better. She feels that the older she gets, the more she values and likes who she is.

Xenia and I met outside of the hotel and sat on benches across the street. She wore jeans, tennis shoes, and a t-shirt with lots of flags on it and "United Nations" printed below, along with the symbol of the United Nations. Xenia was cheerful, friendly, talkative, inquisitive, and thoughtful. At the beginning of the visit, when I turned on the cassette recorder, she jumped in and spoke directly into the recorder, stating the day, date, time, and place of the interview, for documentation purposes. She also asked me questions about where I am from, about my family, and expressed her pleasure at my doing this research. When



she was happy about something, it was reflected in her voice, which was louder and more animated. This was usually during times we talked about places we had both traveled to, certain topics about autism, and family and friends. When we discussed something that was not as positive to her, like her vulnerabilities or help she has needed, her voice was quieter and lower. During the visit, she laughed easily and often. She was not distracted by traffic driving by, the sounds of the construction workers nearby, or the wind. She was not worried about the amount of time we took, even though she had another appointment to get to at some point and needed to eat lunch. She gave me her undivided attention throughout the whole visit.

#### Eugene Thomas

Quiet, analytical, determined, and a devout Catholic describe Eugene Thomas, a 61-year-old male with a diagnosis of high functioning autism. He is presently retired and lives in a city in the northeastern section of the United States. He lives in a house with his brother and three cats. For the past four years, he has held a volunteer position at a clearinghouse which distributes information about autism. He fills orders by putting together packets of information based on specific requests. He enjoys the flexibility, relaxed environment, and supportive staff, and prefers this over jobs he has had in the past, although he does not get paid.

Eugene has many memories of what it was like for him growing up. When he was a baby, he remembers rocking in his crib, and later singing *nonsense*

songs which he made up to memorize the street names of the city in which he lived. He recalls that when starting school over fifty years ago, *virtually nothing was known about autism*, and he was labeled *deaf, retarded, and everything else*. His mother was advised to put him in an institution but she refused. Eugene considers his mother to be his *heroine* as she fought to help him, twenty-five years before information became available. At one point, she heard about autism on a radio talk show and commented that the *"characteristics of lack of sociability and being withdrawn were just like Eugene."*

He was finally diagnosed as having high functioning autism in 1995, at age 56. He wishes to this day that there had been more information about autism because he *never knew what was wrong* with him and thought he *was the only one in the world like this*.

Eugene is someone who tries hard to please others and do the right thing. He also has strong opinions and creative ideas (a vivid imagination!) about the government, science, science fiction, technology, politics, and the environment. He spends a fair amount of time on the Internet in chat rooms where he discusses and debates political views, among other things. He has, at times, been threatened because of his strong opinions. He is fascinated with these topics and spends large amounts of time fantasizing about new technologies, inventions, and ways of life.

Eugene graduated from college with a Bachelor of Arts Degree in Speech. He had planned to get a degree in Speech Correction but was unsuccessful at Student Teaching and was told by his supervisors that he *needed professional help*. He said that *it seemed that any social situation I got into, I failed*.

In addition to working at his volunteer position and spending time on the computer, Eugene also walks on the treadmill, watches TV, goes to church and Confession, is involved with a group for adults with autism, and attends and participates in conferences on autism around the country. He presently takes medication for depression, which has resulted in his being *more involved with his surroundings and other people*. Eugene is comforted by the various aspects of the Catholic church, *including prayer, novenas, rosary, and the Sacrament of Healing*.

Eugene has struggled his whole life with trying to interact appropriately with others. As he says *there are these social skills that foul me up!* His frustration with not being able to *read the body language and social cues of others like neurotypicals do*, particularly in regards to his relationships with women, is readily apparent. He struggles to understand the difference between romance and friendship, which he expressed to me in our conversations several times. He gave several examples of uncomfortable, difficult, scary, and almost illegal situations in which he has found himself with women. He has had to *stay away from women* because of these problems and has, at times in his life, been accused of *being gay* because he rarely goes on dates.

Eugene also experiences confusion (and sometimes anger from others) when he occasionally takes others' words too literally. For example, someone may suggest that he help himself to some food but then they become annoyed when he eats the whole thing. He wonders why they did not offer him a *piece*.

It also bothered him to be told by former bosses to *go around and smile and be happy* even when he was angry or sad. It was a *problem* when he worked overtime to do a good job but his bosses wanted him to work the allotted amount of time per day. He wondered *what was I to do?*

Eugene held a number of jobs over the years, including being a caseworker, a dishwasher, working in a department store and a stock room, but had difficulty maintaining them, due mostly to some type of misunderstanding of expectations. Sometimes he asked too many questions, sometimes not enough, and sometimes he *bothered the women*.

He is now becoming more involved with autism groups, conferences, and a Board of Directors of an agency which serves people with autism at the local level. He has been a panel member at a number of conferences and has a goal of being an advocate that could *provide meaningful jobs for those people with autism who are now relegated to jobs unworthy of their talents or training, or can't find employment*.

Even though there are times when Eugene becomes frustrated with his autism, he feels more accepted now than when he was younger. He now feels as though he *fits in* because he has this diagnosis and knows there are other

people like him who have *the same problem*. He feels that information about autism needs to become even more widespread and that people need to consult with adults with autism as being *the experts on autism*. He has more opportunities than ever before and sincerely wants to be a part of this effort.

I met with Eugene at the end of a day full of sessions and panels he attended. He was quiet and pensive at times, always carefully wording his thoughts and responses. He wore brown pants and a yellow and white Columbine t-shirt (acknowledging a recent high school shooting spree). We chose to meet in one of the rooms in the hotel after meeting each other in the hall due to the number of attendees wandering around so late in the day. We also wanted to meet away from others so we could talk openly and privately, without others interrupting.

Eugene was sequential in his descriptions of his childhood years and events and showed his anguish at describing his efforts at interacting appropriately with women. Eugene was very close to his mother when she was alive and he often spoke admirably of her. Eugene was also very concerned about the employment situation of adults with autism and brought up this topic a number of times. He was serious, although friendly, and was careful to say and do the "right" things, coming across as respectful, and as a gentleman.

Joe Bower

Calm, soft-spoken, confident, proud, an occasional streak of sarcasm, and an activist for autism are words that describe Joe Bower, a 31-year-old male with

blue eyes and brown hair, who has a diagnosis of high functioning autism. He was born in the Midwest and brought up in a rural area, but currently lives near a large city in the Midwest. He holds two masters degrees, one in Medieval and Roman History, and the other in Library and Informational Science. He currently lives alone in an apartment, has a car, and works as an Information Specialist at a university.

Joe was diagnosed as having autism at age 3 ½ and again at age six. When he was young, he was echolalic (echoes of phrases previously heard), a "runner" (ran quickly away from his mother and his home every chance he had), watched records spin around and around, and was also labeled as deaf and mentally retarded. From a very early age, Joe's mother kept searching and fighting for both an appropriate diagnosis and school programming. Joe credits his family (his mother in particular) for helping him get to where he is today. They taught him functional skills and discovered ways to motivate him to talk. His family also helped him develop social skills, including *not being honest all of the time or you would get in trouble, don't discuss certain topics, don't sing on the school bus or watch raindrops race down windows, and don't wear your clothes inside out and backwards*. His siblings wanted him to follow these rules so they did not look bad and he would not look *weird*. One rule he especially had difficulty with and did not follow very well was to *act normal*. Because his siblings *didn't understand* that he had autism, they just *forced* him to play with

them. Joe's mother worked tirelessly at pushing for as normal a life as possible with opportunities to experience many things and develop necessary social skills.

As a child, Joe noted that he was not aware of his mother's fear or sadness about him being a runner, he showed no ideas of ownership of toys or other belongings, and he was not aware of what others thought of him. Eye contact continues to be difficult for him, especially with new people or in new situations. As he says *Either you get eye contact or you can have a conversation with me. You can't have both.*

During his school years, Joe was very good at all kinds of trivia, including music and history trivia, and by fifth grade he had a strong interest in history and knew this was one of his greatest strengths. In high school, he was the captain of the History team.

Growing up, Joe tried all kinds of sports but was a *klutz* and was usually cut from the team. He has many memories of being bullied, teased, taunted, and harassed daily by peers from the sixth grade to the tenth. This humiliation really made him aware of his differences. He stated that he internalized his feelings about those incidents and *did not feel like a worthy or good person until age 25.*

By the time he was in college, Joe was interested in meeting young women and dating, but was unsuccessful in his attempts to start a relationship. He often *drove them away by calling them so much* and not recognizing their feelings of harassment. He has had one satisfying and successful relationship,

but had to end it because they lived too far away from each other. He still very much wants *to get married and be a father*. He stated that he still does call people too much *on the phone*, but is getting better at not doing this as often.

Joe considers employment to be a *hot topic in autism* as the majority of adults with autism are underemployed or unemployed. He has held several jobs in his life, from dishwashing to telemarketing, to bagging groceries, to cataloging microfilms. His jobs have lasted anywhere from one week to one year. He described his frustration at not being able to hold a job because he did not want to tell anyone he had autism. *I wanted to make it on my own merit*. He feels that employers need to be educated about autism and should be clear and specific in their expectations and directions.

Joe keeps a busy schedule in that he works full time, participates in several church activities (the Methodist church is a very important part of his life), visits with family and friends, reads, listens to music, and sometimes goes out to eat. Joe is *committed to the cause of helping people with autism* and has been a speaker at conferences on autism for over 13 years. He attends and participates in at least ten to twelve conferences per year. He has also written several articles for journals and newsletters and will continue doing so. Joe believes that he can help others with autism by serving as a role model and feels he can help educate the public about autism. He tried for years to *fit in and be like everyone else* but he finally realized that *fitting in and being myself was a paradox*. *It is impossible for someone with autism*.



After years of trying hard to fit in, he now feels comfortable with who he is and has no interest in being *normal* as he feels *too many neurotypicals are narrow-minded, imprecise, unaccepting, and capable of mean and evil things*. As he says *I'm eccentric, I'm odd, and I'm quite proud of it. We're here to stay and society needs to change!*

Joe and I met early in the morning on the second day of the conference. He was heavily scheduled for this conference, as he was speaking at a number of sessions and participating in several activities, as well. He was a few minutes late for our appointment and was concerned about this. He carried a few items with him, such as a briefcase, and wore a two-piece suit, which he wore because of his speaking engagements. He explained to me that he was anxious to be done with his speaking engagements so he could get out of the suit and wear *something more comfortable*.

Joe described his background and school experiences in great detail, while also including his reactions to and opinions of some of the things that happened to him. He was passionate at times during these reflections. Joe has spoken at many conferences and was comfortable and at ease answering questions and talking about his life.

### Summary

Chapter III contained vignettes from each of the three participants in this study. I summarized information given to me by the participants over the course of the study. Each story was written to include background and other information

about their lives, families, and upbringing, descriptions of personality and topics on autism about which the participants are passionate. These issues have been expanded in great detail in the next chapter, along with the presentation of an overarching theme and several assertions, including supporting verbatim narrative taken from the data with discussions of related literature.

CHAPTER IV  
THEMES, ASSERTIONS, AND DISCUSSION WITH  
REFERENCE TO THE RELATED LITERATURE

Included in this chapter is a statement of the overall main assertion of the study and a discussion of this assertion. Themes related to the overall main assertion are presented, with accompanying supportive data, related literature, and a discussion of each. As described in Chapter II, the themes and assertions evolved through analysis of the data, which included initial visits and interviews, follow-up interviews, and the reading of published and unpublished material written by the participants, all in which they described their backgrounds, life experiences and their perceptions of those experiences. Following are the overall main assertion, three themes and several sub-assertions which were developed through the data analysis process.

Overall Main Assertion

High functioning adults with autism want to be considered *experts* in the field of autism, have opinions on, and want to be consulted on issues related to autism.

Theme One: High functioning adults with autism identify with their own unique culture.

\* sub-assertion #1: High functioning adults with autism take pride in their role and see the need to educate others about autism.

\* sub-assertion #2: High functioning adults with autism view *neurotypicals* as *narrow-minded*.

\* sub-assertion #3: High functioning adults with autism have no desire to be *neurotypicals*.

Theme Two: Support systems contributed to their feelings of self-worth.

\* sub-assertion #1: High functioning adults with autism believe that positive family involvement and support help individuals with autism develop skills necessary to be as successful as possible as adults.

\* sub-assertion #2: The spiritual aspect of their lives and their connection to a church provided comfort and support.

Theme Three: High functioning adults with autism have developed opinions on a wide variety of topics, especially those related to autism, and have suggestions for what could make a difference in the lives of people with autism.

\* sub-assertion #1: Group living arrangements and activities are dehumanizing.

\* sub-assertion #2: Unemployment and underemployment are real problems for people with autism.

\* sub-assertion #3: Behavior issues need to be addressed individually and positively.

\* sub-assertion #4: Individuals with autism need support to develop social skills.

Following is a discussion of the overall main assertion, each theme and sub-assertion, with supportive verbatim narrative and accompanying related literature.

#### Overall Main Assertion

High functioning adults with autism want to be considered *experts* in the field of autism, have opinions on, and want to be consulted on issues related to autism.

Individuals are very well-read in this field and are knowledgeable about current information. Over time, they have formed opinions on a wide variety of issues and have come to realize that they need and want to be the ones to help spread the word about autism and increase awareness across the country and even around the world. Their openness, willingness, and eagerness to do just this has been reinforced and has resulted, over time, in increased interest and involvement on their part. They have an intense desire to learn as much as they can and share that information with others. As Xenia said, *I read just about anything I can get my hands on!* They hope their efforts will educate the public and help other people with autism.

Most published material on high functioning adults with autism does not contain information and quotes from them about their lives and their views on life. Most personal information that is included in these materials usually contains short excerpts that illustrate a characteristic of autism. Some selections are used to describe what it is like having autism by a person with autism and how things felt and seemed to them as they were growing up. One exception to this is the book High-Functioning Individuals with Autism (1992), edited by Schopler and Mesibov. There are four essays written by high-functioning adults with autism about their lives, and life in general, from their point of view. There are a few autobiographies written by adults with autism as well.

Theme One: High functioning adults with autism identify with their own unique culture.

As high functioning adults with autism, these participants are proud to be a part of the recent interest in the higher end of the autism spectrum. They know that more information has become available and interest in the higher end of the spectrum has increased. As information has become more widespread, they, too, have learned more and see the value of parents and professionals learning from them.

\* sub-assertion #1: High functioning adults with autism take pride in their role and see the need to educate others about autism.

Throughout this research study, all three participants expressed their appreciation of having an opportunity to share their thoughts on autism and of

the need to educate society. They believe that more people need to be educated about autism and one way to do this is to learn from individuals with autism themselves.

Xenia explained what she believed to be the reason why parents and professionals want to learn about autism from the individuals themselves. She is proud to have the interest and ability to contribute what she knows about autism in order to help those who have autism.

*People hunger to hear the experiences that people with autism have from the sources themselves. People hunger to know why their kids do, feel, and interact the way they do. People with autism put into words what so many parents know from the gut. Also, we give them new insight into things they never thought of before. People come up to me and say that they can read about the other stuff on autism but that it was extremely important to hear from the source what autism is really like. I feel it is important for people to know about people like us. One of the paths to acceptance is education. I am like a missionary for autism. I am proud that I, in some small way, have helped someone in understanding autism. I'm proud that I can contribute by writing articles, too. I want to help people with autism; of course, there is some self-interest - I have autism! I read a lot of this stuff simply because, besides liking it, I want to spread this information out to people. I want to write some autism stuff in*

*Espanol and I would love to travel to different countries to talk about autism, talk to autistic people.*

Eugene had a sincere desire to provide information which would help us understand the thoughts he has as well as those of other adults with autism.

*I hope that our thoughts will contribute greatly to your thesis which will provide educators and students of the future with insight into our deepest thoughts and the workings of our imagination. Through people such as you and your students and colleagues, we will become more widely known to special educators of the future and historians.*

Joe passionately explained his reasons for wanting to educate parents and professionals about autism. He felt that speaking at conferences is an opportunity to do so and is also proud that he can help others by sharing what he has experienced.

*I am committed to the cause of helping people with autism. I want to see people who are proud to have autism and accept themselves for who they are and all that they are. Too often in the past, people didn't listen to people with autism. Most people do not know about autism, much less what a person deals with. So, educating people about autism is a key. At conferences, one unspoken rule is to not let things get to your head. Always remember why you are doing it, to help people. There are no "stars", only people that want to help people. I am no different at conferences than I am outside of conferences. I am always me and I*



*never lose track of why I am doing things. I think with what's happened with my life, I'm kind of a role model. I've accomplished things. Parents come up to me and say I'm an inspiration and I like that. I'm glad when anything in my life helps people.*

No references were found in the literature to support this assertion.

\* sub-assertion #2: High functioning adults with autism view *neurotypicals* as *narrow-minded*.

The participants spoke a great deal about how they used to want to *fit in*, to *be normal*. At some point in their lives, they realized they could not *be normal* and still be themselves at the same time. What they discovered about so-called *normal people* over time has resulted in them not wanting to *be normal*.

Xenia expressed her frustrations with the unpredictability and narrow-mindedness of neurotypicals. She felt that they are not open to new thoughts and ideas and are not willing to change.

*Many NTs are very narrow in their view. I can look at different points of view. With me, my view is not the only way. Most people with autism get frustrated with NTs because very often, it's the so-called "normal" people who lack empathy because many of them don't want to listen to any point of view besides their own. Most people with autism I have spoken to are happy being who they are, it's the society they're not happy about. They find most "normal" people narrow and biased. A lot of people with autism believe NTs really don't want the truth. We find that NTs are*

*unpredictable. They may say "hi" to you one day and then the next day, they don't. You ask yourself "What the hell did I do?" You have to figure it out yourself, get to know the person.*

Eugene has not had the support he has needed until recently so is only now becoming more comfortable with who he is and is more outspoken about his frustrations with neurotypicals. He explained how people with autism understand each other and how he views neurotypicals.

*More people across the country need to be aware of people with disabilities and more understanding. They need to be concerned about the well-being of disabled people. Neurotypicals, when they give advice, talk of "common sense," which are but two words to me; they have no meaning. However, you are NT and you are trying so hard to understand us that you are writing your thesis on us. There are a number of NTs that are just like you. One of my friends divides NTs into two categories: High Functioning, such as yourself, and Low Functioning, who do not understand us. This is a joke, but it shows my belief in this subject.*

Joe was very outspoken with his opinions of neurotypicals. His self-proclaimed sarcasm occasionally surfaced during our discussions about neurotypicals. He was very sure of his feelings about this topic and expressed himself clearly.

*The thing that needs to be fixed is the more than extremely narrow minds of some people. They need to be widened. Our main enemies are*

*prejudice and discrimination. Autism plays a part in all that I am, think, and do. Autism is not just what you see on the outside, but how you think and do on the inside. The differences are in how I think, how I perceive, and how I get things done. Neurotypical people tend to believe that if you do not show signs of having autism, you do not have autism, especially if you had the signs and now, they can't be seen. Well, compare that with an iceberg. Icebergs are seven-eighths underwater. You only see one-eighth of the iceberg. Behaviors and actions can be seen but you cannot accurately guess the causes unless you know what is going on in the person.*

No references were found in the literature to support this assertion.

\* sub-assertion #3: High functioning adults with autism have no desire to be *neurotypicals*.

Because of the experiences these individuals have had with *neurotypicals* and because of the opinions of neurotypicals they have developed over time, they expressed no desire in being a *neurotypical*. They saw characteristics of people with autism as more desirable and wanted to explain why.

Xenia felt that people with autism are more predictable and non-competitive. She felt that

*most people with autism have a sense of fairness; it's like "right is right and wrong is wrong." We are non-competitive because to be competitive, you have to have a certain amount of social skills. And even if we have*

*the social skills, we always get beat. I'm not competitive and the whole capitalist view is very jarring to me. Some people bitch about taxes - I go by the idea of "If you want something, pay for it." Society needs to accept all people and know that we aren't all like "Rain Man." I liked "Rain Man", though - I watched it four times straight.*

She expressed that people often do not recognize what is normal and what is not.

*People forget that just because someone is so-called "normal", doesn't mean they don't have problems. Even if someone does something slightly eccentric, society doesn't like it. However, I have no desire to be conventional. It bores me to death!*

Eugene explained his preference in choosing friends with autism to turn to when he needed help and gave an example of why he has done so.

*it was (a female friend with autism) who understood my motives (during a difficult time) when it seemed that everyone, my NT friends and family, appeared to abandon me. In my communication with my autistic friends, it seemed that our minds are fused as one mind. That felt and still feels good to me. This is the reason that if I need advice on personal problems or behavior, I turn to those in the autism spectrum, rather than even to my own family.*

Eugene explained the difficulty he has had in reading cues from others and how that has bothered him until recently.

*Usually, NTs seem to be able to read the body language and social cues of others. I can't seem to be able to do that very well. I have to struggle so hard to achieve what NTs take for granted and I was a little envious of their ease in socializing. The only way I'd like not to be autistic is if it could make me somehow know these social skills. It would be good to understand socialization completely, but with the developing autistic society, these wishes are beginning to go away in my mind.*

Joe described the process he went through in coming to the conclusion that he does not want to be a *neurotypical* and wants to be who he is.

*I have been told in the past that certain things I do are weird and unacceptable, but I am not going to change them now. Sometimes, people's reactions would teach me stuff, but not as much now, because I really don't care what other people think of me as much. I used to be ashamed of my differences and knew very well that I was different and that I reacted to things differently. I really wanted to be like everybody else. Now, I don't want to be like anybody else, period. I don't necessarily see the idea of NT as perfection. Hey, regular people do stupid, mean, and often evil things that people with autism would never do. I am supposed to look up to that? I don't think so! Besides, people with autism are more honest, more caring, and don't mess around with things that are not important, like small talk and wasting time. I am tired of having to do 100% of the changing and there is no change with most*

*people without autism. I refuse to do so, because that takes away my humanity. I am wary of any talk that takes away the humanity of people with autism. I am not "broken" and do not wish to be "fixed", thank you very much. To ask a victim to change and be like those who oppress would be unthinkable. To ask someone with autism to be like a person without autism is the same kind of thinking.*

Joe was very clear when he stated that he has no intention of being anyone other than who he is.

*I can conclude that other people's inability to accept me is not my problem. Is that our problem that others can't handle the truth? People who cannot handle bluntness, cannot handle reality! I am who I am and I don't really wish to change. If I am weird, I am weird, and proud of it!*

No references were found in the literature to support this assertion.

#### Theme Two: Support systems contributed to their feelings of self-worth.

All three participants often spoke highly of the support systems in their lives and how much they valued those supports. They believed that those supports helped them develop feelings of self-worth and higher self-esteem.

\* sub-assertion #3: High functioning adults with autism believe that positive family involvement and support help individuals with autism develop skills necessary to be as successful as possible as adults.

Many times over, I heard how important family is, or has been, to the participants in this study. Mothers, in particular, have played the biggest role and

all three participants have or had very close relationships with their mothers. From an early age onward, the families, especially the mothers, were very active in helping their family member with autism learn, grow, and experience life. It appeared as though their families' efforts at teaching how to talk, interact, play games, and use manners (i.e., how to *fit in*) played a large part in helping Xenia, Eugene, and Joe get to where they are today. When all three participants were young, there was very little information, if any, available on autism. Their families, for the most part, had no knowledge base of autism and basically "forced" the rules of society and social skills on these individuals. The following are some comments the participants had to say about their families.

Xenia shared that her parents were given a grim diagnosis when she was three years old, suggesting that she would *never learn how to talk, read, or write*. Her father had all of her siblings spend time with her every day, trying to get her to talk and learn other skills. Her siblings played spades and other card games with her; one sister taught her about life and others took her to amusement parks. Her father used Coke to try to get her to start talking. She believes all that her family did helped her a great deal.

*Not only did my family help me with all of the chaos and confusion, but also with people and professionals. My mother did not understand autism until 1987. I was diagnosed by age 10 but Mom did not understand much then because of miscommunication between her and the doctor. They (family) and I wish that the information that is available today could have*

*existed years ago. It would have helped everyone. When I was younger, they didn't know what it (autism) was. It is true that my family helped me a lot over the years. Also, they get better with understanding me as time goes by. I'm getting closer to people in my family, talking to them more. I was never close to my father when he was alive. He was a rage-aholic. He had very little patience with me because I was different. I am closest to my sister who is closest to me in age. I talk to her and my Mom weekly on the phone. My family is providing more support, emotional and financial, for me. I am realizing I can't do things alone and I just need their support.*

Eugene explained how difficult it was for his mother when he was young, as information about autism was virtually non-existent. She fought against the medical establishment who advised her to institutionalize Eugene.

*Doctors called me deaf, retarded, and everything else. My mother knew those diagnoses were wrong. She said "He can't be deaf"; I had perfect pitch. My mother was told that if I didn't respond in six years, I'd have to go to an institution and there was no way she would put me in an institution. She knew the expression was within me and by the force of her will, she got it out of me. Parents, like my mother, were the heroes and heroines of the age. There were no support groups; they had to fight it by themselves. My mother was fighting alone. She was troubled by my manners and became frustrated that I wouldn't learn them. She worried*



*whether she was a good mother or not. She is my heroine, doing things by herself that the autism community would not do for 25 years. My dad tried to understand but he was deaf for most of his life from a childhood accident and was struggling with his own problems. We often clashed over wanting to work; when he got sick, he stayed out of my way and saw that I did a good job. As time went on, and especially when my parents died, I drew closer to my sister and the brother that was closest to me in age.*

Joe shared a great deal of information about the work his family, particularly his mother, did on his behalf to find the right diagnosis and treatment/education for him.

*Mom knew, when I was very young, that there was something different about me. I was a "runner", was echolalic when I did start talking, watched records spin around, and screamed when the music was turned off. Mom did not accept the diagnosis of mental retardation I was given at age 3 ½ and did not agree with the doctor who labelled me as deaf when I did not signal during a hearing test. Other IQ tests given to me resulted in IQs of 50 and my mother was told that I wouldn't "be able to accomplish anything." "Hospitalization for an indefinite stay" (meaning institutionalization) was recommended. My mother refused. She was called "hostile." We were sent to Mayo where disciples of Bettelheim took me away from Mom for testing. Again, the "experts of the day" wanted to*

*give me a diagnosis of mental retardation and stressed to Mom "so this is what you did to your child."*

Joe then went on to explain things that his mother did to support him when he started school.

*When I was eight years old, I started at a new school and did not know anyone, so I went to the back of the room and read encyclopedias. The school wanted to call me mentally retarded and put me in the EMR class. My mother asked them how I could be mentally retarded if I was reading encyclopedias and took me out of this class. She kept fighting for the right diagnosis and education for me.*

Joe also shared what efforts his family made at home to teach him skills which would help him as he grew older.

*At home, my parents taught me functional skills so I could learn to take care of myself. Because food was reinforcing to me, I learned to say Yes and No. When I was very young, we moved out into the country on a farm where life was simplified. The first thing they saw was that my running stopped. I learned other things from my family that helped me develop skills. These were about social rules that would help me not seem weird and not make my brother and sisters look bad. I learned the rules by trial and error and making lots of mistakes but they helped me. Mom has said that "it has only been by pushing the outer limits of his abilities that he's been able to get as far as he has." I think that parents should never*

*underestimate what their child can do just because they have a diagnosis of autism.*

Howlin (1997) suggested that the supports offered by families, teachers, and involved others can directly influence the extent to which high functioning adults with autism can succeed. These individuals need support and assistance early on and throughout their lives. They need many opportunities to develop their language, cognitive, and social skills. Harris (1994) also encouraged parents to set the stage early on with consistency in rules and expectations, setting clear limits on inappropriate behaviors, and providing predictability but flexibility in daily routines. This can help children with autism develop necessary skills to become as independent as possible as adults.

The participants in this study made it clear that their families, especially their mothers, would not give up on them and spurned the professionals who did, risking ridicule by the medical profession. Tantam (1991) pointed out that most parents of children with autism have, at some point, been accused of over-reacting or causing their child's disorder by their emotional reactions. Frith (1991) suggested that it must be irritating to parents of children with autism when others accuse them of either over-reacting or under-reacting to their child's behaviors.

As Lorna Wing noted in the Foreword section of Siegel's book (1996), "parents of children with autism spectrum disorders do not, in general, have a high opinion of professionals" (p. vii). They know very quickly whether professionals are trained in working with people with autism and do find, for the

most part, that too many are not trained. Siegel (1996) reminded the reader that thirty years ago it was standard practice to assist families of children with autism and other disabilities, by putting them in an institution, forgetting about them as best they could, and getting on with their lives. The families of all three participants refused to do that and, in fact, did all they could to prevent institutionalization from becoming a reality.

Harris (1994) recommended that parents of a child with autism be resourceful in finding others to give them help, lend a hand, or provide respite. She noted that participating in parent support groups can help parents learn about the needs of their child and of the family as a whole. Support such as this was not available for the parents or family members of the participants. As was stated several times, *Mom was fighting all alone.*

Fortunately, more information on the autism spectrum has become available and widespread. However, as Myles and Simpson (1998) pointed out, parents and families of individuals with autism, including Asperger's syndrome, have to deal with situations in which they have not received much training. They need to educate themselves with the information that is now available. As the participants pointed out, *it would have helped if all the information available today was available when I was younger.*

Family involvement continues to be necessary to the successful development of individuals with autism. With the support and information available today, parents, while continuing to play a large part in their child's lives,

do not have to do it alone. As Holmes (1998) pointed out, "families are central to the design of new programs, and they are the most powerful advocates for services for people with autism" (p. 253). Joe summed it up well when he stated *I think that it was the work of many people who loved me that got me where I am now.*

\* sub-assertion #2: The spiritual aspect of their lives and their connection to a church provided comfort and support.

All three participants made frequent references to their spirituality, especially the role the church played in their lives. In one way or another, religion had been an important part of their lives while they were growing up. All three participants made reference to the church's increasing significance in their lives as they have grown older.

Xenia considered herself to be *spiritual and religious*. She stated that she regularly attended an Orthodox Christian church. *I am proud I am part of a church that's wonderful.* Her philosophy of God was apparent during many of our conversations. *God has everything to do with our lives. What He plans and what we plan are not always the same things.* Xenia occasionally started and ended a sentence with favorite phrases of *I thank God that ....* and *May God help us in our efforts.*

Eugene grew up in a Catholic home and had always been involved with the church in some way. He was a *rebel* to the men in his family who *followed*

*the Latin custom of the men not going to the church and went to Mass every Sunday with his mother and sister.*

*Spiritually, I am a Roman Catholic attached to the old but willing to accept the new as it is provided by the leadership of the church. I am comforted by prayer, especially the novenas, rosary, and the Sacrament of Healing.*

Eugene felt that church did not mean a great deal to him when he was young but that his *faith began to get stronger over the ensuing years*. Eugene, too, made references to his spirituality and the rituals and customs of his church as they related to his daily living. Going to Confession, attending the *Saturday Vigil Mass*, and discussing religious customs and events were a part of our conversations. Eugene also recently attended *the occasion of (a friend's) class of children with autism receiving their first Holy Communion*.

Joe stressed the importance religion and being a part of a church has had in his life. He stated that he was a *member of the United Methodist church and involved in the choir, and a group called Journeys, a group for 20- and 30-year-olds*. When he was younger, he and his mother *started looking for churches where we would be comfortable*. They chose the Methodist church, which he joined at age 17 and *has never left*.

Joe stated that, like the other participants, church has *grown in importance as I have gotten older. It has been a very accepting place for me*. He stated that his faith *has helped* him, especially in his *self-worth and esteem*.

As evidenced by his involvement in his church, he believed that *church is very important to me*.

In the review of literature, I was able to find only two references made to religion or spirituality as it related to individuals with autism. One reference was made in an article written by the mother of a young adult male with autism. Becca Hornstein (1997) stated that, in the religious community, young people with autism can "learn to advocate for themselves in a safe environment" (p. 486). Groups associated with a religious community can help them develop skills to live as independently as possible. Most importantly, Hornstein believed that congregations can welcome people with autism and participate in religious events together.

Howlin (1997) suggested that "church or religious groups can also provide much-needed support and social contacts" (p. 267). She stated that the church has much to offer individuals with autism in a "protective and predictable environment" and it may be "more tolerant than society as a whole" (p. 267).

Xenia identified *spirituality of people with autism* as an area which needed to be addressed and studied in the near future.

Theme Three: High functioning adults with autism have developed opinions on a wide variety of topics, especially those related to autism, and have suggestions for what could make a difference in the lives of people with autism.

As mentioned previously, high functioning adults with autism have read a great deal of information about autism and have a great deal of technical

information. They have read books and articles and have attended conferences on autism. They have met and talked with speakers at conferences and authors/experts in the field of autism. Through this education and because of their own experiences, they have developed opinions on many topics. They want others to hear their thoughts on these subjects and hope they will use their suggestions when working with people with autism.

\* sub-assertion #1: Group living arrangements and activities are dehumanizing.

The participants expressed negative feelings toward group living arrangements, especially institutions and large group situations. All three felt that group living could be dehumanizing and believed that efforts need to be made to provide supports necessary for individuals with autism to live in the community.

Xenia had concerns about residential options for people with autism. She felt institutions are *too big, too oppressive, too demeaning; they're just too anti-human*. She was specific in her suggestions about group homes. They could be successful if the agency *never allows more than six to a home, with matched personalities*. She felt that group home staff need training in how to work with individuals with autism. She pointed out that the *ordinary workers aren't at autism conferences*, and this would be a good place to receive training. Overall, however, Xenia stated that *I'm for community things and apartments and stuff*.



Joe was not in favor of group homes but felt that agencies need to move slowly to deinstitutionalize so appropriate supports are in place. He stated that *the institutions should be shut down, if you work toward it and get the supports set up in the community. Don't shut them down too quick.* Joe does not like it when groups of individuals with disabilities go on outings in the community together. He feels they should go out with one or two people only as it brings too much attention when they are in groups. As he stated, *their idea of a community outing by doing the herding concept is the way to devalue the person.*

Eugene has also been a part of the effort to bring people into the community by volunteering to *guide a friend I had chosen who was going to go into community life.* He has helped individuals slowly adjust to community living.

There are several residential placement options available for individuals with autism. These include autistic communities/large settings, small group homes for individuals with autism, mixed group homes, independent living programs, and institutions. The reader may refer to Appendix D for specific information on these programs. No one environment is the best or ideal environment. As noted by Baron-Cohen (1993), almost three-fourths of the people with autism do need some type of residential support system, and because people with autism have varying needs and skills, they need to have a variety of options available to them to meet these needs, especially as these needs and skills change.

Holmes (1990) identified several key issues in assuring the successful operation of group homes for individuals with autism. Among them were well-trained staff, actively involved parents/guardians, a highly motivated board, adequate funding, responsible administration, and day services for the individuals.

Van Bourgondien & Elgar (1990) suggested that homes that were built specifically for people with autism concentrated more on communication and preventive behavior techniques. They also identified a need for future studies to examine what essential services were needed for the "development and life satisfaction of adults with autism" (p. 306).

\* sub-assertion #2: Unemployment and underemployment are real problems for people with autism.

All three participants spoke at great lengths about the problems they have had in obtaining and maintaining successful employment. They spoke of the problems they experienced with employers and difficulties completing assigned job duties. They also addressed the issue of finding a job commensurate with their ability levels and education/training.

Xenia has held several jobs, all of which have ended for any number of reasons. She shared some of her job experiences and concerns with me.

*Some of us have very good jobs, more of us need decent jobs. I'm just trying to get a decent job with decent pay and benefits. I don't have any health insurance. I have a degree in Political Science and have had lots of jobs. I have*

*cleaned cat cages, done janitorial work (which is boring, boring, boring), office work at the VA, been a medical transcriptionist and a telemarketer (which I hated but I learned how to do public speaking), and worked in a group home on the early morning shift. I left after almost a year because I don't like the high turnover rate. I don't tolerate high turnover. Minimum wage is not enough for this job, working in a group home. It's not the same as flipping burgers. I wish they would pay the people who work with people with disabilities more money. Damnit, pay the people well. Shovel out the bucks!*

(When we started this research, Xenia was looking for a new job in a *totally different field*. She got one doing data entry near the end of this study).

Eugene has also worked at a large number of positions in various places of business. He provided a great deal of information about those jobs and the reasons why he was terminated.

*I worked as a caseworker and was asked to leave five months later. I could have used support in asking the proper questions. I started in the food service industry after that and the only job I could get was washing pots or doing dishes. I also worked as a volunteer at the developmental center to guide a friend that I had chosen who was going to go into community life. I had odd jobs, working in the hospital in the stockroom, and working in department stores in the same capacity. During the summers, I would rent out beach chairs and umbrellas and parked cars with my oldest brother. In the hospital and department store jobs, I was*

*fired because either I asked too many questions, or didn't ask enough, or bothered the women, whatever that meant. It would just kill me when the bosses would say that you had to go around and smile and be happy when you felt angry or sad. Since autism was barely heard of, I couldn't figure out why I was having such bad luck. There were no job coaches then. If I had such support, I could work until I were 65 or 70, and have a good job, one which I could truly love.*

Eugene shared what it was about his current job that has made it successful for him.

*In my present job, it is the best. Most of the co-workers are experts on how to handle people with autism. They tell me to take my time; if it is too much, then stop and do the rest the next time I come in. As a matter of fact, they become angry if I should rush and try to do a large job all at once. Usually they thank me for doing a good job and appreciate my work. If jobs in the work a day world were as flexible as my volunteer job, it would be quite pleasant.*

Joe has also experienced innumerable jobs in the past and he shared his frustration at not being able to maintain any of them. He explained that he had not wanted to inform his employers of his having autism but how the situation improved when he did finally tell one.

*Employment is a hot topic in autism. I have had lots of jobs which have lasted anywhere from one week to one year. This was very frustrating for*

*me. I was not able to keep the part-time jobs that I had most of the time. I often needed to ask for help and never did because I did not want to look stupid. I had offended an administrator by not being good at people skills. I was not fast enough to keep up. I didn't tell any of my employers that I had autism because I wanted to make it on my own merit and I did not want special treatment or pity from people. I would rather die than get pity. I had to learn that I could not keep jobs unless I told them I had autism. After these experiences where I had not told the employers that I had autism, the next time that I applied for a job (as a bagger), I told them I was autistic and that I needed time to learn my job. The boss told me "We have lots of time." Now I have two Master's degrees and work in the resource center at a university. It is a good job.*

Joe expressed his opinion about what people need to know about individuals with autism in regards to work skills.

*People with autism have bad experiences with jobs. It is not that we do not work hard, or have problems with being prompt, not being on time, or unwilling, because we are not that at all. It is that we are not very good at dealing with people in social situations. More jobs get lost, because of not being able to work together, than any other cause. It can range from just being odd to taking some time to learn things, like I deal with, to having temper tantrums and behavior problems. The most important rule at work is to get along with others at work. I think that jobs usually are 80% social*

*(conversation, lunch, breaks, chit-chat) and 20% work. People with autism are better the other way around! Our society values surface over substance. This hurts people with autism.*

In the past, community employment was not an option for very many adults with autism (Suomi, Ruble, & Dalrymple, 1993). However, there are currently several options available to meet their varying vocational needs. Sheltered workshops are generally available to those who require more support and supervision but allow them to learn tasks and increase skills. Traditional "benchwork jobs" are generally performed in this setting (Suomi et al, 1993). Workshops usually serve individuals with other developmental disabilities as well and the interaction with these individuals give adults with autism a chance to form friendships and practice communication and social skills. The large heterogenous group setting in workshops, however, may make it difficult to individualize programming and maintain specially trained staff.

Enclaves in industry and mobile work crews are another available option. These small groups of individuals allow for some integration into the local work community and some individual support but also draws attention to the members of the group (Suomi et al, 1993; Mesibov, 1994).

Supported Employment is a program which emphasizes "real work for real pay with ongoing, time unlimited support" (Parents' Alliance for Transition & The Task Force on Education for the Handicapped, 1990). The most important role of the job coach is to train the individual for the job and then fade his or her

presence from the job site as much as possible when the individual has learned the job (Unger, Parent, Gibson, Kane-Johnson, & Kregel, 1998).

Individuals with autism usually have difficulty generalizing skills learned in simulated situations, so the place-train model (placed on a job site and then trained on the job and job-related behaviors) has resulted in more successful job placements and experiences (Suomi et al, 1993). Unfortunately, sufficient funding and trained staff are not always available to provide the ongoing support that adults with autism may require to successfully maintain their job (Wehman, Gibson, Brooke, & Unger, 1998). Adults with autism often experience unsuccessful job experiences because of their inappropriate social behaviors (Suomi et al, 1993). Generally, it is not the actual performance of specific job tasks that causes the problems but rather the deficits in social skills that cause them.

Adults with autism may have difficulty interacting with co-workers and supervisors, working for long periods of time, dealing with changes in the workplace, and appropriately caring for personal and hygiene needs. However, with the support of specially trained job coaches, adults with autism can learn the skills needed to work successfully at a variety of jobs, including office workers, computer operators, dishwashers, assembly line workers, painters, farm workers (Autism Society of North Carolina, 1998), housekeepers, food service employees, file clerks, laborers (Suomi et al, 1993), bicycle repair persons, musicians, and law office assistants (Baron-Cohen, 1993).

The participants in this study are very active in increasing awareness of the unemployment/underemployment problem for adults with autism. They have suggestions and recommendations for ways to improve the employment situation for people with autism.

Xenia advocated for the use of a job mentor, someone who could take an individual with autism under their wing, so to speak, and guide them to meaningful and satisfying employment.

*I like the idea of having job mentors. This would be the development of a mentor service to help the individuals with autism bridge the gap from high school, vocational program, or college to employment. A mentor would be an individual already established in a career who could use his or her creative energy to guide and develop the creative talents of an autistic person and lead them to a satisfying job. One person can make a difference in how successful the person with autism will be. The most exciting idea is getting people from business and industry involved - it's those people who hire and fire and who know the ropes in their particular specialty. A creative person who enters into the autistic person's world and brings out their best will not only do service for the person with autism, but for their place of employment as well. Another reason I like the idea of a mentor service is that high functioning people prosper when there is that one special person who has the time to help out when problems arise or when something needs improving. Somehow that one*



*person makes a difference. And if that person is from industry, then it's even a greater boon.*

Eugene has spent a great deal of time working out an idea of the establishment of a national foundation which would help educate employers about individuals with autism and to help find jobs for these individuals.

*We need to start a foundation with the cooperation of the (local provider) to provide meaningful jobs for those people with autism who are now relegated to jobs unworthy of their talents and training, or can't find employment. A National Support Group could start a foundation to help high functioning autistic adults who are trained but because of social skills, can't get a job. They wouldn't need too much support. The ASA would be a good place to spread this idea of an employment agency and to establish new industries that will be staffed by people with autism. My plan consists of three options:*

- 1. Having (local provider) expand its facilities from its base of operations to the rest of the country;*
- 2. Initiate and expand some apprentice program for those who are talented in a field; and*
- 3. Job fairs to be held at all future autism conferences geared to the individual with autism.*

Joe's suggestions for successful employment experiences are geared toward the individuals with autism themselves, based on his many experiences.

Professionals and family members can assist the individual in learning and experiencing these suggestions.

*First, find out what you are good at and get a job in that area. It helps to get as much education and training as you can. It is OK to try a number of different jobs. I learned how to be honest with my employers about having autism. It is important to get along with people at your job. It is just as or even more important than what you know about your job or how you do your job. You can know all about your job and do it better than anybody else, but lose the job because you cannot get along with your co-workers. It helps to try to be cheerful when you work. Make sure to understand the rules, especially the unwritten ones. Ask to have them clarified or written down. Don't get onto co-workers for not following the rules. It is not any of your business and they will resent you for that. If I need help, I should ask for help. Get support help when you need it. It helps to have a colleague critique you about how you are doing and what to improve on.*

\* sub-assertion #3: Behavior issues need to be addressed individually and positively.

The participants expressed strong opinions on the topic of behaviors. They were vocal in their feelings toward Lovaas' early work with children with autism. Joe defined this method of Applied Behavior Analysis (ABA) as

*a very structured style of learning based on repetition. It has its good points and its bad points, like telling parents they can cause autism. It doesn't generalize very well and once a child gets into a particular pattern, its hard to get out of it.*

Joe expressed his disdain for Lovaas and the early methods and why he felt they should not be used. He felt that *Lovaas is bad and they're making money off of autism by making only the families with more money being able to afford to send their child.* He stated that *behaviors don't exist in a vacuum. They communicate something, so you need to do a functional analysis of why it's happening. You need to replace these behaviors, not just get rid of them.* As alternatives, he suggested the use of *positive behavior support, which looks at behavior as a form of communication, and sensory and auditory integration therapy.*

Xenia also shared negative feelings about Lovaas and ABA. She later asked me if I had noticed that she did not mention Lovaas' name while discussing the topic of behaviors. *I hate Lovaas because he is for adversives. ABA is a cult.* She did offer alternatives to ABA and explained why. Xenia believed that

*there are ways to accomodate the differences without exterminating them. What may work for one person may not work with someone else. No one method by itself is the magic pill. Use ABA with sensory integration,*

*social stories, motor planning, and nutritional. Try and figure out the problem, learn how to interpret the behaviors.*

Xenia stated that *you have to have high expectations* and shared this advice:

*Don't let kids get away with murder. You need to have high expectations. If you shoot for the stars, you'll get them to the stars. If you expect them to fly with eagles, they'll fly like an eagle. If you expect them to walk around on the ground like a chicken, they'll walk around on the ground like a chicken.*

The participants referred to the Lovaas Young Autism Project from the 1970's. This behavioral model followed a pattern of child/therapist interactions where the "adult directs, models, and reinforces and the child responds with imitation and compliance" (Cohen, 1998, p. 89). In this method, intrusion began immediately as the child was instructed to attend to the therapist with eye contact. Cohen (1998) also noted that the therapist responded to the child's inattention or stereotypical behaviors with sharpness and/or physical punishment.

Lovaas' methods have been criticized over the years for a number of reasons, among them the association with punishment (electric shocks, spanking). However, Lovaas discontinued the use of electric shock treatments when it was determined that the aggression and self-injurious behaviors they were intended to decrease, returned when the treatments were completed (Cohen, 1998).

Holmes (1998) cited many studies which documented Lovaas' success with using aversive techniques. Despite this success, changes were made in Lovaas' programs. Cohen (1998) described changes to be that Lovaas no longer insists on eye contact at the beginning and he now allows physical contact with a parent for comforting if the separation is too stressful for the child. The child is also now allowed to engage in his/her ritualistic or stereotypical behaviors for short periods of time.

An attraction to Lovaas' current programming is the documentation of outcomes, or collection of outcome data. Cohen (1998) noted that parents like seeing proof or documentation of success. This has attracted parents today to Lovaas' methods of behavioral intervention.

Cohen (1998) noted that some behavior intervention programs intrude forcefully into the lives of those with autism (i.e., Lovaas' early programs) while others are more gentle, combined with the use of enticement. This may include imitating the individual's behaviors and movements. She cited Stanley Greenspan's work in which he recommends to parents and professionals to "follow the child's lead, join in, and expand what the child is doing" (p.98). There are many types of behavior intervention programs available, which can be confusing to parents and professionals. Cohen (1998) stated that there generally is agreement among professionals as to the value of early intervention. Myles and Simpson (1998) noted that individuals with autism often experience

difficulty with generalizing behaviors; intervention programs which promote generalization and maintenance are the most effective.

Howlin (1997) identified a need to increase others' understanding of why behaviors occur. This may increase the acceptance of some behaviors, or at least improve others' understanding of the importance of some. Howlin (1997) also stated that attempts should be made to modify behaviors rather than stop them as a person with autism may go on to develop new and possibly more difficult behaviors. No one right treatment has been identified, although there is a long list of proclaimed miracle treatments, fads, and cure-alls that have not proven to be successful for large numbers of individuals with autism (Cohen, 1998).

\* sub-assertion #4: Individuals with autism need support to develop social skills.

Individuals with autism require assistance and support in developing appropriate social skills. Professionals working with these individuals need to find ways to help them learn and develop the social skills needed for success and to learn the rules that are required for successful reciprocal interactions.

Both Eugene and Xenia are involved in Social Skills groups for people with autism. Eugene's group meets twice a month with four graduate students as facilitators. The numbers in this group are growing. Eugene noted that there were sixteen people at the last meeting, where *we talk, it's a social thing*.

Sprinkled throughout our discussions, Eugerie expressed the frustration he has had in trying to learn social skills, especially as they relate to dating.

*When it came to trying to figure out these social problems, I felt isolated and alone. I was a little envious of neurotypicals' ease in socializing. I felt that I fitted in after I was finally diagnosed as having high functioning autism, and that there were people just like me who had the same problem I did.*

Eugene is grateful to have other individuals with autism in his Social Skills group, as well as other friends with autism, to whom he can turn for support.

Xenia's group meets weekly on Tuesday evenings. She started attending this group partially because she wanted to meet people when she moved to this city, and partially for the free food! She said *I'm a sucker for free food!*

Laughing, Xenia stated that, at this group, *I'm surrounded by men. They're all cute, too!*

Edelson (1999) described the use of Social Stories (short stories to teach socially appropriate behaviors) to teach social (and other) routines, how to do an activity, how to ask for help, and how to respond to feelings. By using Social Stories, an individual with autism can rehearse the scripts and rules needed for successful social interactions.

Both Joe and Xenia are advocates for the use of social stories. Joe stated that *Most people with autism are visual learners, so use social stories to teach the social skills that are needed to be successful.*

Xenia stated that social stories would have helped immensely *to help me with socializing with my peers. I had a hard time getting along with other students. The reason why was because of the way I came off socially. At that time, I had no idea that I was doing that because there were no gentle techniques like social stories or explanations to the other students on why I did things different.*

One treatment approach that has been used is operant conditioning (Matson, 1994). Target behaviors are defined and reinforced and/or punished. A disadvantage to this approach is a lack of generalizability. Another treatment approach is the cognitive-behavioral approach (Matson, 1994). Internal control is learned by using self-reinforcement and self-regulation strategies. A disadvantage to this approach is that it requires significant cognitive and verbal abilities.

Another treatment approach includes the use of medications. Larkin (1997) suggested the use of neuropeptides, such as oxytocin, which has been shown to increase social behavior in animals. Edelson (1999) suggested the use of beta-endorphin inhibitors, such as Naltrexone, to increase social behaviors. Other medications may be used to treat different symptoms exhibited by individuals with autism, including depression, anxiety, obsessive/compulsive behaviors, and self-injurious behaviors.



Another treatment approach often used when working with individuals with autism is Sensory Intervention, including auditory training, visual training, and sensory integration (Edelson, 1999). Some individuals with autism experience hyper- or hypo-sensitivity to sensory stimuli and the above-mentioned programs can be helpful in reducing or increasing the sensitivity to sensory stimuli.

The most popular and commonly used treatment approach is Social Skills Training (Cohen, 1998; Edelson, 1999; Howlin, 1997; Matson, 1994; Mesibov & Stephens, 1990; Ozonoff & Miller, 1995). There is a variety of methods in this category but they all have a couple of points in common, which include helping individuals with autism develop and use the skills needed to successfully interact with others, using skills that others would appreciate and reinforce, and showing them that social interactions can be enjoyable and desirable.

Social skills can be taught individually or in group situations. Many suggest that the use of Social Skills groups results in more success for individuals with autism as their "odd behaviors may be more easily overlooked than in a mainstreamed environment" (Siegel, 1996, p. 118) and that it reduces isolation and gives them opportunities to experience some success in a social situation and feel as though they truly belong to a group of their peers (Stoddart, 1998). Howlin (1997) described the necessity of conducting Social Skills groups that focus specifically on the deficits related to autism, not the use of "mixed"

groups/mixed disabilities. Social skills can be taught through the use of role plays, videos, and demonstrations and rehearsals.

### Summary

In Chapter IV, I presented an overall main assertion that high functioning adults with autism want to be considered as experts in the field of autism and want to be consulted on issues that affect their lives. I stated that they are passionate about educating others about autism and are proud of who they are.

They see, and believe in, the value of others learning about autism directly from *the sources* themselves. They are proud to have autism and do not desire to be a neurotypical, whom they see as narrow-minded and biased.

Over time, with experience and education, high functioning adults with autism have developed opinions on a wide variety of topics related to autism. They believe that group living is dehumanizing, issues of employment are a big problem, behaviors need to be addressed individually and positively, and the use of gentle and supportive techniques is the best way to teach social skills.

CHAPTER V  
SUMMARY, CONCLUSIONS, LIMITATIONS,  
RECOMMENDATIONS, AND REFLECTIONS

Summary

The purpose of this study was to investigate and describe the perceptions of three high functioning adults with autism about their life experiences. The need for this research was documented in Chapter I. Three adults diagnosed as having high functioning autism were the participants in this study. We met, visited, and interacted over a nine-month period of time, beginning at a national conference on autism in July 1999 and ending in April 2000. Each participant lived in different cities across the United States.

Qualitative research methods were used to study the perceptions of the life experiences of high functioning adults with autism. These methods included initial visits and interviews, observations, follow-up interviews, and the use of published and unpublished material written by the participants. Chapter II contained a thorough description of the methodology used in this study.

In Chapter III, vignettes describing each of the participants were shared. Information in these vignettes included background and family information, current life experiences, and concerns the participants have for the future.

In Chapter IV, the overall main assertion, three themes, and several sub-assertions were stated. Each theme and assertion was documented and supported with verbatim data and related literature. These themes and assertions were stated as follows.

#### Overall Main Assertion

High functioning adults with autism want to be considered *experts* in the field of autism, have opinions on, and want to be consulted on issues related to autism.

Theme One: High functioning adults with autism identify with their own unique culture.

\* sub-assertion #1: High functioning adults with autism take pride in their role and see the need to educate others about autism.

\* sub-assertion #2: High functioning adults with autism view *neurotypicals* as *narrow-minded*.

\* sub-assertion #3: High functioning adults with autism have no desire to be *neurotypicals*.

Theme Two: Support systems contributed to their feelings of self-worth.

\* sub-assertion #1: High functioning adults with autism believe that positive family involvement and support help individuals with autism develop skills necessary to be as successful as possible as adults.

\* sub-assertion #2: The spiritual aspect of their lives and their connection to a church provided comfort and support.

Theme Three: High functioning adults with autism have developed opinions on a wide variety of topics, especially those related to autism, and have suggestions for what could make a difference in the lives of people with autism.

\* sub-assertion #1: Group living arrangements and activities are dehumanizing.

\* sub-assertion #2: Unemployment and underemployment are real problems for people with autism.

\* sub-assertion #3: Behavior issues need to be addressed individually and positively.

\* sub-assertion #4: Individuals with autism need support to develop social skills.

### Conclusions

The results of this study led me to conclude that parents and professionals need to work with and listen more closely to high functioning adults with autism. They have developed opinions of their own on a wide variety of topics related to autism and can shed light on current and past philosophies, treatments, and methods, which should lead to increased awareness and improved societal attitudes.

I believe that all three of the participants have developed these opinions over time, based on the experiences they have had, support they received, and more recently, encouragement from parents and professionals to serve as resources on autism. Their passionate enthusiasm to educate society with the

goal of improving the lives of others with autism is fascinating and admirable, to say the least. They have dedicated their lives to this cause and have become connected to the field of autism nationally.

The humiliation they have suffered, the technical information they have learned, and the advice they have to share can provide us with invaluable information. This enlightenment can, and should, lead to improved societal attitudes and increased awareness and acceptance.

#### Limitations

1. I confined my study to a qualitative examination of the perceptions three high functioning adults with autism have of their life experiences. The scope of my study, which involved participants who attended one national conference, interviews, observations, and material written by the participants, limited me to constructing it around the three participants.

2. My reliance on those three volunteers may have resulted in the possible effects of a self-selecting data pool on this study's outcomes. In other words, this non-random pool of volunteers may have skewed the outcomes.

#### Recommendations

The following recommendations have been made for parents and professionals involved with individuals with autism.

1. Parents and administrative staff must take responsibility to learn all they can and assure that all staff who will be working with individuals with autism of any age are properly and thoroughly trained. It is imperative that parents and

staff are knowledgeable in this area. Parents need to attend workshops, join support groups, read current literature, and consult with others so they can learn as much as possible. Provider agencies should send staff to training sessions and conferences on autism so they can become knowledgeable in this field. Staff need to be paid well in order to reduce staff turn-over which can be very disturbing to some individuals with autism.

2. Parents and professionals must listen to and consult with, high functioning adults with autism. They have valuable input which needs to be considered as treatment and placement decisions are being made. Many of them have spent a great deal of time learning about autism itself and the various treatments and issues related to autism. As they have experienced many of these firsthand, we need to hear what they have to say and consider their ideas whenever possible.

3. Those involved in organizing national conferences on autism should continue including high functioning adults with autism as session and panel speakers. If possible, organizers of such conferences could solicit information from these adults as to what topics they feel would be important to include. They should also continue offering opportunities for these adults to interact with each other during conferences, if they desire.

4. People interested in the area of employment should take the advice of Eugene, who suggested job fairs as opportunities for employment of individuals with autism and to increase employers' awareness. I would go one step further



and suggest the offering of sessions for these adults only, at national conferences, to improve and increase their employability skills, job awareness, and job seeking/maintaining skills.

### Reflections

Because of the lack of sufficient information about high functioning adults with autism, especially documentation by the adults themselves, I did not know what to expect when I started this qualitative research study. Needless to say, what I have learned and experienced has been exciting and at times, overwhelming and mind-boggling.

I tried to thank the participants often for their thoughts, commentaries, and explanations; however, they kept expressing to me their gratitude for having the opportunity to "spread the word" about autism. While I tried to not offend or bore them, or intrude too deeply into their daily lives, they were trying hard to answer my questions and share their thoughts in a way I could understand. I was humbled by their technical knowledge and their patience with me, ashamed for their humiliations, and appreciative of the baring of their souls. At times I laughed, and at other times, I wanted to, and did, cry. They were not embarrassed yet they were not looking for sympathy. They are who they are, and I am a better person for knowing them.

I have always been intrigued by this strange, mysterious, confusing, and at times, *weird* (to use their word) disorder. This experience has reinforced that

intrigue; it has actually intensified it. I have a strong need and desire to continue pursuing research in this field and hope to touch, and be touched by, many lives.

I have made three new wonderful friends and have promised to continue communicating with them. We plan to meet again at another national conference in the near future!

## APPENDICES

## APPENDIX A

Following is the definition of **Autistic Disorder** obtained from the Diagnostic Statistical Manual (DSM- IV):

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, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
- (d) lack of social or emotional reciprocity

(2) qualitative impairments 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 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 (1994, p. 70-71)

## APPENDIX B

Following is the current definition of **Asperger's syndrome** obtained from the DSM-IV:

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
  - 1. 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
  - 2. failure to develop peer relationships appropriate to developmental level
  - 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
  - 4. lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
  - 1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
  - 2. apparently inflexible adherence to specific, non-functional routines or rituals

3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
  4. persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
  - D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)
  - E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood
  - F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia (1994, p. 77).



## APPENDIX C

Dear

I am writing to confirm the plans we made for the research for my doctoral degree. The title of my dissertation is "Adults with Autism: Where Are They Now?" As we discussed, I am a doctoral student in the Department of Teaching and Learning at the University of North Dakota. For the dissertation research, I will be completing a study on the experiences of provider agencies, parents of individuals with autism, and adults with autism themselves as they left the school setting and started receiving adult services. I am interested in how the process went and how the lives of these individuals are going now. I would like to see what types of services are available, how those involved feel about those services, and what information they feel others need to know about the unique needs of adults with autism. I hope to be able to contribute to program planning and development, and to the successful delivery of services for adults with autism. I also believe that, through your participation in this study, you will also be contributing to making more information available to parents, professionals, and other adults with autism.

For the research, I will interview you during a pre-scheduled time during the week of the annual convention of the Autism Society of America in Kansas City in July 1999. The interview will last for approximately two hours and will occur at a pre-designated room/area at the convention.

When interviewing the adult subjects, either their parent or guardian will be present. I will audiotape the interviews, which will later be transcribed by only me. Any notes that I take will also be later transcribed by only me. All notes and tapes will be kept locked at my home and will not be shared with others. While in Kansas City, the tapes and notes will be kept with me or locked in the hotel room. At the end of three years, all tapes, notes, and consent forms will be destroyed. We will stop and reconvene later if we need to, due to stress, tension, or other disruptions. The guardian or parent of the adult subjects will let me know when we may need to stop. The session will be terminated at that time for the day. I will be alert as to any possible indicators of stress on the part of the adults with autism while being interviewed. These may or may not include excessive echolalia or laughing, pacing, and self-abuse.

To protect your identity, I will change your name and all identifying information about you, including the name of the provider agency, places of residence and work, family members' information, name of city and state. If, at any time, you wish to withdraw from this research project or have any shared information removed, please let me know. I will respect your wishes. Termination of your participation in this study will result in no harm to you in any way. You may also refuse to reschedule should we need to stop the interview at any given time. If you are interested in knowing about the results of this study, I would be willing to share them with you.

A risk I foresee is that my presence may be an intrusion or disruption in your daily life and routine. If this becomes too difficult for any subject, I will talk to you (and guardian/parent for adult subjects) about re-organizing the interview schedule or even perhaps about your withdrawing from the project. I will ask that the guardian/parent of the adult subjects be responsible for informing me of the need to re-organize, restructure, or withdraw. You have the right to not reschedule additional interviewing time if you choose to withdraw or terminate. Should you experience a need to seek counseling or other professional treatment as a result of your participation in this study, I may be able to recommend someone to you to see but you will be responsible for this cost.

As we discussed, there may possibly be a need for me to contact you again at a future time at your home (for adults with autism and/or parents in the study) or place of employment (for providers). This may be because of the need for clarification of, or obtainment of additional, information, or as a follow-up to your original answers. This letter serves an informational purpose for you and, by your signature below, you are consenting to participation in this project, under the above conditions. If you have any questions or need additional information, please contact me at (701)298-4475 during the day, and at (701)234-9482 in the evenings, or my advisor Dr. Lynne Chalmers at (701)777-3187.

Thank you, in advance, for your interest and participation in this research project. I appreciate your support.

Sincerely,  
Karen Hurlbutt  
2411 30 1/2 Ave. S. #103  
Fargo, ND 58103

\_\_\_\_\_  
Provider representative signature    Date    \_\_\_\_\_    Consumer signature    \_\_\_\_\_    Date

\_\_\_\_\_  
Parent signature    \_\_\_\_\_    Date

## APPENDIX D

### RESIDENTIAL PLACEMENT OPTIONS

Following are some of the residential options currently available for individuals with autism:

\* Autistic communities/large settings -

These are larger, structured environments that are able to specialize in the care of people with autism. Staff are specially trained and the opportunity to grow socially and emotionally while decreasing behavior is an advantage. Many of these exist in the country, and are beautiful farm, or market-garden settings. Disadvantages include the size, the isolation from community life, and the separation from family. This type of setting also brings more attention to the individuals with autism and makes them more conspicuous (Baron-Cohen, 1993).

Examples include:

\* Bittersweet Farms -- a rural Ohio farm community for adults with autism.

On the property are the main house which houses 20 residents and staff, the activities building which contains a classroom, summer kitchen, art room, root cellar, and a screened-in bicycle corral. A greenhouse and woodworking shop are in one building along with the machine workshop and storage areas. The barns, greenhouses, and gardens are equipped for year-round use. This

program, an interdependent community, is based on the farmstead model, which provides meaningful personal, vocational, and recreational opportunities through residential and day programs (Kay, 1990; Bittersweet Farms newsletter, 1995).

\* Kern County Autism Center - The Kern County Autism Center, located in Arvin, California includes a residential facility and day program for adults with autism, on nine acres of land in a small farming community. Activities and instruction are based on functional living skills, community involvement, socialization, and recreation (Kern County Autism Center, 1998).

\* Small group homes for individuals with autism -

The biggest advantage to this option is the opportunity for individuals to interact with the local community for work and leisure activities. These homes are designed to be as much like any person's home (Baron-Cohen, 1993). Disadvantages include not having enough trained staff, management strategies may not be consistent due to lack of specialized staff, and there are limited spaces due to the small size.

Examples include:

\* Eden Family of Programs - These services exist in Central New Jersey. Children and adults are served at Eden. A day school was established in 1975, group home services added in 1980, and employment services in 1983. There were originally five group homes, all for males, and plans were made to add another home for women (Holmes, 1990). Eden programs emphasize specially trained staff, predictable schedules, and consistent programming. Now, the

Eden II Adult Services Program has expanded to include more than 40 young men and women with autism. The goal of the programs is to maximize independent functioning and participation in the community (Eden II & Genesis, 1999).

\* The May Institute - The May Institute took over and now manages three group homes for adults with autism in Cape Cod. The May Institute's philosophy on successful implementation of services is on maintaining trained and competent staff. The May Institute also serves children and emphasizes parent training and home-based early intervention programs. The specially trained staff from the May Institute also provide consultation to local agencies and schools (Luce, Christian, Anderson, Troy, & Larsson, 1992).

\* The TEACCH Model - Division TEACCH in North Carolina, began in the 1970's with the mission of offering a full array of services needed by people with autism and their families. The primary goal is to prevent unnecessary institutionalization by helping to prepare people with autism to live and work more effectively at home, at school, and in the community. These services include diagnostic and family training services, consultation and training of teachers in the local schools, residential and vocational services. The most common residential service is the small, community-based group home for adults. Independent living skills training also occurs in apartment settings. The Carolina Living and Learning Center is a rural alternative to the group home.

Vocational programs include supported employment, crews and enclaves, sheltered workshops, and the rural residential program (Mesibov, 1994).

\* Mixed group homes/communities -

These facilities exist due to the pressure to integrate individuals with developmental disabilities. The emphasis on group activities, lack of trained staff, inadequate programming, and the uneven developmental profile of individuals with autism (need areas would be different) are all disadvantages to this option (Howlin, 1997).

Example -

\* Glenwood Inc., in Birmingham, Alabama - This is a mental health agency which serves children and adults who have a diagnosis of Autism/Pervasive Developmental Disorder, mental illness, seriously emotionally disturbed, and behavior disorder. Glenwood provides short and long-term residential services and educational/day treatment services (Glenwood, Inc., 1999).

\* Independent living -

There are a variety of choices within this option, including having staff live in the same building and being available for emergencies or checking on the individual, having staff provide training as needed, or just having the individual live on his/her own with a minimum of support provided. Advantages include the fact that this is the most integrated option, the individual can choose with whom they live, and training areas are individualized. Disadvantages include cost of

the program, availability of trained, specialized staff, and the possibility of some unstaffed time.

Examples -

\* CSAAC (Community Services for Autistic Adults) - CSAAC's mission is to help individuals with autism remain in their communities to live, work, and play. Services include Intensive early intervention program for preschoolers, Community School of Maryland for children and adolescents, and residential and vocational programs for adults (CSAAC, 1999).

\* Judevine Center for Autism -- Judevine Center, in St. Louis, Missouri believes in the ability of people with autism to thrive in their natural communities if given proper supports. A range of services exist to provide these supports. A residential therapy program is available for those who need intensive treatment with the goal of returning residents to a less restrictive environment. Smaller group homes which emphasize daily living skills and integration into community activities are another option. Judevine also serves individuals in apartments with a goal of developing independence. Judevine also provides supported employment services (Judevine brochures, 1998).

\* Living at home -

Some adults with autism continue living at home with their parents. Some people choose this option due to a lack of other services and/or dissatisfaction with the available ones, or just because the family is happier living together. This situation can lead to restriction of family life and it can become more difficult for

elderly parents to take care of their adult child. One study showed that parents of adult children with autism were experiencing more difficulties caring for their children now that they were adults (Holmes & Carr, 1991). Family support services such as Respite Care are also available to families choosing this option.

\* Institutions -

There are some institutions still in existence in the United States today. For example, in Camarillo, California, the Autism Program at the Camarillo State Hospital and Developmental Center is one of nine treatment programs at this facility (Perel, 1992). The individuals in this program are those who could not be provided treatment at home or in the community because of their behaviors. A life skills curriculum is utilized in the program and the goal is to place residents back in the community setting.



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