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2013

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Online Community Building by Autistic Adults

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Online Community Building by Autistic Adults

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Dissertation

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

Doctor of Philosophy

The University of Texas at Austin

May 2013

Dedication

I dedicate this in loving memory of my mom Leila Bierer who left us much too soon last Spring (2012). My mom was my first teacher both in ABA therapy and in life. Many of the things that she told me as I was growing up I didn't always believe, but now that I have the benefit of time, I can see that she was right all along. It is true that through faith, perseverance and a little bit of luck, anything is possible, even a dissertation.

Acknowledgements

I would like to acknowledge my committee for all of their tireless work in helping me make this document as good as it could be without driving us all crazy. I would also like to acknowledge my classmates who helped me through the tough times, particularly with all of those weekend and after hours study sessions for statistics classes. I'll never forget you. Finally, I would like to acknowledge all of the researchers before me and who will come after me.

Online Community Building by Autistic Adults

Lydia Nicole Bierer, Ph.D.

The University of Texas at Austin, 2013

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One diagnostic criterion to identify individuals as having an autism spectrum disorder (ASD) is that their communication patterns, social reciprocity, and interactional competence show qualitative impairment (American Psychiatric Association, 2000). And yet, my experience as an individual who was once diagnosed as ASD and my investigations of Internet websites run by and for autistic individuals led me to see that individuals who identify as ASD are not only interested in communicating with others but highly articulate in self-advocating through the affordances of online communication. My research was focused on exploring the communicative experiences of individuals who participated in two websites designed by and for autistic individuals as a means of self-advocacy, WrongPlanet and AspiesforFreedom.

The method used to study the two websites was that of participant-observer. Having joined the online groups by introducing myself, I was able to peruse archived postings and current threads available on the websites. I analyzed threads of postings for themes being discussed and for features showing evidence of what Herring (2004) described as *online community*. Some of the postings were triangulated by interviewing participants. These interviews revealed more personal information about how one

chooses to self-advocate and create community online.

Results indicated that the forum posts of these two autistic-run websites demonstrated evidence of shared community and self-advocacy through the topics discussed. The autistic individuals I studied seemed to want to be seen as having a difference not a deficit. They acknowledged their struggles, but posited that individuals with ASD have strengths that are uncommon and are currently being under-utilized by society. Their use of the Internet demonstrates how autistic individuals are capable of communicating about a wide variety of topics, and are capable of contributing to the conversation about what makes them similar and different from those whom they call *Neurotypical*.

The significance of this study is that insights I present have a different validity than other studies of autistic individuals conducted by non-autistic researchers. Also, by challenging stereotypes of the capabilities of autistic individuals, a path is created whereby all may benefit from the strengths, talents, and insights they are able to provide.

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Chapter 1: Introduction

Websites run by and for autistic individuals have been introduced and are growing in number in the past several years. It has become obvious from reading the content of these websites that many autistic individuals are articulate and able to represent themselves to the world, what I call *self-advocate*. Furthermore, through reading the many first-person and philosophical accounts of what it means to have autism, a new idea has been conceived along with its related nomenclature, namely the term *Neurodiversity* to refer to the acknowledgement that there is more than one way to think and that a person who might be called *disabled* may actually have a different or superior way of perceiving and making sense of his or her environment. Proponents of Neurodiversity acknowledge that “Neurotypical” (NT) individuals comprise the majority but do not represent all legitimate forms of thinking. Some individuals who subscribe to the ideas of autistic empowerment as well as Neurodiversity have made the claim that erasing or “curing” autism is akin to eugenics.

Through the past ten years as I continued to discover this online community of autistic individuals, the following overarching question emerged: what is the experience of individuals who self-identify as being on the autism spectrum as they interact and advocate for issues of interest in online forums? In what follows, I address the following topics in order to build a rationale for my study: prevalence of autism, the construct of Neurodiversity, and autism and the internet

Prevalence of Autism

Autism is one condition among a group of developmental disorders known as *autism spectrum disorders* (ASDs). A person with autism might display any combination of behaviors to include impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive, or severely limited activities and interests. Under the ASD umbrella, Asperger syndrome is one common diagnosis. Lesser known ASDs include Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (National Institute of Neurological Disorders and Stroke, 2009).

Recent data suggest that the prevalence of autism is about 1 in 150 children (CDC, 2009). This is a higher prevalence than was originally thought when autism was first identified and for many years, considered to be rare. Comparing various cohorts of 10 year olds from 1982 when the prevalence of autism was 3.5 cases for every 10,000 (.035%) children to 1990 when it rose to 18.3 cases for every 10,000 (.183%) children (Newschaffer, Falb, & Gurney, 2005), this quintupling of the prevalence in eight years can only be called remarkable. Although autism had received attention by researchers as early as the late 1960s, it was Lovaas (1987) who established that treating autistic children using behavioral modification could result in a 47% recovery rate. This study provided the first glimpse of hope that autistic children could recover and ultimately be placed in regular school courses, despite the fact that this research still garners controversy today (Lovaas, 1989; Schopler, Short, & Mesibov, 1989).

Results from the Lovaas study gave hope to parents of autistic children. In concert with recent legislation surrounding the education of disabled children, many parents

became strong advocates for their autistic children. They insisted that their children receive the same care that the children in the Lovaas study had received. Because Applied Behavior Analysis (ABA, formerly known as Behavior Modification) is expensive to implement, many school districts were opposed to enrolling an ever increasing number of children in this best outcome program. Some parents sued schools, and some schools blamed Lovaas. The controversy surrounding the Young Autism Project (as it later was known) persists to this day.

Authorized in 1990, the Individuals with Disabilities Education Act required schools to educate children with disabilities. This act extended P.L. 94-142 that was already in existence since 1975. Before 1975, schools were not required to provide educational services to disabled children. Due to the fact that children with autism were being given educational services beginning in the 1970's, an increasing number of autistic children are better prepared for and aspiring to attend college once they graduate from high school (VanBergeijk, Klin, & Volkmar, 2008).

Having autism can pose many barriers to functioning depending on its severity. *ASDs* (autism spectrum disorders) are so named due to the wide variation among individuals having autism. Autism can impact individuals in a myriad of ways to include biological, social, and behavioral effects. Sometimes autistic individuals have concomitant challenges such as prosopagnosia (inability to recognize faces) and synesthesia (multi-modal mixing of senses; e.g., hearing colors, seeing flavors). For example, in a self-account, Meyerding (1999) wrote that she had difficulty with keeping track of social encounters due to her sensory issues because she could not track a conversation when there were competing verbal noises in the background. Due to her

prosopagnosia, she had difficulty recognizing individuals with whom she may have had previous contact. She also reported difficulty reading between the lines during conversations and had problems monitoring her own non-verbal cues that she was projecting to individuals with whom she was conversing. This is considered a common feature of autism (Dekker, 2004).

Some experts contend that autistic individuals lack a Theory of Mind, which means that they are unable to take the perspective of another person. However, there is some debate as to whether this is true for all autistic individuals and certainly not for everyone on the autism spectrum (Frith & Happé, 1994). It is widely accepted that many autistic individuals have difficulty detecting sarcasm (Happé, 1993) and idioms (Adreon & Durocher, 2007), as they tend to take what is said at face value (Joliffe & Baron-Cohen, 1999; Meyerding, 1999).

The Construct of Neurodiversity

Upon meeting at autistic conferences in the 1980's, and then by corresponding via computer in the 1990's, which led to the creation of the Autism Network International, autistic individuals began creating a collective identity that was the genesis of the Neurodiversity movement (Sinclair, 2005). When autistic individuals would meet for the first time, there was often a feeling of finding other "aliens" like themselves (Sinclair, 2005; Silverman 2008). According to Bumiller (2008), the simple fact that a Neurodiversity movement exists demonstrates that autistic individuals desire to "reframe their social challenges in political terms" (p. 980). Increasingly, websites created and maintained by autistic individuals have emerged on the Internet with examples such as <http://www.wrongplanet.net> and <http://www.aspiesforfreedom.com>

One of the main ideas behind Neurodiversity is the idea that autism is not a disease to be cured but a legitimate alternative way of being that only needs to be understood in terms of human differences and diversity, not deficit (Brownlow, 2010; Brownlow & O'Dell, 2006; Bumiller, 2008; Robertson & Ne'eman, 2008; Silverman, 2008; Singer, 1999). Singer (1999) stated that by having an autistic daughter, she began to see how autistic individuals had become marginalized, often forced to "act normal," and many of them have responded by forming a "politics of neurological diversity or neurodiversity...a new addition to the familiar political categories of class/gender/race" (p. 64).

The autistic rights movement owes much to the Deaf rights movement. In fact, Blume (1997a) compared the Internet for autistic individuals as being as beneficial as

sign language has been for deaf individuals. "By filtering out the sensory overload that impedes communication among autistics, the Internet opens vast new opportunities for exchange" (p.2). He also stated that in a manner of speaking, autistic individuals have likened themselves to being "a new immigrant group on line, sailing to strange neurological shores on the Internet, and exchanging information about how to behave upon arrival. They want to be able to blend in, to pass, and are intently studying the ways of the natives in order to do so" (Blume, 1997a, p. 10).

Blume (1997b) stated that in the past other individuals have spoken for autistic individuals (e.g., parents, specialists). The traditional view of autistic individuals as being like children who are unable to advocate for themselves is changing. With Internet use gaining popularity in the past decade, autistic individuals are finding their voice, and that voice is online. Blume (1997a) quoted an autistic individual who wrote. "The level of communication possible via the Internet is changing our lives, ending our isolation, and giving us the strength to insist on the validity of our own experiences and observations" (p. 8)

Note that although there is debate within disabilities studies whether to use "people first" language, (e.g., "individual with autism"), there is consensus among many in the autistic community that they prefer to be called an "autistic person" because separating the autism from the person is like separating the femaleness ("person with femaleness") from a woman (Brownlow 2010, Harmon 2004). Thus, in my writing throughout this dissertation, I will often use language that would not be considered appropriate to many in the research or education community associated with disabilities.

Autism and The Internet

There are many examples of autistic individuals heralding the benefits of online communication as *the* vehicle that has allowed them to congregate, be social, find an identity, and organize. Blume (1997b, p. 7) quoted an autistic individual who proclaimed the advantages of online communication

It was through the Internet that I discovered AS and the whole concept of neurological differences. Without the Internet, I'd still be seeing myself as the cause of my own "failure" (failure to be NT)...it wasn't until I met other Aspies [Aspergers] on the internet that I was able to gain a deeper understanding of what being Aspie means.

The same woman also stated that autistics have a special affinity toward the Internet. InLv, an online subscription message board run by Martijn Dekker, has provided her with an effective support primarily because it is not "in person." She continued by stating that being around other people face to face was draining for her (Blume, 1997b). Another autistic individual wrote, "The level of communication possible via the Internet is changing our lives, ending our isolation, and giving us the strength to insist on the validity of our own experiences and observations" (Blume, 1997b, p. 8)

As members of an e-mail message forum (InLv), autistics have expressed that communicating online is freeing, freeing them from the constraints of NT (neurotypical) means of communication (e.g., eye contact, body language). Many autistic individuals report that keeping up with NT modes of communication can be overwhelming and tiring (Robertson & Ne'eman, 2008; Singer 1999). The Internet frees them from this burden, which allows them to focus on their words rather than the "metamessages" that are

endemic to NT communication. Singer (1999, p. 67) summarized the importance of the Internet to individuals on the spectrum:

The Internet is able to supply whatever communicative capacities high-functioning autistics lack. It has begun to do what was thought impossible, to bind autistics together into groups, and it is this which will finally enable them to claim a voice in society.

There is evidence to suggest that many autistic individuals can function well by communicating through an online interface. In fact, there exists a burgeoning self-advocacy movement by autistic individuals modeled after the gay pride movement (Trivedi, 2005). This Neurodiversity movement, which has a strong online presence among autistic/Aspergers oriented websites, espouses the idea that autism is not a disease to be cured (Boundy, 2008; Fenton, & Krahn, 2007; Trivedi, 2005). Rather, they believe that having ASD entails having a qualitatively different way of thinking that is valid in its own right.

The aims as listed by www.aspiesforfreedom.com states as follows:

Our aims are as follows: To prevent eugenic elimination of autistic people by opposing pre-natal testing for autism. To oppose physically or mentally harmful "treatments" targeting autistic people. To emphasise the "spectrum" view of autism, and de-emphasise the differences between the various autistic spectrum labels. To oppose the idea of an autism "cure." To evaluate alleged treatments for ethical approaches. To increase funding for, and access to, autistic support services and ethical forms of treatment. To oppose negative publicity campaigns against autistic people as a group. To help promote an accurate yet positive image of autism. To oppose all forms of prejudice and bigotry.

There exists a large autistic presence online as many people who communicate online within their autistic communities have stated that they find it easier (Brownlow & O'Dell, 2006) and therefore *prefer* communicating online. As Boundy (2008) put it: “Many neurodiverse people, regardless of the form their neurodiversity takes, are more comfortable socializing on the web, because it allows the individual to have a much more thorough degree of control over the experience of interacting with other people” (p. 2). Another explanation for why autistic people in particular have gravitated toward online communication is offered by Ward and Meyer (1999) who stated,

The emergence of effective large-scale self-advocacy for people with HFA/AS was greatly advanced by new computer communication technology in the early 1990's, which for the first time allowed instantaneous contact across vast distances. The advent of Windows technology and internet access exploded previous myths surrounding the competence and capacity of people with autism to communicate effectively (p. 137).

With technology evolving as it has, my study appears to be both timely and relevant.

Researcher Disclosure

Due to the sensitive nature of the population that I studied, I feel it is necessary to disclose some personal information about my history as it pertains to this study. My role in this study was that of participant observer. As mentioned earlier, some autistic individuals are wary of experts telling them what they need or how they should act. I am uniquely qualified to bridge the gap between the “experts” and the autistic participants of my study. According to Brownlow and O’Dell (2006) the autistic individuals they studied expressed the belief that people who have the most knowledge about autism are the ones with autism, and they were suspicious of the experts. However, professionals are loathe to relinquish their power to autistic individuals or even their parents when the autistic individuals were children (Brownlow and O’dell, 2006; Ward and Meyer, 1999).

Having been one of the participants of the original Lovaas study, I know first-hand about the types of expectations autistic people have placed on them. My diagnosis of autism was confirmed through a third party by the diagnostic school for neurologically handicapped children (in Southern California) when I was merely three years nine months old (Ashurst, 1975) as I began Behavioral Modification (now known as Applied Behavioral Analysis, ABA) therapy for 40 hours/week.

Although at age 42 I have “passed” for “normal” by most accounts since I was age 6, I can still see areas where there are residual deficits. This calls to mind the question of whether the behaviors define autism, or the experiences. Thus, I can “act normal” most of the time. As Prince-Hughes (2002, p. xxii) observed, “all of the autistic

people I know (including myself) report that this strategy is not perfect and never hides our uniqueness completely.” As for me, if I am working under conditions of lack of sleep or immense pain, then my defenses are down and I find myself behaving in ways that might be considered “atypical.” For example, when I was working at a job, I began to feel tremendous pain in my feet (from an old Army injury), and I found that the only way I could “deal” with the pain was to rock back and forth to “short circuit” the pain, a behavior that is a well-known characteristic of children with autism.

What I believe I can bring to this study is a sensitivity to my participants that will allow me to earn the trust of activists within the autistic community while still remaining a member of the academic/researcher community.

Rationale and Research Questions

The research suggests that in online discussion surrounding autism, autistic individuals are challenging so-called experts by providing their own ideas of what it means to be autistic. Ward and Meyer (1999) stated that “professionals often found their knowledge outstripped by determined non-professional researchers with autism. This has led to a shifting of the paradigm of field expertise and how closely information can be guarded” (p. 137). Brownlow and O’Dell (2006) directly addressed this issue of traditional expert versus first-hand experiential expert when they stated, “The professionals who are reluctant to share their power with self-advocates typically construct themselves as the experts in autism” (p. 316). The fact that there *is* a concept of a struggle for power between self-advocating autistic individuals and educated professionals demonstrates that there is at least some segment of the autistic population that is more than adequately able to participate fully in communicating and advocating for themselves. My project was an attempt to capture and analyze the words of individuals on the spectrum as they participated and self-advocated in an online forum.

A second aspect of the rationale of this study comes from the affordances that an online form of communication might provide to individuals who are said to be lacking in social skills even as a diagnostic criterion (American Psychiatric Association, 2000). Thus, I was interested in how individuals with autism would communicate with each other in an online forum and in whether they would build a sense of community, what Herring (2004) called *online community*, as revealed through the words they used and how they responded to pleas for support.

Although there have been studies about individuals with autism online, there are not many of them and they have been focused on different issues than I addressed. For example, Brownlow & O'Dell (2006) studied autistic individuals communicating in online chat forums CHECK primarily focusing on the differences between "NT and ASD." In most of these studies, the researchers could not claim they were aligned or attuned with the participants by virtue of also being on the spectrum. By contrast, I hoped to gain the trust of my participants when I revealed to them that I had also been diagnosed as on the spectrum. Thus my study stands apart in that I could participate in the online community of autistic individuals as a participant-observer. The research questions guiding my study were the following:

Research Question 1. What are some of the topics that autistic individuals talk about online?

The rationale that underlay this question was that the field would benefit from understanding what were the issues and concerns that individuals with autism would want to address with each other. On the one hand, would the topics addressed be entirely unremarkable from topics encountered with other groups. On the other hand, would I find topics that were clearly related to issues of the experience of being on the spectrum.

Research Question 2. What evidence is there that autistic individuals create a “sense of shared community” online by their discourse practices (e.g., the way they use language, the way they post, time between messages)?

The rationale for asking this question was that it was important for me to explore a stereotype about autistic individuals' professed inability to be social, to seek response from others, and to be supportive of one another. For example, getting a quick response to a post asking for support would be one way to show that autistic individuals are capable of being social and eager to create a sense of shared community.

Research Question 3. In what ways do autistic individuals participate in self-advocacy? What are the common themes in the posts related to self-advocacy?

This question was important because I wanted to explore the ways in which autistic individuals self-advocate. It is easy to find examples of parents advocating for their ASD children, but it is not as easy to find examples of autistic individuals self-advocating. Such self-advocacy sometimes meet with resistance from parents and professionals and thus goes underground or disappears (Brownlow & O'Dell, 2006). I wanted to see what autistic individuals would do in an online community that could reveal their self-advocacy.

Chapter 2: Literature Review

The literature review will consist of four sections providing background and rationale for the proposed study. The first section will define and discuss autism as a whole and then describe language features common in autistic individuals. The second topic will cover the area of autistic politics, or the political activism of autistic individuals. This is not to be confused with *autism* politics which is the political activism of adults and professionals speaking on behalf of autistic individuals. Subsumed in the topic of autistic politics are the concepts of Neurodiversity and autistic identity, which will also be discussed in the second section of this chapter. Some attention will be given to topics of self-advocacy and self-determination as they pertain to autistic politics as well as examples of personal accounts penned by autistic individuals. The third major section of this review will consist of a description of computer-mediated communication (CMC) and its use for social support. The intersection of sociolinguistics and CMC will also be discussed. Finally, a discussion surrounding the ethics of CMC particularly with special populations will be explored.

Autism

A Google search of the terms *autism treatments* yields about 2,270,000 results (0.39 seconds) (Google, May 10, 2010) yet the search *autistic adults* yields “About 250,000 results (0.32 seconds)” (Google, May 10, 2010), suggesting that there exists much more information about treatments for autistic people (usually referring to children) than about adults. It is only relatively recently that attention to the case of the autistic adult has become more popular as the number of books published on the subjects has flourished (497 book search results on Amazon.com for *autistic adults* versus 980 book search results for *autism treatments*). Sacks (1995) stated of this disparity, “most people speak only of autistic children and never of autistic adults, as if the children somehow just vanish from the earth” (p. 246).

In 1943, Leo Kanner was responsible for identifying the characteristics that identify the autistic person and coined the term *autistic* from the Greek word *autos* meaning “self” because autistic children he observed were often withdrawn and did not seek out social interactions. He has been quoted as saying that the main disorder of autistic individuals is their “inability to relate themselves in the ordinary way to people and situations from the beginning of life” (Kanner, 1943, p. 242, as quoted in Hobson & Lee, 1998, p. 117). Long before autism was found to be a biological phenomenon with genetic implications, and in keeping with the popular behaviorist psychological principles of the 1950’s, Bruno Bettelheim popularized Kanner’s thoughts that autism was caused by poor parenting, specifically by the mother (Meyer, 2009; Sacks, 1995; Silverman, 2008). According to this theory, autism was caused by so-called “refrigerator mothers” who failed to show enough affection toward their offspring which then resulted in autism

(Schopler, Chess & Eisenberg, 1981). In 1964, a California psychologist named Bernard Rimland published a book refuting the thought that mothers caused autism by suggesting a neurological basis for the disorder. He is also credited for helping to establish the ASA (formerly known as the National Society for Autistic Children, NSAC) Autism Society of America, and for founding the Autism Research Institute (ARI) in 1967. Rimland was also the father of an autistic son (ARI, 2010). In the following section, the diagnosis of autism and theories of autism causation will be outlined.

Autism is diagnosed by observable behavior that meets a set of criteria as shown in Tables 2.1 through 2.3 (American Psychiatric Association, 2000).

Table 2.1 The DSM criteria for a diagnosis of Autistic Disorder

Two from	qualitative impairment in social interaction
	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
	failure to develop peer relationships appropriate to developmental level
	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)
	lack of social or emotional reciprocity
One from	qualitative impairments in communication
	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)
	in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

Table 2.1, cont.

	stereotyped and repetitive use of language or idiosyncratic language
	lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
One from	restricted repetitive and stereotyped patterns of behavior, interests, and activities
	encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
	apparently inflexible adherence to specific, nonfunctional routines or rituals
	stereotyped and repetitive motor manners (e.g., hand or finger flapping or twisting, or complex whole-body movements)
	persistent preoccupation with parts of objects
In Addition	Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years.
	social interaction
	language as used in social communication
	symbolic or imaginative play
And	The disturbance is not better accounted for by <i>Rett's Disorder</i> or <i>Childhood Disintegrative Disorder</i> .

Table 2.2 The DSM criteria for a diagnosis of Asperger's Disorder

Two of	Qualitative impairment in social interaction
	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
	failure to develop peer relationships appropriate to developmental level

Table 2.2, cont.

	pointing out objects of interest to other people)
	lack of social or emotional reciprocity
One of	Restricted repetitive and stereotyped patterns of behavior, interests and activities
	encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity of focus
	apparently inflexible adherence to specific, nonfunctional routines or rituals
	stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
	persistent preoccupation with parts of objects
And	The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
And	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).
And	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.
And	Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Table 2.3 taken from NIMH (1997, p. 9) presents a list of characteristics that differentiate autistic and normal infants.

Table 2.3 Behavioral Differences of Autistic and Normal Infants

Autistic Infants	Normal Infants
<p>COMMUNICATION</p> <ul style="list-style-type: none"> • Avoid eye contact • Seem deaf • Start to talk, but abruptly stop developing language skills 	<p>COMMUNICATION</p> <ul style="list-style-type: none"> • Study their mother's face • Easily stimulated by sounds • Continually increase vocabulary and expand grammatical usage
<p>SOCIAL INTERACTIONS</p> <ul style="list-style-type: none"> • Appear unaware of others • Physically attack and injure others without provocation • Inaccessible, as if in a shell 	<p>SOCIAL INTERACTIONS</p> <ul style="list-style-type: none"> • Cry when mother leaves the room and are anxious with strangers • Become upset when hungry or frustrated • Recognize familiar faces and smile
<p>EXPLORATION OF ENVIRONMENT</p> <ul style="list-style-type: none"> • Remain fixated on a single item or activity • Practice strange actions, such as rocking or hand-flapping • Sniff or lick toys • Not sensitive to burns or bruises, and engage in self-mutilation, such as eye gouging 	<p>EXPLORATION OF ENVIRONMENT</p> <ul style="list-style-type: none"> • Move from one engrossing object or activity to another • Purposefully use body to reach or acquire objects • Explore and play with toys • Seek pleasure and avoid pain

Other issues with and methods of diagnosis. One measure used to diagnose autism is known as the Autism Diagnostic Interview-Revised (ADI-R).

The ADI-R operationalizes the DSM-IV definition of autism by establishing thresholds defining qualitative impairments in social interaction, communication, and behavior. For most items, the ADI-R yields two ratings of the degree of impairment in multiple symptoms of autism: the degree of impairment at the present time and a ‘lifetime’ rating of the most severe degree of impairment earlier or ever in the individual’s life, often pegged at age 4–5 years” (Seltzer, Krauss, Shsattuck, Orsmond, Swe & Lord, 2003, p. 566).

When the original ADI was first conceptualized in the 1980's, it was designed for research purposes and to be used on individuals who were at least five years old and who had a mental age of at least two years (Lord, Rutter, & Le Couteur, 1994). Another measure of autism was devised as a self-report measure. It became known as the autism spectrum quotient (AQ) (Bishop & Seltzer, 2012).

One characteristic of autism that the DSM-IV does not address is the issue of sensory hyper or hypoactivity. The Diagnostic Interview for Social and Communication Disorders (DISCO) was designed to assess the sensory abnormalities that often accompany autism (Leekam, Nieto, Libby, Wing, & Gould, 2007). A meta-analysis of studies investigating sensory issues and autistic children [no such study exists for adults], showed that those with ASD are most different from controls in under sensitivity; and more alike in sensation seeking (Ben-Sasson, Hen, Fluss, Cermak, Engel-Yeger, & Gal, 2009). One way that autism is diagnosed informally is through research and self-identification such as was the case of Meyerding (1998) upon reading the accounts of other individuals with autism on various autistic-run websites. This phenomenon seems to be more common in women and those with milder forms of autism who may have “slipped through the cracks.”

If the proposed changes to the DSM are approved (see www.DSM5.org), Aspergers and other forms of autism would be combined with autism to form an “autism

spectrum disorders” category. This update that is scheduled to be implemented in May 2013 is perceived as an attack on the identities of some Aspergers individuals. Some individuals fear that being “lumped” in with autistics, and that those individuals who have been labeled Aspergers will experience a decrease in status and be more stigmatized by association with the experience of autistic individuals (Tanner, 2010). One analogy, proffered by the child and adolescent psychiatry chief at Chicago’s Children’s Memorial Hospital Dulcan, is that a student of MIT (Aspergers) would not want to be lumped in with somebody from community college (autistic). Although Dulcan agreed with the proposed changes, she stated that it was understandable that some individuals might oppose the new label if it would result in loss of social standing.

Another reason to oppose the proposal is promulgated by those who fear that having only one category may encourage the public perception of high functioning “brainiac” to contribute to less of the needed support for lower functioning individuals (Tanner, 2010).

Diagnosis of an autism spectrum disorder (ASD) typically occurs before the age of three. Estimated costs associated with the care and treatment of autistic children in the United States is \$13 billion per year (Cooper, 1999). *High functioning autism* is defined as individuals who meet the criteria for autism but have normal intellectual functioning as well as a history of speech and language delay (Sanders, Johnson, Garavan, Gill, & Gallagher, 2008). Other views of autism include the suggestion that autism could be a subtype of obsessive compulsive disorder (OCD) as they share many of the same characteristics such as hoarding, perseveration, and rituals (Bejerot, 2007).

Theories of autism. There are three competing theories of autism related to the neuropsychological study of autism. The first one is the executive dysfunction hypothesis. The main idea of this theory is that autistic individuals have deficits in executive control over behavior, which manifests itself in the stereotyped, repetitive behaviors that are the hallmark of an autism diagnosis (Sanders, et al, 2008). The brain structures that are said to be involved are the fronto-striatal and fronto-parietal areas. The second theory is known as the empathizing-systematizing theory of autism. The key point of this theory is that autistic individuals fail to develop empathy. This is said to show up in two ways 1) a lack of “theory of mind” and 2) an inability to respond appropriately to the emotions of another individual. Neuroanatomical studies in autism have suggested that autistic individuals have abnormalities of the amygdala, the brain structure responsible for emotional processing. The last theory is called the weak central coherence hypothesis. With this theory, autistic individuals are said to exhibit weak central coherence, which means that they are weak at processing information in context. Instead, autistic individuals process information in a piecemeal fashion (Frith & Happe, 1994).

The executive function theory of Autistic Disorder (AD) stipulates that individuals with AD have impaired capacities to engage in the mental control necessary in order to maintain a problem solving strategy for the purposes of obtaining a future goal (Lopez, Lincoln, Ozonoff, and Lai (2005). Research suggests that the repetitive behaviors that are typical of autistic individuals have their roots in an abnormal functioning of the frontal lobe, and more generally the research suggests that autistic individuals have difficulty with cognitive flexibility and planning abilities (Lopez et al, 2005). However, the research has not shown support for the suggestion that autistic individuals have

significantly more impairments in response inhibition and working memory abilities. Finally, the research is inconclusive as to whether autistic individuals have more difficulty with generating novel ideas and verbal fluency. From this analysis, Lopez et al (2005) concluded that autistic individuals are strong in working memory and response inhibition and have relative deficits in cognitive flexibility, planning, and fluency.

Language features of autistic individuals. Although many autistic individuals have a good vocabulary, they may use some words in a rote fashion such as when a person repeats a phrase that he or she has heard recently (echolalia) or has heard less recently (delayed echolalia). Another language feature that characterizes many autistic individuals is their difficulty understanding linguistic expressions such as irony, metaphors (Vicker, 2005), and sarcasm (Rajendran, Mitchell, & Rickards, 2005). They may have difficulty understanding that words may have multiple meanings that vary with context. Taking phrases literally is another hallmark trait of many autistic individuals. Many of them have difficulty understanding the main idea from conversations, text, television programs, and movies, and have trouble drawing conclusions and making inferences from these communication forms (Vicker, 2005). In autistic children who are developing language, there exist some idiosyncrasies such as reversing pronouns, referring to oneself as “you” and the interlocutor as “I”, as well as neologisms (“yesbody” for “everybody” the opposite of “nobody”) which was one that I was documented as having said as a toddler (Lovaas, 1977). Furthermore, the speech of autistic children is often marked with unusual prosody (pitch, intonation, loudness, stress, and rhythm) (Ochs & Solomon, 2004).

There exist difficulties in communicating socially for autistic individuals as well. For example, when discussing a favorite subject, an autistic person may begin a monologue about the favorite topic without regard to whether his or her audience is interested. An autistic person may fail to modulate his or her volume when speaking (speaking too loudly, for example). They may stray from their original topic when words or other cues of others in the dialogue send them on a tangent. They may talk aloud to themselves in public, seeming not to notice that others can hear them. They may have difficulty paying attention to an auditory message if they are feeling stressed, agitated, or are highly stimulated (Vicker, 2005). This list is not exhaustive, but is provided to give a sense of the challenges that autistic individuals face when communicating and using language.

Theory of mind can be defined as “an individual’s ability to attribute mental states such as beliefs, feelings, and desires to other people” (Kleinman, Marciano & Ault, 2001, p. 29). A way to assess first-order theory of mind deficit is to administer the Smarties task or the Sally-Anne task. A first-order task involves assessing what the participant believes another person is thinking or feeling (Kleinman, Marciano & Ault, 2001). An advanced theory of mind deficit involves assessing only autistic participants who have passed the first-order test to determine whether they can assess feeling states of others by looking at photos of faces or of the eyes only and then choose whether the person depicted in the photo is either happy or sad. High-functioning adults performed significantly worse than IQ-matched nonautistic participants in the eyes-only condition. An auditory theory of mind test was developed by Kleinman, Marciano and Ault (2001) to test whether

participants would be able to attribute the mental states of other individuals using verbal intonation only.

Individuals with ASD tend to excel at particular skills such as the embedded figures test (developed by Gestalt psychologists) (Frith & Happe, 1994) and the Block Design subtest of the Wechsler Intelligence Scales (Frith & Happe, 1994; Behrman, Thomas, & Humphreys, 2006). Behrman et al. (2006) acknowledged the prevailing belief that individuals with ASD tend to focus on details while often failing to understand the “gist” or Gestalt of the stimulus. Frith (1989) developed a theory about this phenomenon called the *central coherence theory*. This theory stipulates that most individuals process information in a whole before parts manner, whereas autistic individuals do the opposite. It is this “trees before the forest” approach that is called “weak central coherence.” Although autistic activists would most likely object to the negative terminology as well as Frith’s suggestion that this “universal feature of human information processing was *disturbed* [emphasis added] in autism” (Frith & Happe, 1994, p. 121), Frith acknowledged that there could be some advantages to thinking in this manner such as being able to spot details that most people miss. (Perhaps autistic individuals could excel at copyediting, just so long as the subject of scrutiny is not their own dissertation?)

Individuals with autism as college students. Although most attention about autism has focused on children, recently more attention has been given to autistics individuals in later life stages. VanBergeijk, Klin, and Volkmar (2008) acknowledged that there is an increasing number of college-bound young individuals with ASD. They outlined many suggestions for how to ease the transition from high school to college for autistic students. Books devoted to helping autistic high school graduates navigate

college have been written. From the perspective of being a parent with a son with autism, Palmer (2006) wrote a guide to parents about how to prepare their autistic or Asperger child for college. Palmer had learned how to navigate the college system and used her experience to provide some practical advice about how to support a child to self-advocate toward getting disability accommodations and how to encourage a college-bound child to deal with stress in a healthy manner.

Written as a guide for students, Harpur, Lawlor, and Fitzgerald (2002) outlined many strategies that a college-bound autistic individual could use as a resource to assist in transitioning to higher education. Some challenges for autistic individuals who pursue a post-secondary education include managing tasks that require goal-oriented and reflexive thinking (higher level of executive functioning). A few accommodations that are recommended include: assistance with planning and organizing as well as scheduling course work. Tools that are specifically designed for planning and organization can be utilized. Robertson and Ne'eman (2008) (who are both autistic) stated that they used PDAs, the computer as well as organizational and planning aids to help themselves manage their schedules and workloads.

Political Activism Associated with Autism

The political activism of autistics weighs heavily into the rationale and inspiration for my study precisely because of the commonly held belief by most nonautistic individuals that autistic individuals are incapable of complex thought let alone self-advocating or fully participating in securing their rights via political activism.

The passage of the Americans with Disabilities Act in 1990 helped spearhead the challenge to traditional conceptions of disability and provided civil rights activists for the disabled more readily to reach their goals of equality (Bumiller, 2008). As individuals with disabilities are self-advocating for inclusion in a democratic society, the struggle of autistic individuals raises important questions concerning democratic participation of disabled individuals, as autistic individuals are often portrayed as cognitively disabled (Bumiller, 2008).

Although parent and professional support groups have existed at least since Rimland helped co-found the Autism Society of America in the 1960's, groups that are run by and for autistic individuals are relatively new. Sinclair, co-founder of the Autism Network International (ANI) in 1992 (Dekker, 2004) organization, posted a history of ANI the organization that had sprung from a need for autistic individuals to meet and discuss their experiences without the "experts" interpreting everything for them (Sinclair, 2005). These individuals met using a pen pal list compiled by a parent-run organization. Some of these individuals had even met face-to-face at autism conferences run by parents and professionals. However, these spaces were not a comfortable place for many of the autistic individuals, therefore they felt as though they needed their own "autistic space" where they could relax and be themselves (Sinclair, 2005). At the conferences, there was

too much stimulation such as bright fluorescent lights, too many people, too much movement, and too much noise. Add to that was a litany of speakers and professionals all claiming that there was something *wrong* with autistic individuals, that “we’re a horribly defective type of human, and that our very existence is a source of never-ending grief for our families” (Sinclair, 2005, p. 2).

Sinclair was homeless yet deemed “too bright to be disabled” (Sinclair, 2005, p. 7) to qualify for assistance when he began his search for other autistic individuals who were interested in countering the negative portrayals of autism and in advocating for improved social services. The first meeting of autistic individuals was informal and small, with only three in number with Jim Sinclair, Kathy Grant, and Donna Williams who was promoting her new book (*Nobody Nowhere*, 1992) that later became a New York Times bestseller. Sinclair recalled that this meeting resulted in a “feeling that, after a life spent among aliens, I had met someone who came from the same planet as me” (Sinclair, 2005, p. 2).

Over time, the founding members of ANI decided that the mission of the organization should be “to advocate for the civil rights and self-determination of all autistic people, regardless of whether they were labeled ‘high-’ or ‘low-functioning,’ and regardless of whether they were able to participate independently in our language-based network” (Sinclair, 2005, p. 6). They agreed that the way to achieve this goal was to make their newsletter available to parents and professionals who would be able to help affect the lives of autistic people who could not advocate for themselves. However, they decided to keep a boundary so that their pen pal list would be strictly for autistic individuals and confidential. The first issue of the ANI newsletter titled “Our Voice” had

a readership of about 15 subscribers, who mostly consisted of non-autistic parents. An unexpected reaction was the subsequent hostility from established autism organizations. In 1991, a group of autistic individuals attended the ASA conference and made their identity as autistic individuals known during the question and answer sessions of the conferences. This visibility grabbed the attention of the ASA Board of Directors who agreed to allow autistic individuals to have input into the organization of the 1992 conference, to be given some space in the ASA newsletter, and to be provided with financial and/or administrative support to create an autistic self-advocacy organization. However, none of these promises ever materialized, which fueled Sinclair's increasing distrust of those within the "autism establishment." Some ASA board members challenged Sinclair's diagnosis as autistic despite the fact that he had diagnoses confirmed by two separate psychologists both of whom were members of the ASA professional advisory board. Williams was coming under fire of similar accusations once her book had received international attention.

According to Sinclair (2005),

It seems that one autistic person at a time--and preferably a passive one—might be welcomed as an interesting novelty or an amusing diversion or possibly even a valuable source of information and insight. But autistic people organizing together, autistic people pursuing our own interests rather than furthering the interests of parents and professionals--suddenly we were perceived as a threat (p. 9).

Over time the group grew slowly and then once they had established an online presence (ANI-L), it grew more quickly as word spread. Dekker (2004) stated that the movement flowered once the Internet became widely available because it is "essential in

the facilitation of communication between adults on the autistic spectrum” (p. 2).

Eventually, ANI had its own presence in the form of an exhibit at autism conferences.

Although most of the autistic people could not afford rooms at the hotels when they attended the conferences (Sinclair often slept in his car), they managed to find quiet spaces to meet such as in hallways, cloakrooms, and parking lots.

Another online group for autistic individuals was created by Martijn Dekker in the Netherlands. His mailing list called InLv (Independent Living on the Autistic Spectrum) started as a site for activism, but as membership grew, its focus moved toward emotional and practical support (Dekker, 2004). Many members found value in discovering that there were others who were like them. However, Dekker became disappointed as the focus of the site shifted from activism to support, although he acknowledged that gaining this support could be a stepping stone toward advocacy and activism later. He concluded, “mutual validation through emotional support can also be counted as a form of self-advocacy” (Dekker, 2004, p. 8).

Self-advocacy does not often come easily. In the process of seeking more rights and opportunities, Sinclair (2005) learned many painful lessons. He found parallels between his struggles for autistic rights and the struggles that other disenfranchised groups have faced. These are the ways in which disenfranchised groups are discounted when trying to self-advocate, according to Sinclair (2005):

1. If at all possible, to deny that the persons mounting the challenge are really members of the group to which they claim membership. This tactic has been used against disability activists with learning disabilities and psychiatric disabilities as well as against autistic people.
2. If there is incontrovertible evidence that the activists are members of the affected group, to aver that they are rare exceptions who are so unlike

typical members of the affected group that what they have to say is irrelevant to the group as a whole.

3. If it is not possible to deny that the activists are authentic representatives of the affected group, to appeal to the very prejudices and stereotypes the activists are seeking to overturn, and use those prejudices and stereotypes to claim that the activists are incapable of fully understanding their situations and knowing what is best for them (pp. 9-10).

Neurodiversity. The movement to oppose demeaning and dehumanizing portrayals of what it is to have autism was the impetus for the neurodiversity movement (Robertson & Ne'eman, 2008). Blume (1998) coined the term to describe the neurological diversity of autistic, dyslexic, and other people with major differences in cognitive processing. Neurodiversity extends the societal growing acceptance of diversity with regard to sexuality, ethnicity, nationality, religion to include human neurology (Robertson & Ne'eman, 2008).

Autistic identity and labeling practices. Many autistic individuals prefer to be referred to as such rather than the person-first language that has been popularized by the disability rights movement because to many autistics, being autistic *is* who they are, not something they are *afflicted* with (Silverman, 2008). Dekker (2004) has found parallels between the goals of the Disability Pride movement made up of deaf individuals and the Psychiatric Survivors movement. According to him, the autistic community stands with one foot planted in each movement, with the result that “autistic culture today is largely where deaf culture was a century ago. The Internet is for many high functioning autistics, what sign language is for the deaf” (pp. 1-2). Bumiller (2008) stated that the self-advocacy (later known as the Neurodiversity) movement has borrowed heavily from a variety of civil rights campaigns such as gay liberation, and disability rights movements.

Self-advocates have argued that autism is a valid identity worthy of protection against behaviorist interventions (Dawson, n.d.; Silverman, 2008).

In creating an online space for autistic individuals to communicate with each other and to foster community, identity, and a shared language, the concept of the “other” was constructed using words such as *neurotypical* (sometimes in a pejorative manner) to refer to individuals who are not autistic or “not on the spectrum.” Autistic individuals often refer to themselves as *Auties* or *Aspies* (for Aspergers). Those who have conditions that render them similar to autistic individuals but are not officially autistic are often referred to as *cousins* whereas those individuals who have no autistic identity are referred to as NTs (Neurotypicals) (Brownlow & O’Dell, 2006). *Stimming* is the term used to describe self stimulating behaviors such as rocking and flapping, which are used as a means of self soothing (Boundy, 2008; Trivedi, 2005). The term *AC* refers to “autistics and cousins” (Dekker, 2004) which is one way to state anyone who is not NT. Some autistic individuals view their characteristics as not only special but superior (Brownlow & O’Dell, 2006) to those of NTs whom they regard with derision. In fact, Autistic Pride Day (June 18) was founded in 2005 as a celebration of neurodiversity (Bumiller, 2008; Robertson & Ne’eman, 2008). A Canadian organization known as the Autism Acceptance Project has encouraged the expression of autistic identity by organizing art shows, galleries, and other events that feature the unique art, language, and norms/values of autistic individuals, and a mission statement as follows (TAAP, 2010):

We, as autistic people and friends and family of autistic individuals, do not see autism as a “tragic epidemic.” We view autism as a part of life – with both challenges and abilities that deserve to be accommodated. We believe that autistic individuals have the right to participate in all levels of autism advocacy, at all

levels of government, and at all agencies and committees making policies about autism, alongside families and supporters.

Advocacy and support networks for autistics flourished once Internet communication became accessible to many individuals (Bagatell, 2007). As Singer (1999) stated,

...the Internet is able to supply whatever communicative capacities high-functioning autistics lack. It has begun to do what was thought impossible, to bind autistics together into groups, and it is this which will finally enable them to claim a voice in society (p. 67).

Redefining “disability.” Autism is often depicted in popular media as an affliction that leaves the individual functioning at “the boundaries of what is characteristically human” (Bumiller, 2008, p. 970). The movement sparked by the creation of ANI challenged the medical model of autism and its presumption of disability. Instead, they constructed autism as being indicative of a distinct culture. They vehemently opposed the authority of the medical field to define, diagnose, and treat autism as though it were a disease to be eradicated. The term “autistic epidemic” is particularly offensive to these individuals as it frames autism in a very negative light. There exists some activists who want autism to be recognized as a minority group by the United Nations (Bumiller, 2008).

The process of normalization of disabled individuals within society gained impetus after the passage of the ADA in 1990, which required employers to provide “reasonable accommodation” for disabled individuals. The pressure for autistic individuals to appear “normal” in order to keep a job is particularly strong because their disability is *defined* by the inability to understand social conventions (Bumiller, 2008).

According to Bumiller (2008), “simply ‘acting normal’ is a form of adaptation and is even hypothesized as conducive to brain development” (p. 976). Applied behavior analysis (ABA) theory is the most rigid of these approaches because children given ABA are taught functional skills for as many as 40 hours per week (as I was).

Proponents of antinormalization are devoted to pursuing the acceptance of difference and the expression of this difference in an open democratic process (Bumiller, 2008). “As political actors, autistics might be seen as members of just another special interest group and as representatives of a rare disability, yet in their quiriness they contribute to a culture of citizenship that fosters equality without sameness” (p. 980).

Self-advocates tend to favor a social model of disability that conceptualizes disability as being largely the result of a lack of social accommodations to human difference instead of a medical model that pathologizes disability by describing in terms of the physical and cognitive disorders of individuals (Silverman, 2008).

Self-Advocacy. Dekker (2004) defined advocacy as the process by which individuals “find and implement methods to help people in a certain population lead happy and productive lives that meet their own needs (allows for self-determination) and, as much as possible (but no more), meet society's requirements” (p. 3). His definition for self-advocacy is the process by which individuals “find and implement methods to help yourself and others in your own population lead happy and productive lives that meet your own and each other's needs (allows for self-determination) and, as much as possible (but no more), meet society's requirements” (p. 3).

Dawson (n.d.) stated,

Challenging the autism-ABA industry's ethics requires that autistics are seen as human beings with human rights. We do not live in a society that acknowledges this. We are in a society in which autistics have rights only if and when we resemble non-autistics (p. 17).

An official stance of ANI is that of accepting autistic individuals just as they are rather than advocating for research and treatment toward the aim of a cure (Dekker 2004; Sinclair 2005). Dekker (2004, p. 5) extended this by saying:

On ANI and ANI-L the autistic way of being must be respected particularly by not suggesting that a cure for autism must be found even though non-autistic people are welcome to participate. The *positive* [emphasis mine] aspects of being autistic should be focused and strengthened rather than only focusing on the negatives.

Online methods in support of self-advocacy. Online groups like the AUTISM list and its spin-offs are responsible for the increase in parents requesting Applied Behavioral Analysis (ABA), “an intensive method to train autistic children to function within the framework of 'normal' children” (Dekker, 2004, p. 5). Harmon (2004) restated the autistic plea when writing the article titled, “How about not ‘curing us,’ some autistics are pleading.” A 15 year old boy she interviewed responded to a commercial advocating a cure by stating that “we don’t have a disease...so we can’t be ‘cured.’ This is just the way we are” (p. 1). Another boy objected to the use of the word “suffered” in the commercial when he replied, “People don't suffer from Asperger's. They suffer because they're depressed from being left out and beat up all the time" (p. 1).

Self-advocacy and self-determination.

On its Web page (<http://www.sabeusa.org/>), Self-Advocates Becoming Empowered defined *self-determination* as

“speaking up for our rights and responsibilities and empowering ourselves to stand up for what we believe in. This means being able to choose where we work, live, and our friends, to educate ourselves and others; to work as a team to obtain common goals; and to develop the skills that enable us to fight for our beliefs, to advocate for our needs, and to obtain the level of independence that we desire. (SABEUSA as quoted in Wehmeyer, Bersanii & Gagne, 2000, pp. 113-114)

There exist many definitions of self determination. Ackerman (2006), in her paper, outlined some definitions as they pertain to working with disabled children. One definition offered by Deci and Ryan (1985, p. 38) is that self-determination is “the capacity to choose and to have those choices be the determinants of one’s actions” (quoted in Ackerman, 2006, p. 330). Ward (1992 as cited in Ackerman, 2006) defined it as a goal that is crucial for individuals as they become adults. For him, self determination consists of the attitudes necessary to facilitate goal setting among individuals and for those individuals to be able to accomplish what they set out to achieve. A third definition was stated by Wehmeyer (1992, as quoted in Ackerman, 2006, p. 330) as “the attitudes and abilities required to act as the primary causal agent in one’s life and to make choices regarding one’s actions free from undue external influence or interference” (p. 305).

Contrasted with the past when autistics were spoken for by other people, adult autistics are discovering their own voice, and with the Internet, that voice is reverberating around the world. One autistic wrote, "The level of communication possible via the Internet is changing our lives, ending our isolation, and giving us the strength to insist on

the validity of our own experiences and observations" (Blume, 1997b, p. 8). Blume (1997b) quoted one autistic who wrote:

It was through the Internet that I discovered AS and the whole concept of neurological differences. Without the Internet, I'd still be seeing myself as the cause of my own 'failure' (failure to be NT)...it wasn't until I met other Aspies on the internet that I was able to gain a deeper understanding of what being Aspie means. (p. 7)

As more autistic individuals are finding each other and building communities, they are rejected the medical model of disability that frames their strengths as weaknesses and their weaknesses as conditions that much be cured.

Spurred by an elevated national focus on finding a cure for autism at a time when more Americans are receiving autism diagnoses than ever before - about one in 200 - a growing number of autistics are staging what they say amounts to an *ad hoc* human rights movement. They sell Autistic Liberation Front buttons and circulate petitions on Web sites like neurodiversity.com to "defend the dignity of autistic citizens."

By using the Internet to make connections with others of like mind and access scholarly information about neurology, psychology and other topics relevant to autistics, autistic individuals are finding that they have the tools to learn, connect, and self-advocate.

Personal accounts from individuals on the spectrum. As the discourse surrounding autism expands to include those who are so labeled, there is a growing collection of books and articles written by autistic individuals. Meyerding (1998) wrote an article with a thought-provoking title "Thought on Finding Myself Differently Brained" (the term "differently brained" has been used by autistic individuals to frame

their autism in neurological terms). In her article, she described how she stumbled across Aspergers syndrome while surfing the Internet for information on Tourette's Syndrome. The website about Aspergers described characteristics that she saw in herself that had puzzled her for more than 40 years. Her journey continued with each new article further confirming her identity as an Aspergers individual.

Grandin's first book *Emergence: Labeled autistic* is heralded as the first book to ever be written by a "recovered" autistic wrote Dr. Rimland in the forward of her tome (I have an autographed copy that I received when I attended an ASA conference in 1987). Rimland wrote another forward but this was for Williams' book, again commenting on the remarkability of her process toward "recovery." The arrangement of the book is quite unique because it has no Table of Contents and hence no Chapters. It is organized as one undifferentiated chunk of autobiographical information. It is so much so that I had trouble skimming it to find information that would be useful for this section of my discussion. Grandin followed her first book with a more prescriptive and less autobiographical book titled *Thinking in pictures and other reports from my life with autism*. Although she still referred to her experiences, in this book she offered suggestions for how individuals who are concerned for autistic individuals might better relate and understand them (Grandin, 1995). She described in great detail how she cannot think in words, but in pictures, which has proven to be an asset in her career as a livestock equipment designer. She explained one of her language idiosyncrasies of unusual word associations. As a child, she learned the word "prosecution." She would use this word as a catchall exclamation such as when her kite spiraled downward. For her, "prosecution" did not mean the same thing as it did for other people. Another child might say "dog" when he or she wants to go outside,

because outside is where the dog is. So instead of saying “outside,” he or she says “dog” which would make sense to him or her (Grandin, 1995, p 32). She could only conceptualize abstract thoughts by making association with concrete ideas that could be created in a mental picture. For example, the ideas contained in the Lord’s Prayer were incomprehensible to her until she “translated” the phrases into ideas that she could better comprehend such as “the power and the glory” being represented as a semicircle rainbow with an electrical tower (Grandin, 1995).

Gerland (1996) wrote a book in her native Swedish and then had it translated to English. When I communicated on a message board in the late 1990’s about my experiences with autism, she mailed me a copy of her book as a gift. I tried to offer her money, but she refused. The main ideas contained in her book are details of her earliest memories and how they relate to her autism.

Her book has an interesting organization in that her chapters do not have names and the table of contents read as follows:

“The beginning.....9
Continuation.....201
Now.....241”

These headings are barely more descriptive than in the book Williams wrote that had no chapter headings.

Computer-Mediated Communication

As individuals have found roots in online community. Therefore it is fitting for the purposes of studying the online interactions of autistic individuals that computer-mediated communication be defined and discussed. One definition of *computer-mediated communication* (CMC) is “communication that takes place between human beings via the instrumentality of computers” (Herring, 1996, p. 1). Other definitions include: “computer mediated communication is a process of human communication via computers, involving people, situated in particular contexts, engaging in processes to shape media for a variety of purposes” (December, 1997, as cited in Thurlow, Lengel, & Tomic, 2008, p. 15); and “at its broadest, CMC can encompass virtually all computer uses including such diverse applications as statistical analysis programs, remote-sensing systems, and financial modeling programs, all fit within the concept of human communication” (Santoro, 1995, as cited in Thurlow et al., 2008, p. 15). However, in my usage, and in most current CMC researchers’ usage, CMC is more narrowly defined and follows Herring’s delimitations.

CMC can be obtained from a variety of sources such as emails, listservs, mailing lists, newsgroups, bulletin boards, and blogs (Thurlow et al., 2008), all examples of asynchronous CMC (communication that occurs across discontinuous spans of time). Internet relay chat and instant messaging (Thurlow et al., 2008) are two other sources of CMC. Due to their immediate nature, they are known as synchronous CMC. Because computer communication has been around for over 10 years in more developed nations, many of those citizens have become so accustomed to it as to render it an “invisible

technology.” This means that it has matured and has been incorporated into the everyday lives of many citizens (Thurlow et al., 2008).

CMC usage and terminology. With the maturity of CMC has come a set of norms or Netiquette rules that people are expected to follow and that can be enforced rather emphatically. For example, “TYPING IN ALL CAPS” is considered shouting and is discouraged, sometimes outright forbidden, in some online communities. Netiquette can be defined as mostly “unspoken rules about what’s regarded as polite, respectful, sociable behavior online” (Thurlow et al., 2008, p. 65). Many sites offer an FAQ (Frequently Asked Questions) page to inform newcomers explicitly of the rules and expectations of the online group. However, not all rules are so cut and dry.

The social climate of a given message board can dictate what is acceptable versus unacceptable discourse. Enforcement can vary across sites as well. For example, a consumer advocacy site that I often visit (www.consumerist.com) lists in their “comments code” as a guideline, “Above all, don't be a jerk and don't be boring. Ask yourself, is my comment boring, repetitive, or not substantively contributing to an engaging discussion? If you can answer yes, don't hit submit.” And they stipulate that “your comment should be a meaningful response to the issue raised in the post.”

Two instances that often result in “disemvoweling” (“when a moderator removes all the vowels from the comment in question, making it very hard to read”) include: 1) when posters (The word poster is often used in reference to a person who posts. OP is used for Original Poster and Original Post) fail to “avoid blaming the poster or victim or commenting only to be negative” or 2) post comments that are seen as advocating “sexism, racism, homophobia, xenophobia or hatred.” Although many debates on this

site can be rather contentious, the rules state “No flame wars. A bunch of screaming strangers? Boring! Keep cursing to a minimum. Debate the idea, not the person. Pointing out other commenters [sic] spelling or grammatical errors is not a productive exercise” (Consumerist, 2010).

According to Herring (1996), “Netiquette,” or network etiquette, is more than politeness. It encompasses a moral and political dimension in that the rules of netiquette vary according to the values and judgments of the groups of users. Pfaffenberger (1996) viewed Netiquette in a different way when he stated that Netiquette puts no constraints on what is said, but only on how it is said. *Newbies*, or individuals who are new to a message board group, are often directed to an FAQ, or frequently asked questions page, where the rules of posting are explicitly spelled out. These rules could be seen as a form of Netiquette, and failure to adhere to those rules can result in a user being banned by the system operator or sysop.

A definition of *lurking* that attempts to abstain from ascribing a value judgment to the work is offered by Nonnecke and Preece (2000) who stated: “a lurker in a DL [discussion list] is defined as anyone who for prolonged periods receives communications without publicly posting. For many this may mean never posting in some DLs” (p. 1).

When a poster is said to have *flamed* someone, then he or she has written a hostile or offensive message (Ebben, 1994) often with the intent of starting a *flamewar* which is defined as “the whole series of contentious remarks that often result from an initial hostile remark” (Ebben, 1994, p. 158).

In his article about the history of Usenet, Pfaffenberger (1996) stated the following about flame wars:

is an unusually vituperative discussion that has the following characteristics: It's irrelevant to the newsgroup's stated purpose, it's too controversial to be resolved by on-line communication, and it disrupts the newsgroup by pushing more productive discussion off the stage. A good, solid flame war could consume an entire newsgroup's postings for a period of months or more, generating much more heat than light (p. 373).

Flame bait, on the other hand, is a post designed to elicit a flame war. *Spamming* is defined as any message sent on the Internet that contains an "excess of words" (Marvin, 1995; Cherney, 1999) sometimes for the purposes of "bumping" other users off of the network. In America Online chat rooms, some users would utilize "punter" programs to cause text to scroll quickly on the screen of others which could have the effect of causing other users to become logged off their dial-up connection. Currently, *spam* is a term that often refers to unwanted communication particularly of a commercial and/or fraudulent nature.

Trolling is another negative action that is defined as the action an individual engages in for the purposes of passing "as a legitimate participant, sharing the group's common interests and concerns; the newsgroup members, if they are cognizant of trolls and other identity deceptions, attempt to both distinguish real from trolling postings and, upon judging a poster to be a troll, make the offending poster leave the group" (Donath, 1999, p. 45).

CMC use by individuals with disabilities. Identity management becomes an important consideration for disabled individuals who wish to be respected for their views irrespective of disability, who do not want to become invisible, but who have difficulty being heard and participating in face-to-face environments. Findings from a study examining disabled individuals who participated in online forums reported that they felt as though the online medium provided them with the social space where they could express their ideas without fear of censure (Bowker & Tuffin, 2002). The question of when and how to disclose one's status has become an issue of importance, particularly in groups that are not situated around one's identity of disabled (e.g., an online list about model trains). Regarding the choice to disclose, three main ideas have emerged (Bowker & Tuffin, 2002)

1. Relevance – it is appropriate to disclose one's disability status when it is germane to the topic;
2. Anonymity – non-disclosure that creates opportunities to achieve “equity in identity disclosure” (p. 334) meaning that others can get to know the individual as a person before that individual reveals his or her identity as disabled or as an autistic individual;
3. Normality – the idea that disabled individuals are “on par” with their non disabled counterparts online when they have been denied this in their offline life. Another way to state this is that by having control over when or if to disclose online versus face-to-face when autistic traits are more obvious affords the autistic individual more control over identity presentation.

CMC as a means of social support. Brotsky and Giles (2007) studied the online communication of a group of websites devoted to *pro-ana* orientation. The term *pro-ana* comes from the idea that it is acceptable to be anorexic as shown by celebrity models providing “thinspiration” and that efforts to “fix” anorexics should be resisted. One observation concerns itself with the conception of “other” or outsider which has parallels to the autism online community’s concept of NT (Neurologically Typical). Another similarity is in the pro-ana participants’ resistance of any input that comes from an outsider such as a doctor or parent. Just as some autistics see themselves as superior to NTs, some individuals on the pro-ana websites see being “ana” as superior to non-ana (Giles, 2006, p. 468). Outside hostility in the form of ISPs (Internet Service Providers) shutting down these websites has solidified group ties. Like the autistic community, the pro-ana community shares a language (“ana” for anorexic, “mia” for bulimia, “haters” non-eating disordered interlopers who post hostile and abusive messages on proana boards) (Brotsky & Giles, 2007).

Online groups can mobilize and create a formidable social and political force (Brotsky & Giles, 2007; Giles, 2007). One such example is offered by Graham’s (1994, as cited in Cox, 1994) discussion of the origins of freenets and how online speech has evolved to its current form. Managers of freenets began by conceptualizing the purposes of freenets as being analogous to that of a library—an open exchange of information. The manner by which computer mediated communication (CMC) became significant was in its ability to allow individuals the freedom to communicate, and to begin forming a

society that is “egalitarian and decentralized” (Graham, 1994, cited in Cox, 1994, p. 6). Graham warned that the information that was found online was not simply facts, but also consisted of “beliefs, opinions, perversions, darkness, cynicism and bright shining passions” (p. 5 in Cox, 1994), so individuals who access this information should exercise caution. His discussion centered around the idea that CMC can be used as a means for communities that endeavor to participate in political and social conversations that do not require any particular status (e.g., editor of a newspaper) for access. Anyone with a computer and connection to the Internet can join and contribute.

Sociolinguistics and CMC. Studies in sociolinguistics and CMC have undergone a historical transformation over time. The so-called “first wave” of linguistic CMC studies performed in the 1990’s centered around using “the distinction between synchronous (e-chat, instant messaging) and asynchronous (mailing lists, newsgroups, discussion boards) modes of digital communication as a pivotal point for linguistic description...” (Androutsopoulos, 2006, p. 420). Examples of the so-called language of CMC include emoticons, acronyms, the “hybrid combination of written and spoken features, and principal differences between synchronous and asynchronous modes” (Androutsopoulos, 2006, p. 420). Currently, the sociolinguistic perspective rejects the “technological determinism that is implicit in much early work” (Androutsopoulos, 2006, p. 420; Georgakopoulou, 2006) on CMC.

Linguistics features (e.g., representation of spoken language features, emoticons, and unconventional spellings) in CMC have been found to be a function of age, gender, and region rather than simply the medium of communication (CMC). For example,

research suggests that younger individuals engage in more representations of spoken language features than their older counterparts, and female individuals use emoticons more frequently than male individuals (Androutsopoulos, 2006).

By studying two online environments (the Linguist List & The Inquiry Learning Forum) and by taking in the work of scholars before she, six criteria that define online or virtual community is named according to Herring (2004):

1. Active, self-sustaining participation; a core of regular participants
2. Shared history, purpose, culture, norms, and values
3. Solidarity, support, reciprocity
4. Criticism, conflict, means of conflict resolution
5. Self-awareness of group as an entity distinct from other groups
6. Emergence of roles, hierarchy, governance, rituals (p. 355).

In my view, items one and four address issues of sociability, whereas items two and five address identity; lastly, items three and six address support.

Sociability. There are different ways to assess the sociability of a CMC group (e.g., website, blog, chatroom). According to Preece (2001), the purpose of sociability is to support social interaction online through the development of software, policies, and practices. Purpose, people, and policies are the three key components to good sociability. A community is said to have purpose when there exists a shared focus among the members that could be related to a common interest, need, information, service, or support. *Policies* within a community refer to the social norms of the group as well as the

language and protocols that serve to inform how people should interact within the community. These interactions ideally should contribute to group folklore and rituals, which, in turn, provide a sense of group history. Some groups require more formal policies and codes of behavior that are often enforced by a web master or moderator. The people within an online community are those individuals who interact with others in the community and have individual, social, and organization needs. Individuals adopt a variety of roles within the community such as that of moderator, leader, cheerleader, etc. (Preece, 2001). Rovai (2002) examined multiple definitions of community and found the following commonalities in all the definitions he listed: A community must have “mutual interdependence among members, sense of belonging, connectedness, spirit, trust, interactivity, common expectations, shared values and goals, and overlapping histories among members” (p. 4).

Participation can be assessed by counting post frequency, length, and rate of responses (Herring, 2004). Text-based social network analysis a process that allows one to analyze the patterns of interactions between, for example, people, organizations, and states, is another method to assess sociability (Koku & Wellman, 2004). Another aspect of sociability includes criticism and conflict speech acts violating positive politeness (Herring, 1994).

Identity. When communicating online, identity is negotiated by interactions with other participants (Burkhalter, 1999). Because individuals lack the usual visual means of identifying other participants, they must rely on how individuals present themselves with their words. This form of identity can be challenged if an individual’s self-identification

does not match how he or she is presenting himself or herself as interpreted by other participants. One example of expressing identity online was offered by Burkhalter (1999). He described how an African-American woman identified herself as “part African-American” on a Usenet message board before criticizing the practice of black people who choose to “act black” rather than to be themselves. Burkhalter explained that the woman felt it necessary to reveal her identity as being like the others within the Usenet group before making a criticism of the group because otherwise she would likely be attacked as an outsider. Other people challenged her identity by claiming that she had more “pride for the paler side” (p. 69) dismissing her perspective regarding race. In this instance, the responder was using the original poster’s racial identifiers against her (e.g., “part African-American”).

Another way to conceptualize the idea of identity is to examine it through the framework of membership within an online community. In other words, one's social identity includes the online community in which one participates (Androutsopolous, 2006). A participant’s personal identity might be subsumed by one's *social identity*. For example, an autistic individual might identify as autistic, but may also have a social identity as belonging to an autistic advocacy group.

Recently, there has been public discussion about the American Psychiatric Association’s consideration of combining the diagnosis of “autism” with “Aspergers.” A CNN article reported that one individual with Aspergers was vehemently opposed to “lumping” Asperger Syndrome with autism because the word “autism” is associated with deficit, whereas he believed that *Aspergers* afforded some social and status advantages

(Landau, 2010). The Asperger's Association of New England has taken action by writing a letter to the APA expressing their objection to the proposed change. The president of the organization stated, "This is their identity, which is really being taken away" (Landau, 2010, n.p.). It is interesting that autism is being viewed as "less than" by those who identify as Aspergers. This is similar to the within group identity conflict that Giles (2006) discovered when he studied the online community of "pro-ana" (pro anorexia). He learned that anorexics who positively identify as such regard themselves as superior to bulimics, an "ED [eating disorder] ideal" (p. 468), despite both being members of a larger eating disorder community.

Support. There are different way in which support can be given and received via CMC. One example of evidence of online support is through speech acts such as positive politeness (Herring, 1994), that express the desire to be understood, liked, or admired. This can take the form of individuals expressing themselves in a manner that makes others feel supported and accepted. Another way that support can be shown is in reciprocity in communication or turn-taking (Rafaeli & Sudweeks, 1997). In a study of a Usenet board about soap operas (rec.arts.tv.soaps) Baym (1995) reported that one reason verbal humor enhances solidarity is because it "provides it with its social power to create and enhance participant solidarity and group identity...by positioning all the group members as highly knowledgeable and competent readers of the genre" (p. 8). All together sociability, identity and support are all criteria for determining whether individuals who use CMC are part of a community.

Ethical and Philosophical Issues Related to Research with Special Populations and CMC

With any research one must consider ethical issues. This is of particular importance due to the population that I have studied. The controversy over what constitutes public versus private communication on the Internet has been ongoing since the mid 1990's. One perspective is that online postings are copyrighted and thus can be used only with permission except when "fair use" is relevant (Walther, 2002). Another perspective is illustrated by the analogy between observations made in a public space where informed consent is not required and a public chat room where informed consent is also not required (Ess, 2002).

Because online communication can cross international boundaries, it is useful to compare the ethical guidelines of the United States to that of another region, Europe. The ethical guidelines for human research in Europe take a deontological view (Ess, 2002) that there are absolute rights and wrongs, and that a set of rules should be strictly adhered to (Wikipedia, 2010). By contrast, the ethics of the United States with regard to data privacy, according to Ess (2002), takes a more utilitarian approach whereby rights of privacy could come after economic efficiency (e.g., think of websites tracking website clicks, a practice that many accept as inevitable). He stated that these differences between European and American ethical sensibilities occur on a first level. In other words, the differences are in terms of interpretation and implementation. Contrasting this first level with the second level of values, norms, and commitments, Ess (2002) acknowledged that the United States and Europe share the same second level ideals.

When considering issues of public and private communication, one concept that continues to surface is that of an individual's "expectation of privacy." Walther (2002) advocated informing the public of the potential vulnerability of online postings in general rather than debating whether it is acceptable for researchers to use online postings without obtaining explicit consent. Walther (2002) noted:

...it is important to recognize that *any person who uses publicly-available communication systems on the Internet must be aware that these systems are, at their foundation and by definition, mechanisms for the storage, transmission, and retrieval of comments* [italics his]. While some participants have an expectation of privacy, it is extremely misplaced. (p. 207)

Related to the concept of the expectation of privacy is the legal term *reasonable expectation*. Although legally it has been used as a measure of what is acceptable, *reasonable expectation* in legal terms may be very different from individuals believing they are holding reasonable expectation of privacy, but are deemed as having unreasonable expectations of privacy in terms of the law (McArthur, 2001). For example, in a public space, a person can engage in a private conversation with other individuals well within earshot of others not involved in the conversation. Is it reasonable that the interlocutors have an expectation of privacy? Other individuals may pretend not to hear the conversation, but as I have observed in myself, it is impossible *not* to listen to a conversation that is within my earshot and is in English. Furthermore, regarding individuals who carry on lengthy cell phone conversations in public, I would argue that it is unreasonable (particularly given the volume of their voice) to expect that people within earshot are not going to listen to what is said on a cell phone. The Mischance Principle is defined as our being unable to "reasonably expect to maintain privacy over that which

another person could discover, overhear, or come to know without concerted effort on his/her part to obtain this information” (McArthur, 2001, p. 124)

Walther (2002) summarized part of the Belmont Report, a document that outlines how human research participants are to be treated, when he stated that when participants post messages to message boards or other such systems, they do not expect that the public would inspect their comments. Furthermore, when they post, they do so not “with any nascent permission for them [the postings] to be reproduced or analyzed” (p. 206). They have, it is argued, an expectation of privacy, according to the Belmont Report as interpreted by Walther (2002). And yet, the issue is open to interpretation. I do not agree that individuals who post on public message boards can reasonably have an "expectation of privacy" particularly with social networking gaining popularity, making what is posted not only available to those one one's "friend" list, but also to anyone the individuals themselves know.

There is more than one way to obtain consent when studying a population. In one example of obtaining consent, Sharf (1999) joined a breast cancer online support group as a “lurker.” She printed out postings that were of interest to her, developed a research question, then reintroduced herself as a researcher and obtained consent to use the postings of the members (Brownlow & O’Dell , 2002).

After carefully considering all the various arguments, it is my observation that the prevailing opinion online is that there is no expectation of privacy for what people post on websites unless the site is restricted by membership and/or password. Therefore, I will treat the postings as though they were public discourse. However, due to the permanent

nature of online postings (archives), I will exercise caution when quoting anyone, particularly with regard to sensitive topics, as it is possible to ascertain the identity of the poster through creative online sleuthing if one is so inclined. I am sensitive to general mistrust many autistics have toward researchers “using” them as "self-narrating zoo exhibit" (Sinclair, 2005, p. 22). Some researchers caution against interpreting the posts of autistic individuals because historically other people have spoken for them, and it is only since the neurodiversity movement that took root on the Internet that autistics have begun to find their voice (Brownlow & O’Dell, 2002; Seale, 2002). By not checking with them on interpretations, researchers would be engaging in the very practice that autistics are hoping to eradicate.

Privacy and confidentiality. Brownlow and O’Dell (2006) argued that the inherent nature of online self-advocacy groups add further complication to the discussion of participant privacy. They stipulated that “the message posted to a group could be considered ‘private’ in the sense that only group members or those with related issues are the intended audience, not researchers” (p. 687). Although I believe that their definition of internet privacy is too conservative, even if I were to adopt this definition as my ethical guideline I would still be able to participate in research while remaining a member of the “intended audience” because *researcher* and *group member* are not mutually exclusive categories, if only by virtue of my unique dual membership.

Another perspective concerning online research of publicly accessible message boards and websites is offered by Sharf (1999) who stated that the researcher should:

1. contemplate whether or not the purposes of the research are in conflict with or harmful to the purpose of the group. Conversely, the researcher should consider whether the research will benefit the group in some way
2. clearly introduce himself or herself as to identity, role, purpose, and intention to the online group or individuals who are the desired focus of study.
3. make a concerted effort to contact directly the individual who has posted a message that he or she wishes to quote in order to seek consent. It should be clearly explained to the writer what words will be quoted, in what manner and for what purposes the quotation is expected to be used
4. seek ways to maintain an openness to feedback from the email participants who are being studied.
5. strive to maintain and demonstrate a respectful sensitivity toward the psychological boundaries, purposes, vulnerabilities, and privacy of the individual members of a self-defined virtual community, even though its discourse is publicly accessible. (pp. 253-254)

Regarding Point 4, she argued that “only by inviting such feedback can the researcher be assured that she or he has not grossly misinterpreted another’s meaning or intention, or appropriated another’ story in ways that distort or damage” (p. 254). A member checking interview could help accomplish this.

Kanuka and Anderson (2006) provided a very detailed comparison of the various viewpoints of researchers and augmented these with their own discussion and analysis about ethics concerning conducting e-learning research. They proposed that ethics are socially constructed, and thus we as researchers cannot always be certain how individuals from other cultures perceive e-learning research as their ethics may vary. They concluded their discussion by stating that it is not always possible to know *a priori* what is ethical and what is not. Finally, they implored the researcher to engage in self-reflection during the process of research and to use the guidelines provided by Baktin when they suggested that “we must strive to be receptive and perceptive, and struggle to act ethically in each situation” (p. 12).

Online privacy and consent are very timely events as social networking becomes more ubiquitous. A recent example involves a new feature of Google known as Buzz. Although I have not personally tried Buzz, there seems to be major privacy flaws in its setup. When Buzz first went live on February 9, 2010 (Google, 2010), the decision to introduce Buzz's social networking features as opt-out (Carlson, 2010) angered many people on the Internet. Carlson (2010), a writer for a business magazine, pointed out that "the people you follow and the people that follow you are made public to anyone who looks at your profile" (p. 1). In the parlance of social networking, to *follow* means that you are keeping track of the posts of what another person posts. The term was popularized by Twitter but is now being used to refer to any individual whose posts and updates are sent to other individuals using the same service (e.g., "friends" on Facebook and MySpace).

Although information sharing has become popular with the advent of social networking sites, some facets of online remain sacrosanct, such as e-mail addresses. Wood (2010), a writer for a computer magazine, wrote, "We've gotten comfortable with handing out usernames of all stripes across social networks, but the personal e-mail address used to be somewhat sacred--until Google Buzz came along." Her writing suggests that she is bothered by what she sees as a breach of trust between Google and individuals who use Gmail. She concluded, "But I do have an expectation of privacy when it comes to my e-mail, and I think that even in this age of social-networking TMI, most people still think of e-mail as a safe place for speaking privately with friends and family."

Helft (2010), a reporter for the New York Times quoted Marc Rotenberg, executive director of the Electronic Privacy Information Center, an advocacy group in Washington as having said that, “E-mail is one of the few things that people understand to be private.” The director also stated that his organization would be filing a complaint with the Federal Trade Commission for Google’s new use of e-mail as a means of social networking that is misleading and deceptive. After receiving much negative press from both the mainstream media and various online sources of discussion (e.g., blogs, message boards), Google modified some of their practices just two days later (Krazit, 2010). Several posters on the blog site Consumerist expressed that e-mail sharing breaches the trust between Google and the user, but many posters also offered a caveat. Many of these posters made comments to the effect of saying that "anything that is posted on the internet can be used against you later, so beware." They even added that e-mails that originate at one's place of work are not completely private and that therefore the expectation of privacy should not extend to those e-mails.

I mention this case of Google Buzz to illustrate how contentious the issue of privacy continues to be on the Internet. From the opinions I have read, there seems to be a consensus that personal e-mail should be private, but individuals who post comments on public forums should not have “an expectation of privacy.” In other words, blogger beware.

Chapter 3: Method

Before embarking on my full study, I wanted to find websites to study that would have enough activity to provide good data for my research questions. There are many sites created by (and for) autistic individuals, but many of these are not very active. When I perused several sites, I found that there were many blogs, for which the owner of the blog decides and controls the topic, rather than message boards that allow for contributions by large numbers of participants. Of the likely message boards, several seemed defunct and others seemed to attract caretakers and parents of children or adults with autism, rather than offering a place for exchanges among individuals with autism themselves. I eventually settled on two message boards that seemed to have enough activity to proceed with my study, Aspiesforfreedom.com and Wrongplanet.net. These two websites were initially chosen because they have been in existence for more than five years, which means they were likely to be around for at least the duration of my study; and I saw them to be quite active. The two sites, although similar in many ways, were different in one important way. I had to secure permission from the creator of [Aspiesforfreedom](http://Aspiesforfreedom.com) in order to conduct research on that site. No such restriction existed on [Wrongplanet](http://Wrongplanet.net). I then decided to conduct a preliminary pilot study to determine whether the postings would yield interesting insights relevant to my research questions.

Pilot Study

My purpose for the pilot study was to determine whether the postings on the two websites I had chosen would yield promising data that suggested individuals were constructing a sense of community through their online postings. One set of criteria I found useful for this purpose was Herring's (2004) criteria of an online community:

1. Active, self-sustaining participation; a core of regular participants
2. Shared history, purpose, culture, norms, and values
3. Solidarity, support, reciprocity
4. Criticism, conflict, means of conflict resolution
5. Self-awareness of group as an entity distinct from other groups
6. Emergence of roles, hierarchy, governance, rituals (p. 355).

Using these criteria, I analyzed one thread on one site, evaluating whether each posting reflected interesting displays of online community. Such a scant data set for the pilot study seemed justified by the fact that I was able to find evidence quite easily in the first thread I examined.

Posting 1: I disapprove of the choices in this poll. They do not reflect the full spectrum of possible opinions. I say we should not resort to violence because it would be wrong. Questions of efficacy are second to questions of morality. Besides, violence against whom? We're attacking an ingrained prejudice, not a group of people. And anyway, how would that avoid causing further negative stereotypes?

Analysis 1: *The ideas I see expressed in this post are issues of weighing the advancement of one's cause versus one's personal conscience (e.g., morality). Also, I see a pragmatic concern in that an attack on particular people who espouse prejudiced ideas might only serve to reinforce negative stereotypes. The poster uses the pronoun "we" in "we're attacking" to refer to members of the neurodiversity movement. This indicates criteria 2, 3 and 5 of shared purpose, solidarity, and self-awareness of group distinctness. There is also evidence of conflict (criterion 4) by questioning extreme tactics of some Neurodiversity activists.*

Posting 2: This is the dumbest crap I've ever heard of. And I never understood what the neurodiversity movement means when their fighting for their rights? Autistics have just as many rights as anyone else; yes there are prejudices that need to be fought against, but autistics are NOT second class citizens. And I think the movement is extreme enough as it is. Bordering on nutty almost.

Analysis 2: *This seemed a post filled with emotion (e.g., use of phrase "dumbest crap"). This person also acknowledges that autistics are not treated the same as non-autistics but criticizes the neurodiversity movement as being "nutty" (but sadly does not elaborate as to why he/she feels this way). This criticism is indicative of Herring's criterion 4 of an online community. This poster refers to autistics in the third person as though he/she may not belong to this group. However, perhaps this is simply this poster's style of writing when posed with a question that is not of a personal nature.*

Posting 3: We have the same rights as everybody else. We just don't get the same respect, as everybody else.

Analysis 3: *This post seemed to be mostly in agreement with the previous posters who stated (or implied) that autistics deserve the same rights as anyone else. My analysis is that the purpose of this post is mainly to offer support in the form of offering agreement, as no new information is presented. Agreement with previous posters indicates criterion 3 (support).*

Posting 4: I think that violent action is a very bad idea, the neurodiversity movement should remain non-violent. I think that if a mob of AS bombers or gunmen went after anyone who has crossed the ASD community then it would harm our interests very greatly. However I see nothing wrong with taking some actions such as looking for methods of using the legal system to close down some of the neurobigots. If you find out that a neurobigot is in breach of criminal law then make a point of reporting them. For example if a quack medical worker is "treating" autism with snakeoil / chelation / goodness knows what else and does not have the right license (or has breached their license) then write to the medical authority and try to get them into hot water. I think that if a quack gets into trouble with the medical board then it will do some good

Analysis 4: *My favorite part of this post is the term "neurobigot" I had never run across this term before. It is possible that this poster simply coined this word, as*

autistics are known to make up their own words to express their ideas (I hope to find examples of this as I continue). Also, this person advocates working within the current system (e.g., medical board) to effect change. Use of the phrase “harm our interest” definitely indicates a feeling of belonging to the ASD community (criterion 5, self-awareness of distinct group). Using the term “neurobigot” is indicative of ingroup/outgroup membership in that those who do not advocate autistic rights are neurobigots and therefore members outside the group. This is a strong indicator that the poster feels a sense of community with other autistic individuals (criterion 3, solidarity).

Posting 5: Non-violence, if entered into in depth means confronting our own internal conflicts and thus seeking change from the inside- out as opposed to seeking change through more mainstreame [sic] political means. After many years in the peace movement I have learned that our only embracing our own personal shadow can we authentically claim to be agents of real change. violence gets results.....but such results take years to mend.

Analysis 5: *This poster does not appear to be replying to any particular post but rather offering his/her own thoughts on seeking peace by looking within. In other words, this person seems to be saying that the best way to effect change in society is by looking inward. I can see the potential for this viewpoint provoking vehement disagreement among proponents of the neurodiversity movement. This poster seems the least demonstrative of online community except in referring to “can we authentically claim to be agents of real change,” but even that phrase could be referring to the collective “we” as in humans rather than “we” as in autistic individuals.*

Evaluating the pilot data led me to conclude that these two websites would offer interesting posts for me to analyze and that, even with one thread from one site chosen because it seemed to be discussing a controversial topic, I could demonstrate that the individuals writing these postings were building a sense of community online. There is evidence of a shared language (e.g., "Neurodiversity") and other characteristics that made me curious to learn more about how these message board members communicated. One thing I learned is that the "posters" behind the messages I chose were not as central to my study as the messages themselves. The pilot data along with my own experiences reading these websites in the past made me satisfied that there would be plenty of data to analyze in the message board section of these two websites. I could envision how the coding might proceed.

Main Study

The study spanned three phases that had distinct purposes. Phase 1 consisted of observation, Phase 2 consisted of participation, and Phase 3 consisted of follow-up interviews during which I interacted with some of the posters from Phases 1 and 2 for triangulation and member checking. These three phases were useful in answering the research questions: (1) What are some of the topics that autistic individuals talk about online? (2) What evidence is there that autistic individuals create a “shared identity” online by their discourse practices (e.g., the way they use language, the way they post, time between messages)? (3) In what ways do autistic individuals participate in self-advocacy? What are the common themes in the posts related to self-advocacy? More specifics of the data gathering procedure and data analysis plan for each phase are outlined below.

Phase 1. I observed online communications among self-identified ASD individuals on two websites 1) <http://www.wrongplanet.net> and 2) <http://www.aspiesforfreedom.com> in May 2012. I chose these websites because they have had a relatively long history. [Aspiesforfreedom.com](http://www.aspiesforfreedom.com) was created in June 2004, while [Wrongplanet.net](http://www.wrongplanet.net) has been around at least that long.

Figure 3.1 Wrongplanet Main Message Board Page



Figure 3.2 Aspiesforfreedom Main Message Board Page



On both websites, I retrieved message board threads that had at least 10 posts and that appeared to be active threads (the latest post was no older than a week from the time of retrieval). This proved to be too limiting, so I loosened that requirement and focused on all the threads that looked to have had recent activity but not necessarily currently active.

Phase 2. This was the phase during which I participated in the discussion when relevant. I assumed the role of “participant observer.” I introduced myself in early May on both websites as someone who had once been labeled *autistic*. I did this to be honest and to hopefully earn the trust of the participants. When I mentioned that I had been a part of the Lovaas study, I received questions about whether or not I identified as being on the spectrum. Therefore, it was clear that some participants needed more explanation from me before I was to be trusted. For this phase, I retrieved message board threads that had at least 10 posts. My participation consisted of me responding to the posts of others in an effort to participate in the discussion of the proposed topics. Because I wanted to mitigate having my involvement change the topics that participants might discuss, I did not attempt to start new threads except to introduce myself. On Wrongplanet my introduction was titled "Not just another researcher" and then I wrote:

Hi, My name is Lydia and I am very interested in learning more about the people who contribute to this message board. I am a doctoral student in Educational Psychology who is in the dissertation stage. What differentiates me from other researchers is that I also had once been diagnosed with autism when I was 3 years in 1974. I was involved in the Young Autism Project from UCLA, so I have also been on the “subject” end of a study from an early age. I look forward to meeting anyone who wishes to talk with me here. Thank You :-D

For Aspiesforfreedom I had to obtain permission from the site founder before I could conduct research on his site. Once I obtained his approval, I wrote the following introduction titled RE: Areas of interest for research (proposals):

My name is Lydia and I am very interested in learning more about the people who contribute to this message board. I am a doctoral student in Educational Psychology who is in the dissertation stage. What differentiates me from other researchers is that I also had once been diagnosed with autism when I was 3 years in 1974. I was involved in the Young Autism Project from UCLA (Lovaas), so I have also been on the “subject” end of a study from an early age.

My study has already been approved by my university's IRB; and if anybody wants to know more details, please don't hesitate to e-mail me.

Although I likely do not meet the diagnostic criteria for a pure autism diagnosis today, I do identify as being someone on the spectrum. I look forward to meeting anyone who wishes to talk with me here.

Lydia

My introduction on the second site was a little more formal because I recognized how leery some posters are to being studied.

Phase 3. During the middle of May, I began soliciting and conducting interviews via email exchanges. My goal initially was to conduct follow-up interviews with seventeen participants whose postings I had questions about and who had at least 1000 postings to their credit. Securing willing interviewees was more difficult than originally planned. If an interview was not possible, I triangulated the data by following the same poster in other threads to see if the poster was consistent across posts over time. I included the consent form in the body of an email along with the interview questions. Response rate was very low. Of seven recruitment letters on one message board, I received two solid responses. From the Wrongplanet website, I attempted to interview 10

more individuals in July, but they never responded. I had two people who offered to participate in my study just after I had introduced myself to the website. For these two who did respond, I had no member check questions for these participants because I had not had a chance to develop them at the time they offered to participate. I attempted to conduct my back-up plan of triangulating their posts by examining other posts they had made on the same subject. This proved moderately successful and provided me with a few more quotes that I used to check my conclusions.

As for attempting to have more general interviews about their perceptions of participating on the websites, I count the two volunteers from Wrongplanet. However, I was never able to secure any other volunteers after numerous attempts. As for demographic data, I found out later that many of my questions are answered in the user profiles of the posters for those who choose to share that information. Furthermore, I found it too limiting to only interview people with 1000 or more posts. The types of questions I asked the selected few participants included asking for clarification on particular posts to ensure that my interpretation matched the communicative intent of the participant being interviewed. I asked questions relating to how the participant was diagnosed, as well as inquired as to the age, sex, and other basic demographic questions. Questions about the participant's civic involvement (autistic activism) were posed, although no attempt to ascertain political affiliation was made. The goal was to ascertain the degree to which a given participant engaged in activism. Questions about sense of belonging were posed, as this question of one's sense of online community was central to my study. Below are the interview questions that I sent via email.

Interview Questions

1. What is your screen name/username? (you may include your legal name as well if you wish)
2. What is your age?
3. Are you male or female?
4. How old were you when you were diagnosed with an ASD (autistic spectrum disorder)?
5. How were you diagnosed with ASD?
6. What are your thoughts about the Neurodiversity movement?
7. Please describe your involvement (if applicable) with the Neurodiversity movement?
8. How long have you been a member of this message board?
9. Please describe your thoughts about your involvement with the online autistic community?
10. When you posted XXX on [date of post], did you mean to say XXX? What do you think?

The purpose of quoting the participant and offering my interpretation of his or her words was for triangulation and member checking.

Data Analysis

The approach I took to analyze the data was Strauss and Corbin's (1998) qualitative grounded theory approach. A Grounded theory is a theory that has come about from data that has been systematically gathered and analyzed throughout the research process (Strauss & Corbin, 1998). A close relationship between data collection, analysis, and theory is necessary for a grounded theory to emerge. Researchers using grounded theory do not usually set out to collect data for the purposes of supporting an existing theory. Rather, their goal is to let the data inform the field by creating new theoretical explanations of a phenomenon. It is through the process of open coding of data that categories will emerge. From there, the researcher might perform axial code as defined by Strauss and Corbin (1998, p. 123) as “the process of relating categories to their subcategories, termed ‘axial’ because coding occurs around the axis of a category, linking categories at the level of properties and dimensions.” The beginnings of theory building are likely to occur during selective coding when the researcher sets out to integrate and refining the major categories to “form a larger theoretical scheme” (Strauss & Corbin, 1998, p. 143). I have examined the conversations to inform the research questions and to look for other themes that might emerge. Although I have approached my data with the open stance of a grounded theory analyst, I was also guided by Herring’s (2004) list of criteria to indicate that online postings are suggestive of community.

Over the course of five months, I analyzed the corpus of posts looking for themes that might emerge from the conversations. I systematically avoided choosing threads in

which I had participated. I have been mindful of assumptions forming about posters based on usernames and tried not to let usernames “color” my perceptions of their online contributions. I discovered that it was easier to analyze the data if I had two computer monitors set up and had two open Notepad programs ready. After analyzing the first thread, I realized that I needed a different system. I created a table by utilizing MS Word. In this table column three had a quote from a posting, in the column just to the right of this was my open coding space. I used this method for the subsequent threads that I analyzed. I took screen shots of the conversations in order to preserve the appearance of the data and to ensure that data was available for subsequent analysis. I analyzed a total of 9 threads of 376 posts by 176 participants. An example of my process is that for Thread 5 of Wrongplanet I began open coding in June, 2013. In July, I made a second pass through looking for relationships among the codes.

Once patterns from open coding began to emerge and I felt I had reached data saturation, I added a fifth column to my table. In this column just to the right of my open coding space, I put my axial codes. The table looks like this.

Table 3.1 Example of Coding table

#	Post Info	Text	Open Codes	Axial codes
1	Mr. Drew- 06-22-2011 04:47 AM	I felt a bit funny. Like...Someone had told me something I already expected, but at the same time I was a bit shocked. It made things allot more clear, and it was nice to finally put a name on something that's been bugging me for a while, but also, I felt like I was a different person. I dunno, it's weird...I'm still trying to get my head round it. How did you feel? Tell me?	Soliciting feelings about getting dx; shocked, clear, changed self-identity	Self-disclose; info seek; <i>identity; emotional</i>

Table 3.1, cont.

2	blossoming tulip - 06-26-2011 12:19 AM	I felt a bit unsettled. I'd never thought I had a disorder or disability of any sort, but I'd realized long ago that I was different, and I had come to accept it and even to be proud of it. I still feel like that now, but when I was first diagnosed I was taken off-guard because I'd thought that the weird things I did were just idiosyncrasies. Realizing I have AS made me feel at first like those things really didn't make me unique after all, but that feeling wore off quickly as I learned more about autism. Now I think knowing about my AS explains a lot about me, but I'm still uniquely me - and actually, I'm rather glad to know there are people out there like me.	Unsettled; not disorder but "different"; come to accept then feel proud; glad others out there w/ AS too	Self-disclose; <i>Emotional (felt different, then proud); identity change over time,</i>
3	Trump - 06-26-2011 12:24 AM	I was Happy to finally have a answer to why i act the way I do.	Happy to have explanation	Self-disclose; <i>Emotion (happy); answered questions about self (identity)</i>
4	Medium - 06-26-2011 10:39 AM	I was pleased when I finally got diagnosed, because it explained 43 years of wondering why I never quite "fit in" with the ease of everybody else, no matter what I did. And I found out that not only are there other Aspies out there, the majority of them are nice people and I like them. Medium	Happy to have explanation for why not "fitting in"; likes most other Aspies ("nice people")	SD; <i>Answered questions about not fitting in (identity); most Aspies nice (accepting of ID)</i>
5	Bird woman - 06-26-2011 11:43 AM	I felt like "Oh great, another reason I'm a freak."	Sarcasm; negative self-ID ("freak")	Sarcasm <i>Emotion (felt like freak)</i>

The discourse practices were in regular font while the Axial codes were in italics. These five posts represent some of the range of responses and provide an example of how I analyzed my data set.

During Phase 2, data collection problems with date stamping were observed. AFF uses GMT-6 (or CDT -1; Mountain daylight time) date stamp, while WP uses GMT +10 (Australia time). Because I noticed this after data collection, in the interest of consistency I kept my new screen shots in the same timezone as the older ones GMT-6 and GMT +10 respectively). When saving as “printer friendly” I realized that one thread on AFF had truncated all messages beyond the first 37 posts. It missed part of page 3 and all of page 4 of the website thread (54 posts total) dated to 4-16-2012 12:21 pm. After pasting into word document in this case, there were: 41 pages, 9749 words, 45307 characters (no spaces) and 55398 characters (with spaces). After noticing the time stamp inconsistency, I also realized that AFF had posts that said "yesterday" instead of the date. Therefore, I had to go back and "clean up" the data to reflect an actual calendar date for those posts.

Thus, as exemplified above, my process of data collection and analysis was iterative and guided by my overarching interest in self-advocacy, community, and what the posters called Neurodiversity, common topics on the threads. Throughout the process, I compared the responses from the interviews with the online postings to see if they represented similar ideas or themes. My study was not, understandably, designed to represent an all exhaustive catalogue of every theme that individuals with autism might discuss, and thus I tended to gravitate toward posts and interview topics that allowed me to answer my research questions.

Data Trustworthiness

Data trustworthiness is the qualitative research equivalent of addressing issues of validity in quantitative research. Explanatory power is to qualitative research as generalizability is to quantitative research. Explanatory power is defined as "the ability to explain what might happen in given situations such as stigma, chronic illness, or closed awareness" (Strauss & Corbin, 1998, p. 267). Triangulation is a method by which a research study is scrutinized to rule out rival hypotheses. Midway through the process of collecting and analyzing the data, I asked a few posters to be interviewed to confirm and/or modify my interpretations of their comments for the purposes of triangulation (Gliner, 1994 as cited in Strauss & Corbin, 1998). They were free to add whatever they felt necessary to communicate their points if I failed to capture them.

My feelings about being on the spectrum probably did not influence which topics I chose to study so much as my curiosity about what participants were saying in certain threads. I do not take a hard line on the cure/no cure debate except to say that the word "cure" is not the correct nomenclature to describe autistic people who learned how to act "normally." The debate should really be "consent to intervention vs. no consent to intervention." I do believe that it is important for any minority group to advocate for rights therefore I am very interested in the Neurodiversity movement. I also believe that issues around autistic adults should be given more attention. People on the spectrum should be solicited for information that could later inform interventions that do not ask the autistic individuals to disavow his or her identity.

Descriptive Statistics

Before presenting the results of my data analysis in the next chapter, I provide here descriptive statistics about the posters themselves as well as usage statistics about the two websites over time.

Demographics for the posters. Note that these descriptive statistics are for the posters on each message board who chose to disclose demographic information.

Table 3.2 Descriptive statistics of posters for both websites

	AVERAGE AGE	Number of Males	Number of Females	Undisclosed	Total
WP	27.5 years (N = 85)	79	73	0	152
AFF	29.67 years (N= 12)	10	6	8	24

Table 3.2 shows the average ages for the posters of both Aspiesforfreedom and Wrongplanet. Notice that the average ages for both sites are comparable. The N stands for the number of participants who disclosed their age. Interestingly, there were nearly equal numbers of men and women represented in this sample. The Wrongplanet website was more active than the Aspiesforfreedom site which might account for the disparity of participants between the two sites.

Table 3.3 Posters' ASD identification

	ASD	Doesn't ID ASD	Unsure
WP (152)	83 (official) + 26 (unofficial) + 19 (other ASD)= 128	4 (NT) + 4 (family member with ASD) =8	16
AFF (24)	12 (Official DX Aspie/HFA) + 3 (self-DX Aspie/HFA) = 15	2 (parent/friend/relative)	1 (other) + 6 (blank)=7

Table 3.3 shows the number of posters who identified as having a diagnosis of being on the Autism Spectrum (ASD), whether self-diagnosed or officially diagnosed. The one poster in column three "unsure" for the AFF website actually wrote "other," whereas six participants left their response blank. Posts from these participants were still used in the analysis because I had attached pseudonyms to the participants in keeping with the Institutional Review Board's requirements. Most participants of both sites identified as being on the Autistic Spectrum Disorder, which is what one would expect given the purposes of these two sites. Some participants did not have an official diagnosis, therefore they were identified as being unofficially diagnosed or self-diagnosed. Sometimes the terms *Aspie* [having Asperger's] and *HFA* [high functioning autistic] are used interchangeably, and the table shows this ambivalence.

For the posters included in my analysis on Wrongplanet, their individual post count ranged from 2 posts to 36,700 posts for one person. The average number of posts for those who participated is 2628. However, due to there being a few *extremely* active posters relative to most post counts, a better metric is the median, which turned out to be 770 posts per individual.

Figure 3.3

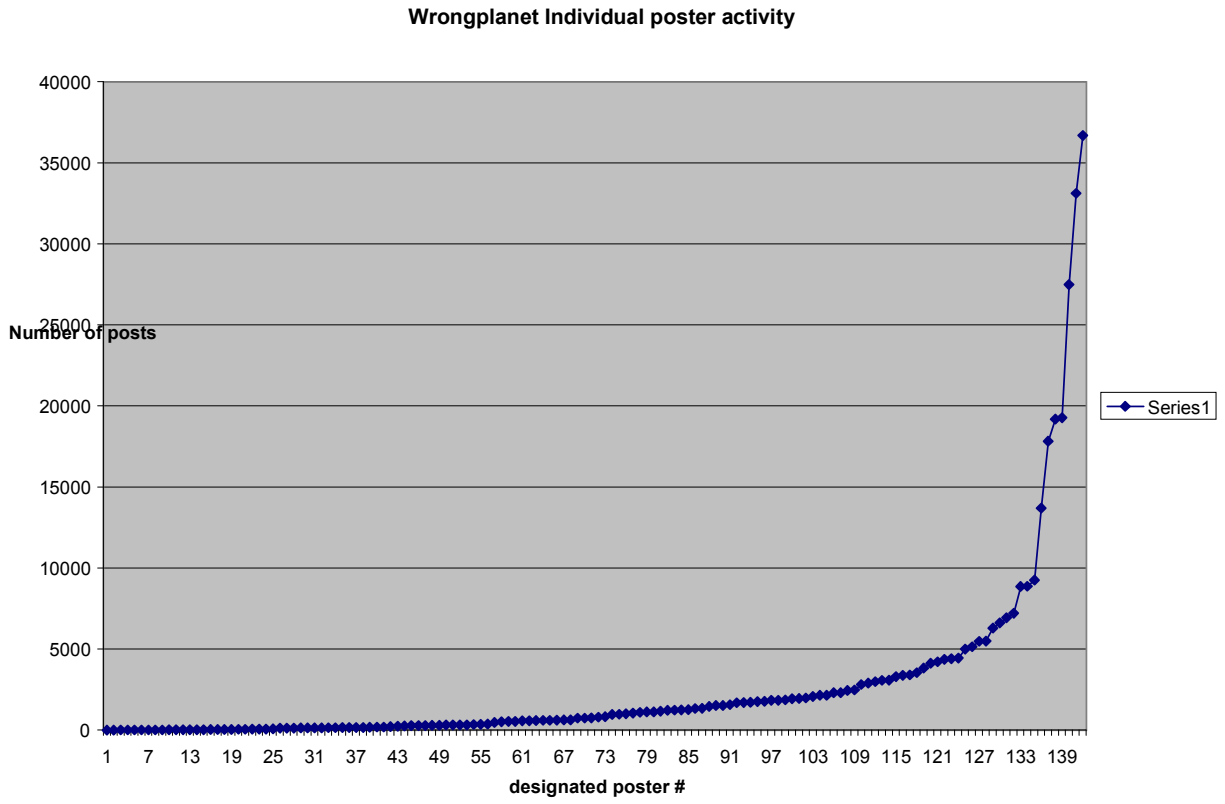
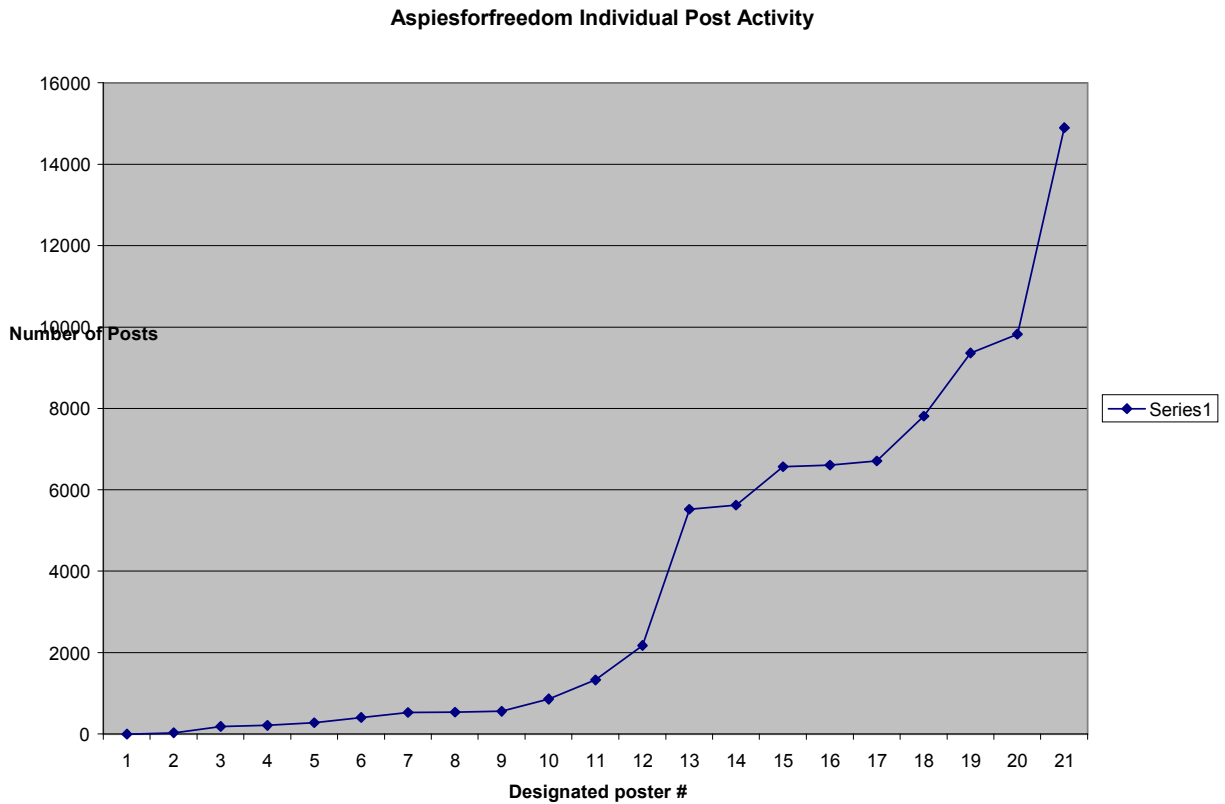


Figure 3.4



For the posters included in my analysis on Aspiesforfreedom, their individual post count ranged from 2 posts to 14,902 posts for one person. The average number of posts for those who participated is 3813. However, again, the median is a better metric when a few individuals are skewing the mean. In this case, the median number of posts per individuals was 1331, and if I exclude the extreme three outliers, the median becomes 713 posts per person.

For whatever reason, some individuals post thousands of messages whereas others may only post once or twice. The three most active posters on Wrongplanet post between 20 and 30 posts per day (Wrongplanet.net, 2013). The three most active posters on

Aspiesforfreedom post between 5 and 20 posts per day (Aspiesforfreedom.com, 2013). This disparity among posters could be the result of the active posters only posting to one or two websites, whereas the less active posters on these two sites might split their time among many other websites. Or they may have other IRL (in real life) things to do.

Demographics of the websites and analyzed threads. As shown in Table 3.4, each thread I analyzed on each of the websites differed in the number of posters and posts. The threads I analyzed differ in a few interesting ways. Threads 2 and 6 were both quite popular having 58 and 55 unique individuals posting to them. By contrast, thread 4 elicited relatively few responses from only seven participants.

Table 3.4 Number of Postings and Posters for Threads For Wrongplanet

Thread	Number of Posters	Number of Posts
1	23	34
2	58	97
3	25	28
4	7	17
5	20	38
6	55	111

Table 3.5 Number of Postings and Posters for Threads For Aspiesforfreedom

Thread	Number of Posters	Number of posts
1	4	16
2	16	20
3	7	15

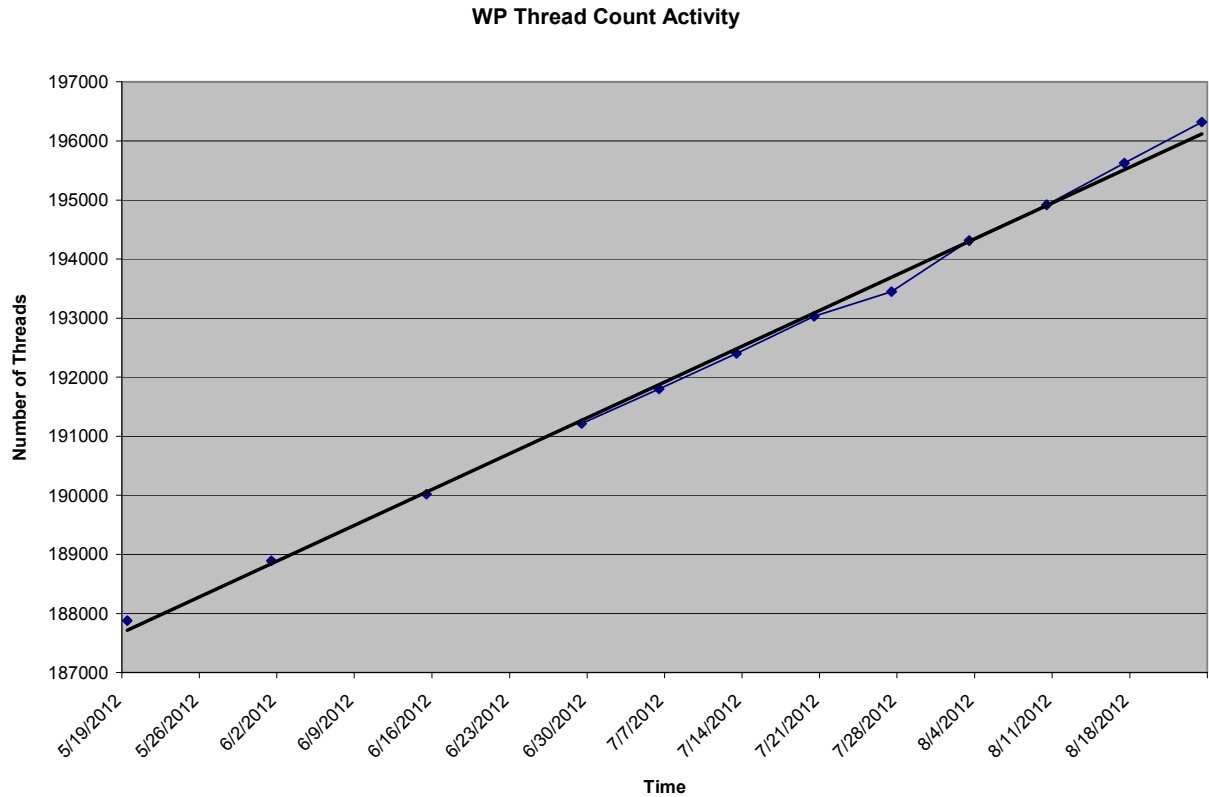
By comparison, the threads I analyzed from the website Aspiesforfreedom can be characterized as not being very popular. Thread 2 has the most unique participants with 16 participants contributing 20 posts.

The threads with few participants but having many posts are what I have termed "deep yet narrow" -- meaning that these attracted few participants engaging in a thoughtful discussion over many posts. The threads with many participants relative to the number of posts I have termed "shallow yet wide." These responses are often the result of the OP (original poster) asking the members a poll type question. An example of this is shown in thread 2 of Wrongplanet where participants are asked whether they would take something that would cure their autism if offered. The terms "shallow" and "deep" are not meant to connote value, but simply to be metaphoric in nature of the ways the thread developed. Of course, threads can be shallow and narrow, which would probably be threads with fewer than 10 posts (not included in my study). Threads can also be deep and wide, which could be what thread 6 on WrongPlanet website about socializing with LF [lower functioning] individuals with autism has turned out to be after the point I captured the data.

The activity among the two sites differed in amount, but both seemed to follow a predictable trajectory as shown in the following graphs. The first two figures refer to thread count and post activity respectively on Wrongplanet from May 19, 2012 to August 18, 2012 (98 days total). On May 19, 2012 there were about 188,000 threads on Wrongplanet. The values on the X-axis are dates (time), whereas the Y-axis represents number of threads on the first graph and number of posts on the second graph for the

entire website. Figures 3.7 and 3.8 provide the same information for the Aspiesforfreedom website.

Figure 3.5 Wrongplanet thread count activity over time



As mentioned previously, Wrongplanet is a more popular site than Aspiesforfreedom. Wrongplanet was created in 2006 whereas Aspiesforfreedom was created in 2004. Many of these threads shown above are long dead. However, new threads are constantly being created at a fairly consistent rate. The websites archive all posts on their sites making it easy for me to search back to the first post of each website.

Figure 3.6 Wrongplanet post count activity over time

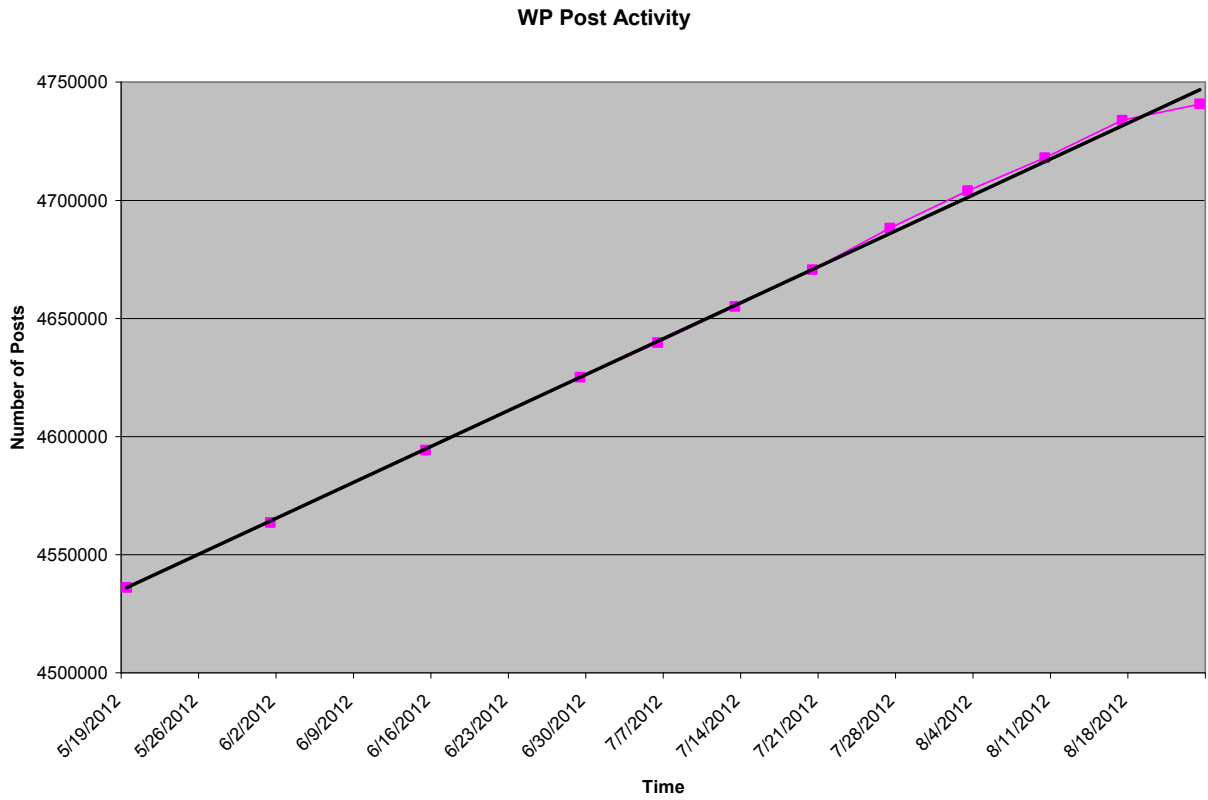


Figure 3.6 shows that the number of new posts is about the same at each week. This demonstrates that the site is still quite active and popular.

The next two graphs refer to post activity and thread count activity on Aspiesforfreedom from May 19, 2012 to August 18, 2012.

Figure 3.7 Aspiesforfreedom thread count activity over time

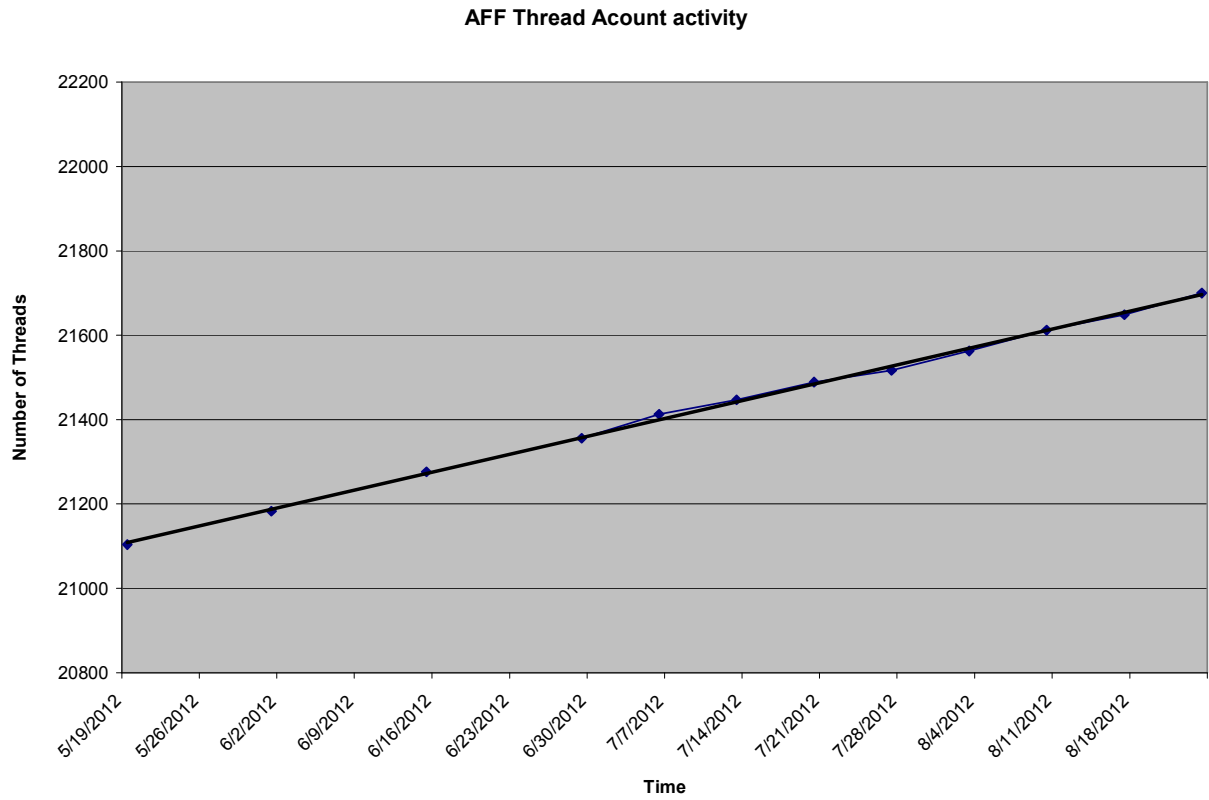


Figure 3.7 shows the number of new threads that have been created over time. Many of the threads that exist on Aspiesforfreedom are not active threads. However, new threads are always being added.

Figure 3.8 Aspiesforfreedom post count activity over time

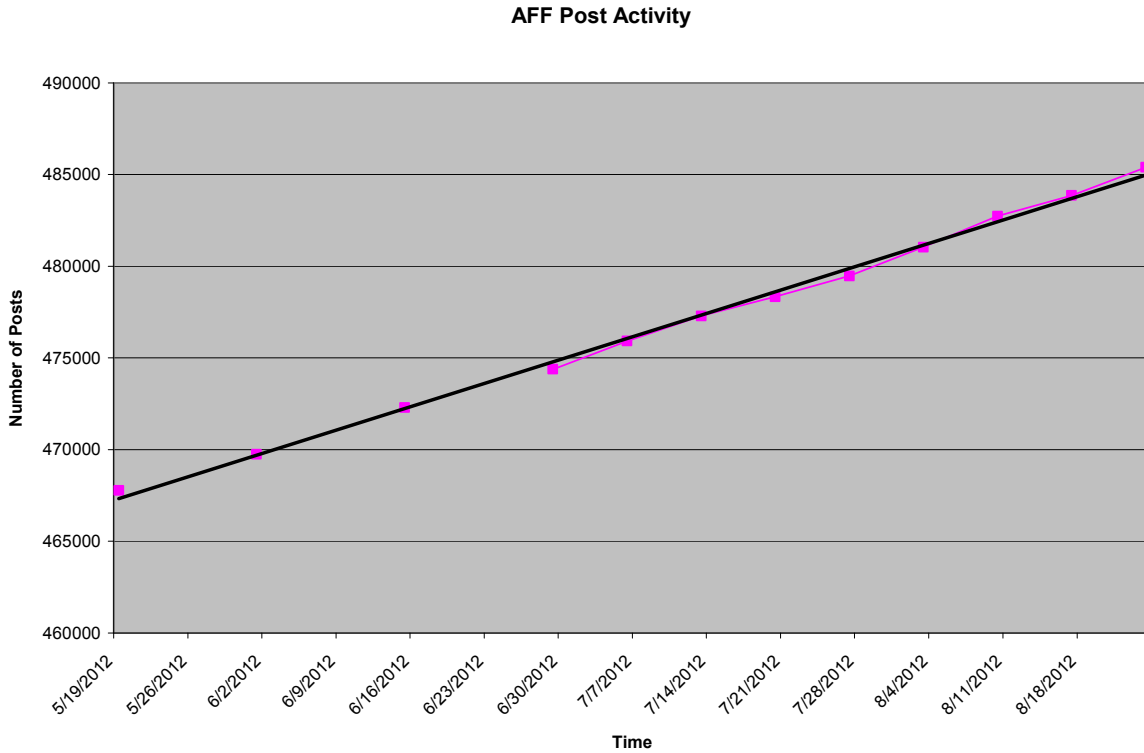


Figure 3.8 demonstrates that the site is still popular and active, as indicated by that fact that the number of new posts has continued to be about the same each week.

On August 18, 2012 the member count for WP was greater than 70,000 whereas AFF had a member count of 55,073 people. WP averaged 24 posts per thread; AFF averaged about 22 posts per thread, making them equivalent on that measure of activity. WP averaged about 2088 posts per day in the span of the 98 days, whereas AFF averaged 180 posts per day during the same time frame.

Timeline

In the fall (September to October) of 2010 I collected and analyzed the pilot data. I began phase 1 around July 2011 where I observed websites and picked a few that might be good for analysis. Later that year I eliminated threads that were too old and/or not active enough (>10 posts). Early 2012 I began analyzing the websites I had retrieved from the websites. This process reached a peak of activity during the summer and early autumn for about 5 months. This was around the same time that I began phase 2 where I introduced myself and participated in some discussions. Phase 3 came shortly thereafter. Here is where I coded all the threads I had picked for analysis and began my interviewing process around the 4th month. The characteristics that informed my choice for which threads to analyze was how recent the thread was, how many responses there were (activity) and whether the topic was interesting to me. I would pick a topic about job rejection over the finer points of how to cook a meatloaf, for example.

Chapter 4: Results

In this chapter, I organize my report of results in terms of the research questions..

Research Question 1

What are some of the topics that autistic individuals talk about online?

To address the first research questions, I analyzed the content of the threads on both websites. The topics ranged widely. Tables 4.1 and 4.2 present the titles of the different forums for both sites. For each, I have delineated different topic threads, including in the table threads that received more than 10 posts. This is not an exhaustive list of the forums or threads within each forum. These examples demonstrate the variety of topics addressed by members of these message boards.

Table 4.1 Wrongplanet forum topics

Forum title	Thread topics with sizable (>10) Posts
Autism Politics-Activism and Media Representation	<ul style="list-style-type: none">• Hidden Autistics;• Which one is more offensive? (Autism speaks 1 in 110 equating autism with cancer; autistics soaking 35 billion in funds worldwide)
Bipolar-Tourettes-Schizophrenia and other Psychological Conditions	<ul style="list-style-type: none">• What counts as intrusive thoughts?• Bipolar/Aspergers support and chat thread• Long-term side effects from antidepressants

Table 4.1, cont.

General Autism Discussion	<ul style="list-style-type: none"> • Autism in France Psychoanalysis, Packing, other travesties • autism reality documentary • first time in history the NT/AS open hotline
Getting to Know Each Other	<ul style="list-style-type: none"> • Post a picture of the real you • Map for all Earthbound members of WrongPlanet • Aussies Unite - A forum for any Aussie Aspies • The Dino-Aspie Ex-Café (for Those 40+... or feeling creaky)
News and Current Events	<ul style="list-style-type: none"> • Chick-fil-a and the homophobic sandwich • Olympics (Are you watching?)
Social Skills and Making Friends	<ul style="list-style-type: none"> • Friendship Board - Age 19 Onwards • Regional Meetup & Networking Thread Index • Friendship Board - Ages 15 through 18 • Has anyone else felt like social outcast/misfit?
Work and Finding a Job	<ul style="list-style-type: none"> • Finding and Keeping jobs - Tips and Advice • Screening for autistics? (and mental illness) psych test/job • Suggested/Not suggested Jobs for Aspergers.
The Haven	<ul style="list-style-type: none"> • Say something positive about yourself • Raves • Rants • Self-compassion - and getting better at it

Table 4.1, cont.

Politics, Philosophy and Religion	<ul style="list-style-type: none"> • Why is it okay for some vegetarians to eat fish? • [Poll] Is Economic Superiority Due to Cultural Superiority? • Is workable Communism really impossible?
Television, Film and Video	<ul style="list-style-type: none"> • My Little Pony: Friendship Is Magic. • What movies have you seen recently? • Make a random pop culture reference.

Table 4.2 Aspiesforfreedom forum topics

Forum title	Thread topics with sizable (>10) Replies
Autistic Pride Day	<ul style="list-style-type: none"> • I found where the “wear blue” thing came from and it ain't good • Pride?!?!?!?!?
Minority group status	<ul style="list-style-type: none"> • Declaring ourselves a minority group • Double-plus ungood. (Combating Autism Act) • Autism rights movement in a primary/secondary school!
General Research	<ul style="list-style-type: none"> • Poll: Alcohol for Autism • Adults with Autism - forgotten? • Cannabis / Marijuana, effective counterbalance • treatment?
Treatment in Society	<ul style="list-style-type: none"> • Tyranny of the majority, I tell ya! • A sick society • Anti-vax people annoy me • Why do Aspie Males Often Struggle With Dating and Relationships

Table 4.2, cont.

Support	<ul style="list-style-type: none"> • Positivity thread! • finding a thrill. • It's been nice knowing you guys. • are these statements indicative of mental illness? • depression possible. • help insects in my kitchen!!
Cooking	<ul style="list-style-type: none"> • Meatloaf • Anyone like sushi? • May the god of beef forgive me, for I have sinned
Misc interests	<ul style="list-style-type: none"> • Random Punctuation [sic] And Grammar • Is this an anomaly in the Pacific Ocean or a glitch? • Will anyone take LEGO donation? • Voyager spacecraft about to leave our solar system
Entertainment and Media	<ul style="list-style-type: none"> • Does anyone else find the Syfy channel sexist? • rate the last movie you watched • Doctor Who. • Sherlock Holmes- Aspie or not.
Action against pro-cure groups	<ul style="list-style-type: none"> • They're at it again...this time with the DSM-V criteria :(• If this cure is made... • NEED HELP - I'm under anti-vaxxer attack • What gay rights groups can teach us.
Activism discussion	<ul style="list-style-type: none"> • Autism Speaks, Our enemy (redux3) • Teaching self-advocacy classes. • Poll: February 18 -- "Day Without an Aspie" survey. • Contact the DSM-V Committee to Protest the Newest Changes

My next step was to take each thread heading from Tables 4.1 and 4.2 and to group the thread titles into categories as shown in Tables 4.3 and 4.4.

Table 4.3 ASD related thread titles grouped into categories

<i>Category</i>	<i>Threads</i>
Support	
Thread 1	It's been nice knowing you guys.
Thread 2	are these statements indicative of mental illness? depression
Thread 3	help insects in my kitchen!!
Thread 4	What counts as intrusive thoughts?
Thread 5	Bipolar/Aspergers support and chat thread
Thread 6	first time in history the NT/AS open hotline
Advocacy	
Thread 7	Hidden autistics
Thread 8	Declaring ourselves a minority group
Thread 9	Double-plus ungood. (Combating Autism Act)
Thread 10	Autism rights movement in a primary/secondary school!
Thread 11	Adults with Autism - forgotten?
Thread 12	Tyranny of the majority, I tell ya!
Thread 13	A sick society
Thread 14	autism reality documentary
Positive feelings	
Thread 15	Say something positive about yourself
Thread 16	Raves
Thread 17	Self-compassion - and getting better at it
Thread 18	Positivity thread!
Thread 19	finding a thrill.
Negative Feelings	
Thread 20	Rants
Thread 21	Pride?!?!?!?!?
Negative groups (e.g., autism speaks)	
Thread 22	which one is more offensive? (Autism speaks 1 in 110 equating autism with cancer claiming autistics soak up 35 billion in funds worldwide or the ones passing out information about myths and further information on human rights?;
Thread 23	Autism in France Psychoanalysis, Packing, other travesties
Thread 24	I found where the "wear blue" thing came from and it ain't good
Dating/friendship	
Thread 25	Post a picture of the real you
Thread 26	Map for all Earthbound members of WrongPlanet
Thread 27	Aussies Unite - A forum for any Aussie Aspies
Thread 28	The Dino-Aspie Ex-Café (for Those 40+... or feeling creaky)
Thread 29	Friendship Board - Age 19 Onwards
Thread 30	Regional Meetup & Networking Thread Index
Thread 31	Friendship Board - Ages 15 through 18
Thread 32	Has anyone else felt like social outcast/misfit?
Thread 33	Why do Aspie Males Often Struggle With Dating and Relationships

Table 4.3, cont.

Medicine	
Thread 34	Long-term side effects from antidepressants
Thread 35	Poll: Alcohol for Autism
Thread 36	Cannabis / Marijuana, effective counterbalance treatment?
Thread 37	Anti-vax people annoy me
Work	
Thread 38	Finding and Keeping jobs - Tips and Advice
Thread 39	Screening for autistics? (and mental illness) psych test/job
Thread 40	Suggested/Not suggested Jobs for Aspergers.

As shown in Table 4.3 and later in Table 4.4, the topics that these autistic individuals chose to discuss ranged from discussing the workability of Communism to discussing "meatloaf." There were many thread titles that were associated with advocacy for autistic individuals, support (whether seeking or providing) and friendship, which is not surprising given the titles of the websites themselves. *Aspiesforfreedom* implies that Aspies may not have enough freedom currently and are seeking it. The name *Wrongplanet* implies that the members of that board feel as if they are part of an "other" group. These feeling of not having freedom or of being on the wrong planet may be the reason that so many of the posts are about advocacy and trying to belong (support/shared identity/friendship). For example, under the *support* category there is a thread titled "it was nice knowing you guys." Upon further inspection, it would seem that the OP (Original Poster) of this thread wanted to be asked not to leave. (OP was the term often used on these two sites to refer to the person starting a thread.) This individual seemed to feel slighted by something or someone on the message board and was thinking of leaving. Not surprisingly many other individuals posted responses such as "don't leave" or "it won't be the same without you." This is why I grouped that thread under support. The preponderance of dating/friendship threads refutes the stereotype that autistic individuals are not interested in social activity, even if they may define "social activity" a bit

differently. For some posters, it may be enough just to know that there are other individuals out there who understand them.

One of the threads categorized under *advocacy* is titled "a sick society." The OP of this thread wrote about how the mortality rate for autistic individuals is between twice to 5.6 times the mortality rate for non-autistic individuals. According to this post, the causes of death that are not natural include asphyxiation, as the claim is that caregivers are abusing, and sometimes killing, autistic individuals and getting away with it. The poster provides links to relevant studies and warns the reader that the topic could be disturbing. I categorized this under advocacy because the thread read like a call to action to the individuals on the site. The OP wrote post #3 as a response to post #2 (which was from a parent) , which concluded with, "We have to start the education of NT's [Neurotypicals] from an early age."

It did happen as I read through the postings that a thread would change or shift to another theme or topic midway through the thread topic even though postings continued to be attached to the same thread. For example, in the AFF thread titled, "Rejected from a job and I have no idea why," some themes about office politics emerged. There were many posts offering emotional support, such as offered by one poster who wrote, "Sorry you did not get the interview." Many posts offered advice on how to market oneself to a potential employer. One poster offered an opinion of science professors as being rude and opinionated and therefore not worth the energy to join the "stagnant pool of bottom feeders who all agree with the boss." Later in the thread, someone cautioned the original

poster (OP) not to be too negative online because online postings may not always be fully anonymous.

The original topic did not always shift so dramatically. An example of a thread with no shift in topic occurred on the AFF thread titled “How did you feel when you first got your diagnosis.” Here, the main themes that emerged were "glad to have an explanation" expressed in four posts, and "like a freak" or some other negative self-label expressed in three posts.

The WP thread, “horrible thing said about autistic people on the news” had themes that diverged considerably from the original topic, namely the intelligence of Paris Hilton who was the person who supposedly had said the "horrible thing." There were eleven posts that questioned the veracity of the OP's story because the Paris Hilton story had not been reported anywhere else. The next most prevalent theme with six posts was the indication that the poster of posts 2 and 4 had fallen for "troll bait" (*Troll bait* refers to what a *troll*, or poster who is trying to incite a fight, writes on a message board to "bait" the others into responding). Five posts addressed Paris Hilton's intelligence attributing the lack of it to her drug use. There were other themes with fewer posts such as three posts each claiming that Paris should die, people's fascination with the lives of celebrities, and the dishonesty of the OP (perhaps trying to start a flame war). Toward the end, the thread turned into a discussion of how to tell when a poster is *trolling*, or inventing stuff to rouse the other posters.

Thus, an overall conclusion to Research Question 1 is that the autistic individuals who post to these two websites talk about a variety of topics, some of which directly

relate to autism, and these I am particularly addressing in my analyses. However, many of the topics addressed on these websites are simply general topics (See Table 4.4) that one might find on any website on individuals who somehow self-identify as sharing a similar interest or identity.

Table 4.4 General topic thread titles grouped into categories

Food	
Thread 41	Why is it okay for some vegetarians to eat fish?
Thread 42	Meatloaf
Thread 43	Anyone like sushi?
Thread 44	May the god of beef forgive me, for I have sinned
Politics/social studies/ current events	
Thread 45	Chick-fil-a and the homophobic sandwich
Thread 46	Is workable Communism really impossible?
Thread 47	[Poll] Is Economic Superiority Due to Cultural Superiority?
Entertainment	
Thread 48	My Little Pony:Friendship Is Magic.
Thread 49	What movies have you seen recently?
Thread 50	Make a random pop culture reference.
Thread 51	Olympics (Are you watching?)
Informational	
Thread 52	Will anyone take LEGO donation?
Thread 53	Random Punctuation And Grammar
Geography /Astronomy	
Thread 54	Is this an anomaly in the Pacific Ocean or a glitch?
Thread 55	Voyager spacecraft about to leave our solar system

Research Question 2

What evidence is there that autistic individuals create a “sense of shared community” online by their discourse practices (e.g., the way they use language, the way they post, time between messages)?

The second research question was addressed by examining how the language of posts was used, and other metrics such as the time between messages. In addition, sense of shared community might be detected by whether the postings on these two message boards in any way reflected several or all of the characteristics of an online community as delineated by Herring (2004). Thus I looked for evidence of active, engaged participation and a core of regular participants; some sense of cultural norms being developed, evidence of solidarity, support, and reciprocity, ways of managing conflict and resolving arguments; and self-awareness of the group as a special entity. Although Herring did not claim that all features of her scheme would need to be present in order for an online community to emerge, I was influenced by her suggestions as I coded the postings in my data.

On the Wrongplanet thread, “Total lack of encouragement for graduate studies,” there was considerable evidence of social support for the OP. For example, post #2 was posted only 34 minutes after the Original Post, and the thread received a total of 34 posts in three days. Many of the posts were from the same few posters, but there were also four posters who posted only once, whom I have termed “single posters.” There were three posts that addressed the OP in less than 24 hours. On post 15, the OP posted, “Thanks. I hope to get another research paper published in a slighter better ranked journal this year,”

which seemed to indicate that he or she had resolved the issue, and the topic did not need further discussion. There was only one post after that.

A different Wrongplanet thread called, "Telling teachers about your autism," received five responses within the first hour. Within a week, the thread had a total of 12 responses many of them from single posters. This thread did not elicit many responses, but soon after one week, there was a little series of exchanges between two of the posters. There did not seem to be much interaction, however, just the act of answering the question implies that you or someone close to you is on the spectrum. Even though this thread was short, just the fact that the OP received any responses at all was important to note.

A Wrongplanet thread, "Would you socialise [sic] with LF [lower functioning] autistic ppl [people]?", elicited over 100 responses. The first response was posted just five minutes after the OP, and there were 64 responses in less than one day from the OP. Although many of the participants differed on where they claimed to lie on the autism spectrum, they still shared the identity of being on the spectrum. This thread seemed similar to discussions around who is superior/inferior in a historically marginalized group. For example, gay men who are "straight acting" are often sought for companionship (if you read personal ads). Another example is the dilemma of value attached to the gradations of skin color among African-Americans, with light skin considered more attract by some.

From the Aspiesforfreedom website, there was a similar thread showing evidence of social support. From the thread titled "rejected from a job and I have no idea why," the first 15 (of 16) responses were posted within three days of the OP. These 15 posts came

from three posters, with the original poster contributing eight posts. The themes in the posts ranged from offering emotional support to providing suggestions for success next time. One example of a post that was both emotionally supportive and informative was from Frosty who wrote:

Sorry you did not get the interview. It is possible that the person/people who got the interviews were recommended by someone - I get the sense that those types of jobs are given to people who know someone or who even went to school there... more "known" entities. That said, I think any person who applies and finds out a job has been filled should do a follow up - and send a cover letter...

Another thread from AFF dealt with the issue of a separate space (Aspergia) for people on the spectrum. This thread received some early posts (8 posts in two days).

However, there was then a gap of 11 days before the OP responded to three of the previous posts, which then seemed to reinvigorate the thread. Diner quoted

Hulk Wrote:

Calm down dear, it's only a [tongue emplanted firmly in cheek] proposal...

Humans aren't wired for diversity. That's the biggest problem on your side...

Very few people, and none on this site (unless you know of any?), actually want a nation-state that is dominated by Autists. It's more of a symbolic protest. Sure, neurodiversity would be great, but you generally don't have any impact if you're dispersed. It's hard to explain my reasoning.

Not that I see anything wrong with seperation; you're the one honking the horn for diversity after all, and how does diversity arise?

Then Diner responded with:

What is the point of separation? Do you think you won't have problems with other being b-tchy or snotty if you're away from all the mean ole NTs? Emergency situation, abandon all NTs? :p xD It will be the same.. some people being b'tches. Just about different things than what they complain about (or, they may shock me by being complete hypocrites).. imagining an asprie circle of popular jerks at an all asprie school. Rofl.

There was a total of 15 posts in two weeks. Some themes that emerged included three posts calling *Aspergia* a “separatism” or "micronation" spawned through frustration over a lack of rights or as a symbolic protest. Four posts listed and/or agreed with the benefits of a separate nation as being a "safe haven from the rest of the world," as well as being a place where it might be easier to obtain gainful employment and to live independently and with dignity. In other words, the idea of *Aspergia* to many of the individuals in this thread was symbolic. Most posters expressed a desire to have a safe space to be themselves and to have more rights in the world at large.

In conducting axial coding, several themes emerged. There were themes relating to the function of the communication (e.g., self-disclosure, seeking/providing information, pro-social/politeness strategies, providing social support), as found, for example, in the thread about lack of encouragement for graduate studies. Table 4.3 illustrates how language was used (17 posts).

Table 4.5 Discourse practice used by posters for thread about lack of encouragement for graduate studies

Discourse Practice	No. of posts expressing this
Start thread asking for social support (OP)	1
Provide social support	12
Info seeking	3
Provide info	4
Self-disclosure	2

For the thread asking "Why do you have meltdowns?," the first 24 posts yielded the following responses (see Table 4.5)

Table 4.6 Discourse practice used by posters for the thread "why do you have meltdowns?"

Discourse Practice	No. of posts expressing this
Start thread asking for feedback (info seeking) (OP)	1
Provide social support (agree or disagree w/ politeness)	11
Disagrees w/o using politeness	3
Info seeking	8
Self-disclosure	8
Provide info	8

Tables 4.5 and 4.6 show that most of the posters in these two threads offered support, which is consistent with what the OPs [Original Posters] were seeking. The OP in Table 4.6 was seeking social support whereas the OP in Table 4.5 was seeking information. These practices suggest that there is pro-social behavior among the participants of these threads, which refutes the stereotype that individuals with autism do not experience empathy for others nor know how to socialize.

In the thread about how one felt upon receiving a diagnosis of autism, several discourse practices were shown (see Table 4.7 below; 20 posts).

Table 4.7 Discourse practices used by posters for the thread about getting a diagnosis

Discourse Practice	No. of posts expressing this
Start thread asking for feelings about Dx (info seeking) (OP)	1
Provide social support (agree or disagree w/ politeness)	4
Disagrees w/o using politeness	1
Info seeking	1
Humor	2
Self-disclosure	8
Provide info	5

In Table 4.7, the largest number of posters provide self-disclosure about getting a diagnosis. This suggests that individuals with autism are self-aware at least to the point of knowing how to self-disclose on a message board.

Table 4.8 Discourse practices used by posters for the thread about being rejected for a job

Discourse Practice	No. of posts expressing this
Self-disclose about not getting job; (support seeking) (OP)	1
Provide social support (agree or disagree w/ politeness)	6
support seeking	1
Humor	1
Self-disclosure	2
Provide info	7

As shown in Table 4.8, many of the posts provided social support and information support. There was some self-disclosure mostly coming from the OP.

Table 4.9 Discourse Practice for the thread about Aspergia

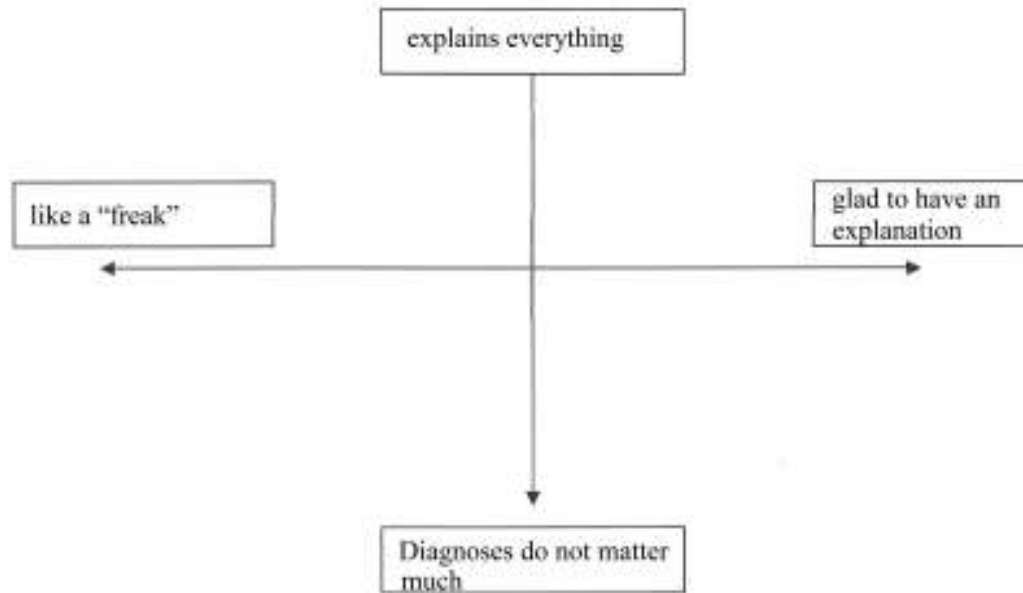
Discourse Practice	No. of posts expressing this
Self-disclose about not getting job; (info seeking) (OP)	1
Provide social support (agree or disagree w/ politeness)	4
Info seeking	3
Humor	2
Provide info	11

In Table 4.9, many of the posts provided information support. There was also evidence for social support postings, as well as information-seeking and using humor.

Tables 4.5 through 4.9 indicate that, despite the stereotypes often associated with autistic individuals, autistic posters are capable of communicating using the same discourse practices that non autistic persons might use. Of particular interest was the fact that many posters were able to use humor or politeness to calm everyone down to avoid what might have turned into a contentious online fight or flame war.

In addition to discourse practices, there were also topical themes that seemed to be at a more general level. Some included expressing emotions such as pride, sarcasm, humiliation, distrust, or dislike for doctors/researchers, and searching for one's identity. Finally the topic of the value of a diagnosis was a major theme among the postings. In the thread about how individuals had felt upon receiving a diagnosis, axial coding was used to consider two opposing yet common themes. (See Figure 4.1)

Figure 4.1 Range of responses after getting a diagnosis



Several posters had very strong opinions about their experiences of finding out that they had an ASD. Most seemed glad to have an explanation, but there were a few who felt worse about themselves after hearing of their diagnosis, as shown in the figure above. An example of an individual who felt that the diagnosis explained everything and was glad (among other emotions) to have a diagnosis is shown by Dylan who wrote, "I started sobbing. I was relieved and angry, overwhelmed, excited, giddy, sad... It explained EVERYTHING. The following weeks were rife with 'aha' moments. I had felt like an enormous failure my entire life. The diagnosis was validating."

In reference to the thread about an autistic separate space (Aspergia), a few themes emerged from axial coding that I symbolized in the following figure (Figure 4.2).

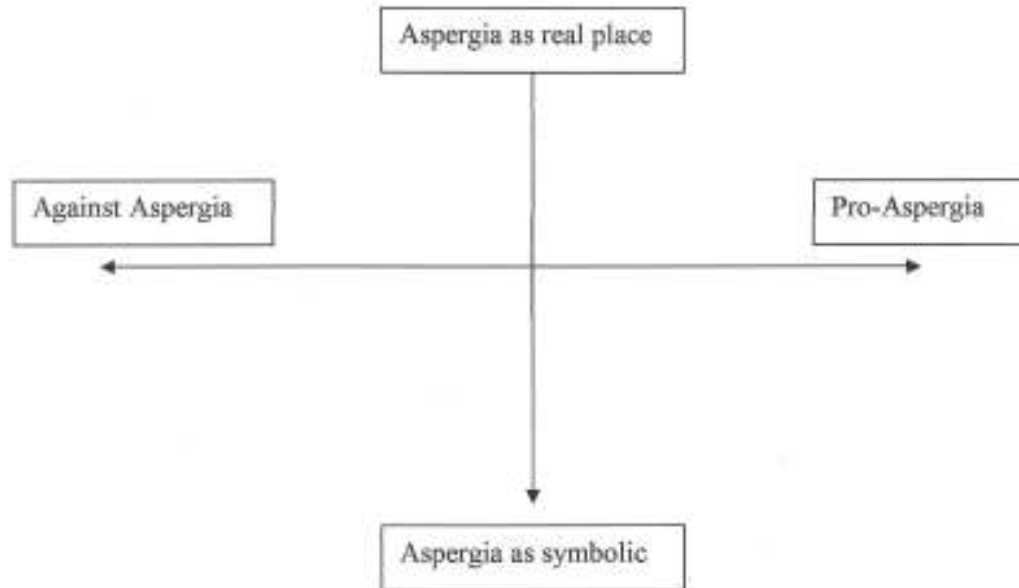
Some posters thought of Aspergia as being a real place whereas others conceptualized it as being metaphorical. Some posters saw Aspergia as negative because it encouraged separatism, which they saw as being opposed to the idea of Neurodiversity. Others thought that a place that was designed with individuals with autism in mind would be a safe haven. An example of an Against Aspergia, and Aspergia as a real place is demonstrated in the following post by twins:

The big benefit I think we can gain from talking about Aspergia is the knowledge that an all autistic nation would collapse on itself in a very short time. If we assume that all the world's autistics were living there, the rest of the world wouldn't last much longer.

This poster seemed to view Aspergia as untenable because without all the autistic individuals in the world, the Neurotypicals would suffer. A moderately pro Aspergia, and Aspergia as fantasy is shown in the following post by El:

I think it is more a fantasy. It is just impractical to have an aspie country, town or even apartment complex. There could be an aspie retreat or coop but funding is just too much money. It is more an expression of why aren't people getting rights and maybe they need a revolution. It is really that people need to feel more accepted and getting what they need.

Figure 4.2 Range of responses on whether Aspergia is a real place and whether it is a good place



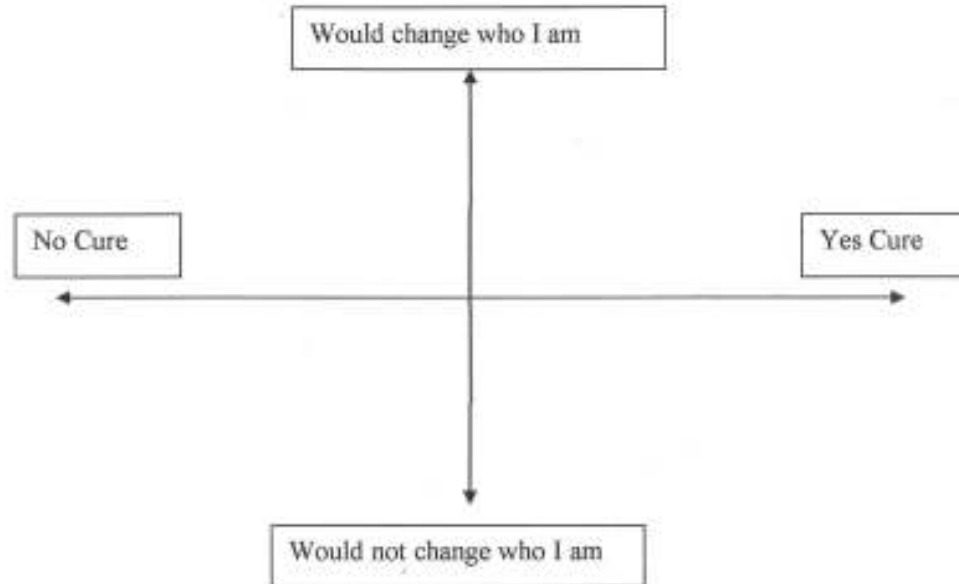
In the thread about whether an individual would “take a cure” if offered, the following themes emerged the most often (See Figure 4.3). The cure/no cure debate seemed a common occurrence on these websites and also seemed to be a topic that incited emotional responses. I attribute that to being such a core question about one's identity. Some individuals stated they would take a cure only under certain conditions; therefore these individuals could be plotted on the graph as being between the "yes absolutely" or "no, never" ends of the spectrum. One example of a post that demonstrates a Yes cure, but would not change one's identity is in the following:

Absolutely [would take a cure if offered]. I see a lot of people who say that they wouldn't necessarily want to change who they are, but I don't think there is anything special about who I am--if anything, it just causes a lot of problems for me. If a cure for AS could help me live a more fulfilling life, with friends and a job and some independence and such, then why not?

This poster did not seem to attach much value to having an ASD identity, and therefore he or she seemed more ambivalent about whether a cure would change who a person is. This next example illustrates posters with the view that they would not want a cure (the more common view) and it would change who they were. Benjamin wrote:

No... Because I am very happy with who I am at the moment, and I feel a cure would change that, and take away a lot of my personality. Also, a lot of positive things are coming out of the fact that I do have AS. I'm not saying it's all good, having it. It isn't. But nor is it all good being NT. But I can only speak for myself.

Figure 4.3 Range of responses about what a cure would do and whether or not a cure is good



I conducted four interviews with two participants from Wrongplanet and two from Aspiesforfreedom for the purposes of member checking their posts to the message board as well as for getting their thoughts on such concepts as Neurodiversity. These first two interviews were from members of WP and happened early on in my study, before I was prepared to capture their exact words. At the time of these interviews, I was

barely entering my Phase 2 where I introduced myself to the message boards. I conducted the interviews by private messaging and email.

The first interviewee was a 50 year old man who was diagnosed with autism at age 42 after having been misdiagnosed with ADD, ADHD, avoidant personality disorder, and dysthymia, since childhood. When I asked him what the “online autistic community” meant, he responded that the Wrong planet forums had been his lifesaver. This aligns well with the theme that it is more important to have common interests with someone than whether an individual was lower functioning, or higher functioning. In his case, the common interest was talking about autism.

The second interviewee was a 63 year old male college graduate who had self-diagnosed his condition using online tests six months earlier. I asked him what "online autistic community" meant to him, to which he replied that it was a good thing for a variety of reasons, including that having such a community allowed for dissemination of information and the ability to connect to others who seem like one's self. This also aligns with the theme of wanting to socialize with individuals having common interests, which in this case, is talking about autism via the message board. This poster also appeared to be experiencing a sense of shared community when online.

I also interviewed *Medium* [not her real online name] a 50 y/o woman diagnosed as autistic at age 45 who was from Australia and had been a member of AFF for about five years. Some common themes emerged during the interview, such as that the Neurodiversity movement seemed good for raising awareness in the greater community, and AFF was a good website toward that aim. Like many regulars on the message

boards, she found it comforting to know that there were others like her who did not "fit in with the rest of the herd." This aligns with the theme of finding like-minded individuals with whom to socialize and is similar to the feelings expressed when autistic individuals received a diagnosis, feelings of relief expressed by many individuals (interviewees and posters) when they had received their diagnosis.

Research Question 3

In what ways do autistic individuals participate in self-advocacy? What are the common themes in the posts related to self-advocacy?

In answering Research Question 3, I looked for ways that posters on these two websites actively embraced the idea of *Neurodiversity*. Recall that *Neurodiversity* can be defined as the acknowledgement that there is more than one way to think, and that a person who might be called *disabled* may actually have a different or superior way of perceiving and making sense of his or her environment. Although my usage is primarily with regard to autism, the word *Neurodiversity* was coined in 1998 by Blume to describe the neurological diversity of autistic, dyslexic, and other individuals with major differences in cognitive processing.

In examining the message board threads, several themes emerged that were related to self-advocacy. Additionally, self-advocacy has taken many forms. One poster self-advocated by educating individuals in his college classes about autism. Another poster reported the creation of a video of how autistic individuals were being mistreated in France. The creation of the two websites that I studied is also an act of self-advocacy. Finally, the thread about interacting with LFA's addressed important issues of difference within the autistic community.

An example of a thread about self-disclosure of one's autism in college settings, is shown in the following. Responses claiming that disclosing should occur on a need-to-know basis was common. As one poster stated, "I also told professors for whom I needed

to get accommodations. But there were a lot more professors who never knew than who did know. I basically tell my diagnosis as a need-to-know basis.” This tactic of using a "need to know" basis for self-disclosure was endorsed by many posters. However, some posters wrote they used their diagnosis as a vehicle for educating others. For example, one poster used his diagnosis in school as a means to dispel myths about autism when he, “wrote a paper for another of my classes speaking out against the autism stereotype.” Some of the posters indicated that they were afraid to tell or did not feel that it is necessary. Most posters seemed to take the issue on a case-by-case basis. Some posters expressed regret in disclosing their diagnosis because their professors then treated them as if they were slow in learning and understanding. One poster described her experience in the following way

Yup I've learned my lesson. One of my professors was lucky that I didn't smack her, she tended to treat me like I was the slowest one in the room...Then her theory was disproven when I was the only one to get an A on the first quiz. The look on her face was the best moment of the semester.

The reported negative outcome after self-disclosing justifies in part for how careful some individuals were in deciding whether to disclose or not.

One topic on the Wrongplanet website under the “General autism discussion” heading had the following title, “Autism in France: Psychoanalysis, Packing, Other Travesties,” posted by the site's founder. The thread had a link to an article and a call for action:

What can we do about it? It is time to say “enough” to France, which has been already condemned by the Council of Europe in 2004. Even though 2012 has been

declared the year of National Attention for Autism by the French Government, no real decision has been made to stop abuse.

The site's founder posted a video about “autism reality” that included his observation that people with autism who cannot speak can write with depth and intelligence as evidenced on his website Wrongplanet. At the end of the video, he said, “Autism is not a bad thing or a good thing. It's just a difference. And I think once society starts seeing it that way, we're going to be in a better place.” That attitude seemed to be very common among the posters on his site. Although a few individuals with autism claimed superiority, most individuals on the spectrum simply wanted their differences accepted without a value attached to it (good/bad) as I attempt to demonstrate in the following analysis.

The WP thread “would you socialize with a LF [lower-functioning] autistic people?” elicited many responses from a large number of posters, with a few posters submitting as many as eight total posts. There was only a five-minute gap from OP and the first response. Within the first 24 hours, there were 64 responses to the OP. In this particular thread, respondents quoted (capturing the words of a previous post) often and quoted others' quotations to the point that it became difficult to follow. The overarching theme was that it is more important to have some common interests with someone for the purposes of socializing than whether a person is labeled LFA [lower functioning autistic], or HFA [higher functioning autistic].

When one poster referred to LF autistics as “retards,” many posts chastised him for using such language. The topic of the thread threatened to be hijacked, as a lengthy and humorous discussion followed about whether the avatar of the offending poster should include fangs because of his use of inappropriate language. Another poster

questioned whether a LF autistic would even want to socialize with him, thus questioning the very premise of the OP. One poster stated,

Depends on the person, actually. Being severely disabled doesn't necessarily mean being extremely introverted. So you might meet somebody who can't use language at all but still wants to interact with people, or someone who's highly verbal and talks like a book but is so introverted that they don't ever initiate contact. It's really a matter of stereotypes. People like Autism Speaks are perpetuating the idea that autism means you're a hopeless case, and telling the world that autism is always this huge stereotypical thing...I guess it all comes down to: Don't make assumptions based on what category someone's been shoved into. Get to know them for yourself before you decide. Knowing somebody's been labeled "LFA" tells you nothing other than that somebody, at some point, labeled them that way.

This poster questioned the utility of labels and the accompanying stereotypes. Specifically, he advised that it is wise simply to know someone well before deciding on whether or not to be friends. According to this poster, a label should not be used to make a decision without getting to know the person. One poster likened the LFA/HFA debate to the cure/no cure debate, stating that many In Real Life (IRL), Aspies (HFA) turned out to be jerks, and he stated a wish that there were more people who functioned like he does.

Another poster remarked that except for extreme examples, it was intriguing how similar LFA and AS/HFA individuals were in their sensory and “stimming” [self-stimulating such as finger flicking] issues. Some debate occurred about whether dealing with LFA individuals is easier than dealing with the “mind games” of NTs [Neurotypicals]. Later in the thread, someone likened the person who made the “retard” comment to "a famous German with Asperger's" referring to Hitler. This statement prompted a new discussion around Hitler and whether the linked article was

in German or in a Scandinavian language. Some posters expressed that they preferred to socialize with lower functioning individuals for reasons such as curiosity, and lowered expectations of social reciprocity and of words.

Two posters related a story about being out in public and being mistaken for belonging to the “group home people” (e.g., LF). Another poster expressed sadness that some individuals with LFA are hidden away because, “They're people, too, and we miss a lot” [by not having them available to socialize with]. Another poster responded to the hiding away of those diagnosed as LFA as evidence that NTs need to adapt a bit so that they can have individuals whose behavior can be challenging rather than having it always that those with ASD [autism spectrum disorder] must do the adapting to fit into a "Neurotypical" world.

A few parents who posted on this site related stories of trying to socialize with their own children. One anecdote about a conflict on the playground elicited quite a few responses about whether the parent had handled it well. This exchange indicated that parents were/are welcome to post to this site so long as they are accepting of those with ASD (not “curebies”).

Another form of self-advocacy is acknowledging the benefits of being autistic. This Neurodiversity viewpoint is shown in the following WP thread.

On the thread titled, “If there was a cure to autism would u” there was a lively discussion around identity and autism. Nine posters flat out stated "no," they would not like a cure. Sixteen people said no but added that a cure would mean changing

who one is and losing other positive attributes that autism can afford an individual (e.g., "love unique view of life and being easily entertained by one thing for hours"). There were nine posts from individuals who said that they would take a cure if it were safe and met certain conditions. One poster said, " If there was a cure it should be optional, but at this point, I think my answer is YES. I'm completely sick of constantly struggling and spending my life in utter confusion."

There were eleven posts bemoaning the cure/no cure debate as being too simplistic, annoying, and loaded. Seven posts expressed agreement that the focus should be on how to gain acceptance in society and how to deal with prejudice. One poster wrote, " Not really. If anything NT's should be cured. I mean this in all seriousness." Six posts said that a cure via ABA (ridding of symptoms) does not rid the individual of autism or of the gene that might be passed on to the next generation. And there would still be the memories of being an Aspie that could still exert influence. Four posts simply stated in one way or another that being normal is boring.

Overall, there was evidence of self-advocacy with many respondents stating that they would not take a cure for autism were it offered to them. Some posters wrote that they would take a cure but only for practical reasons (e.g., medications are expensive, job are hard to find with ASD). The question of cure stimulated many responses. One poster responded to the unpopular notion of taking a cure stating, "You're not the only one who'd take a cure, you're just probably the only one who's said so on this thread. These threads [about taking a cure] pop up from time to time and a lot of people are probably

sick of them.” The common theme associated with not taking a cure seemed to say that to be rid of one's autism is to change a person fundamentally. Most of the individuals who responded indicated that they liked who they were, autism and all.

Table 4.10 List of Threads by title and Research Question

Thread Number	Title	Shared Community (RQ2)	Self-Advocacy (RQ3)
WP 1	horrible thing I heard on the news	No	Yes
WP 2	if there was a cure to autism would u?	No	Yes
WP 3	telling teachers about your autism	No	Yes
WP 4	total lack of encouragement for graduate studies	Yes	No
WP 5	why do you have meltdowns	Yes	No
WP 6	Would you socialise with LF autistic ppl	No	Yes
AFF 1	Rejected from a job and I have no idea why	Yes	No
AFF 2	How did you feel when you first got your diagnosis	Yes	No
AFF 3	What is this Aspergia thing?	Yes	No

Table 4.10 shows all the threads I have analyzed related to Questions 2 and 3. The post counts range from 10 to 111 posts. Shared community was ascertained through the use of discourse practices such as how many times individuals responded to a post, the time between posts and how language was used to indicate a sense of shared community. The "yes" and "no" represent whether that research question was answering in that thread.

The result of triangulating the data by interviewing members of both message boards is shown below. As an example of shared community, interviewee Medium, concluded her correspondence to me by writing,

So I really believe that for humans to become something more than merely a more sophisticated version of a herd of cattle, we need to embrace all forms of Neurodiversity. My biggest fear, and that of many of the people who post on the AFF site, is that the genetic basis we feel is at the core of autism will be identified and then foetuses regularly tested for, and aborted if they are found to be Autistic. They want to get rid of people who are "not like them", but that would also prevent the next Einstein or Newton, for example, being born. Which would be a great tragedy, not only for Autistics as a community, but the humanity as whole.

This poster's writing has elements of advocacy for autistic individuals, perhaps at the self-advocacy level.

I also interviewed *Paging*, a 21 y/o man diagnosed at age 8 or 9 who had been a member of AFF on and off for five years. Some themes that emerged during the interview include, Neurodiversity as self-advocacy, his role as contributor and helper on the AFF website, and how his "strange behaviors" had led to his diagnosis.

As for his self-advocacy, he wrote that he would speak up on forums that excluded autistic people (e.g., twitter's #AutismChat that has no autistic people as "experts"). He also had formed the Freak Liberation Front Facebook group, which had grown to include dozens of people from around the world. Freak Liberation is a concept that includes Neurodiversity, mad pride, and disability rights, among other related movements and ideas. Individuals in the group "seek to re-appropriate the word 'freak' in

a positive sense." For this individual, self-advocacy was very important. And as is quoted below, he was interested in a semi-separatism as a means of creating safe spaces where autistic individuals can be themselves fully. He credited ASAN (autistic self-advocacy network) with helping the cause, but because he lived in a rural area, he saw change as slow. He wanted to convert all the great ideas from the message boards to action such as the building of supportive institutions. On 04-24-2012, he wrote,

What we should discuss, and what is being discussed, is a form of 'limited' separatism. By this we mean, the creating and maintaining of spaces, communities, and institutions, defined and controlled by and for autistic people. Aut separatism means social clubs and safe spaces run for and by us. It means peer-support mental health care, sensory-friendly study and social space, and aut-run intentional communities. It means defining our collective space together, for and by ourselves, and asserting an identity and solidarity based in our shared experiences and needs. Separatism exists within, or 'near to', the hegemonic and ableist society, but separates itself from the fundamental assumptions and norms underlying that society. Aut separatism means creating aut-centric spaces, both physically and socially, in which our needs and perspectives are not simply accommodated, but affirmed and made the normative standard."

I responded,

Did you mean to say that pure separatism isn't desirable because it deprives us of what the greater society can offer. However, a semi-separatist state in given circumstances might be desired so that particular sensitivities and proclivities can be accommodated for? Perhaps if the disease model of autism spectrum disorders were replaced by a more inclusive view (e.g., embracing diversity of all sorts) then separate spaces wouldn't be needed? Or not needed as much as some people argue for? What do you think?

He seemed to agree with my interpretation. Then he responded with,

I believe that pure separatism is undesirable and unrealistic. Building a society is difficult, and we are not going to move off into the woods somewhere and forge one, as tempting as some find that. It is unlikely. I do not endorse the idea of Aspergia the homeland because it is utopian...I believe that NT allies can change the conversation in autistic spaces, and can assert their own privilege and dominance. The GLBT community, the feminist movement, the black liberation

struggle, and other movements against kyriarchy have used safe spaces. I believe we should explore this option for the neurodiversity movement, as well. Having more accommodation and more understanding would reduce the need for these, but at the end of the day, no matter how well NTs seek to accommodate me, many of us will always feel out of place, Other-ed, and alienated. Navigating NT spaces is exhausting, and likely always will be- for this reason, I feel there will always be a need for spaces defined for and by us.

In general, the themes from the message boards aligned with some of the themes from the interviews. Most particularly, the feeling of relief upon finding other autistic individuals online seemed similar to the relief that some individuals felt when they received their diagnoses. I also thought that it aligned with the theme of finding similar individuals with whom to socialize. Self-advocacy was a theme that was common to the interviewees and the message boards.

As a last point, I want to note that my first two interviewees agreed to participate even before I had asked them to. The second two interviewees were very excited about my research. The last one, Paging, expressed gratitude that someone in my position would do this sort of research.

Chapter 5: Discussion

In this chapter, I will address the following four topics. First, I will discuss my findings and relate them to the existing literature. Next, I will identify the major limitations that constrain the generalizability of my study. Implications for practice or how my study can inform practitioners will be explored in the third section. Finally, I will provide ideas for further research.

Findings Connected to the Existing Literature

Far from the notion that individuals with autism are not capable of meaningful communication and building community, autistic individuals in this study, representing those who choose to participate in an online forum, were seen to have successfully created community and to be able to self-advocate. Several themes emerged from the data. The next few paragraphs provide examples of the types of topics that the participants chose to talk about online. Many of the threads that were analyzed showed one or more of Herring's (2004) criteria of an online community:

1. Active, self-sustaining participation; a core of regular participants
2. Shared history, purpose, culture, norms, and values
3. Solidarity, support, reciprocity
4. Criticism, conflict, means of conflict resolution
5. Self-awareness of group as an entity distinct from other groups
6. Emergence of roles, hierarchy, governance, rituals (p. 355).

Evidence of Herring's (2004) criterion #1 of active, self-sustaining participation and of having a core of regular participants can be seen in the post count of the individual posters on the threads I analyzed. On Wrongplanet, individual post count ranged from 2 posts to 36,700 posts for one person. The average number of posts for those who participated was 2628. However, because there were a few *extremely* active posters mean is skewed toward the larger side. A more appropriate statistic is the median for WP [Wrongplanet] was 770 posts per individual, and for AFF [Aspiesforfreedom], was 713 posts per person.

Herring's criterion #2 of an online community having a shared history, purpose, culture, norms, and value is demonstrated in the Wrongplanet thread, “would you socialize with LF [lower functioning] autistic people?,” a thread that elicited 111 responses. The overarching themes were that it is more important to have some common interests than whether a person is labeled LFA [lower functioning autistic], or HFA [higher functioning autistic].

The same thread also showed evidence for Herring's third criterion, which is solidarity, support, and reciprocity. There was only a five minute gap from original post (OP) to first response. Within the first 24 hours, there were 64 responses to the OP [Original Poster]. This quickness to respond shows reciprocity, particularly because respondents quoted each other's posts often and quoted others' quotations. Another thread showed evidence of Herring's third criterion. When a poster was trying to understand why he did not secure a job, he seemed to be participating in self-advocacy in

asking for help from other posters. The poster also was showing participation in a shared online community as shown from the exchange below.

Legend Wrote:

Frosty Wrote:

Legend Wrote:

Yeah, my brother tells me not to burn bridges all the time too. On reflection I think it was a blessing in disguise. It means now I'm focused on trying to get a job in Taiwan.

I can't help but think that this is a small world and in your "field" even smaller and anyone doing a search of LSE London school... MIGHT actually find this thread - and then they might be able to tell it was YOU who posted etc., and then you would never get a job there even years later-- (overreacting? paranoid? private.. I think just careful)

(I feel like you should ask to take the NAME of the company you applied to away ...)

You have to be a member of the forum to read this thread, so it won't be a problem.

During this exchange, the poster named Legend had an *expectation of privacy* that Frosty warned against as Walther (2002) reminded it is "extremely misplaced" (p. 207) to expect such privacy. In this posting, I see evidence also of Herring's second criterion of shared history, purpose, culture, norms and values.

Another theme frequently discussed involved viewing autism as a difference rather than a deficit. In fact, one of the main ideas of the Neurodiversity movement is that autism is to be seen as a legitimate way of being rather than as a disease that needs a cure. The Wrongplanet thread titled, "If there was a cure to autism would u" prompted a

lively discussion about identity and autism. Many posters responded with a plain "no" to the question. Most interesting was the notion that to take away the autism is to take away part of one's identity. Many posters saw the two as inseparable. Others were annoyed at this topic being brought up again and again as it tends to stir controversy.

The WP thread "horrible thing said about autistic people on the news" had themes that considerably diverged from the original topic. As mentioned previously, there were eleven posts that questioned the OP's story because it was not reported anywhere else. The next most prevalent theme with six posts discussed whether some posters had fallen for "troll bait." Trolling is defined as the action an individual engages in for the purposes of passing "as a legitimate participant, sharing the group's common interests and concerns" (Donath, 1999, p. 45). Ganging up against the troll shows group solidarity, with the troll seen as an outsider trying to stir up controversy. This falls in line with Herring's (2004) fourth criterion of online community which is criticism, conflict, means of conflict resolution.

As mentioned earlier, there was much evidence that autistic individuals create a sense of shared community. This self-awareness as a group that is distinct from other groups meets criterion #5 of Herring's criteria for online community. The best example can be seen in the thread about Aspergia with its indication of a desire to have rights by establishing a separate space (Aspergia) for people on the spectrum. Some themes that emerged include three posts referring to Aspergia as a separate place or "micronation" spawned from the frustration at a lack of rights or as a symbolic protest. Most posters expressed a desire to have a safe space to be themselves and to have more rights in the

world at large. The fact that there are autism-run websites proliferating seems to provide some individuals with autism a safe space to be themselves just as Dekker (2004), an adult with HFA (high functioning autism), meant when he said, "The Internet is for many high functioning autistics what sign language is for the deaf" (pp. 1-2).

In the same thread, one poster referred to LF [lower functioning] autistics as "retards" and was quickly chastised for using that language.

Popeye wrote:

Last time I checked, people with average or above-average intelligence typically don't like interacting with retards. I don't see how it'd be any different within the autism spectrum. Or the "purple people eater spectrum", for that matter.

dragon wrote:

WOW - maybe you ought to photoshop some fangs on that ultra cute bunny icon there, ... At least everyone would have a fair idea of what they're in for...

My kid learned that using the word 'retard' was considered bullying in kindergarten...

According to Pfaffenberger (1996), the poster could have said "retarded persons" and still voiced his opinion that he did not want to socialize with Lower Functioning Autistics (LFA). The fact that the group was so quick to correct him showed that there were norms of speech within the message board group that needed adherence. Also, Popeye was acting against the norms of the group, which is an example of a poster not conforming to the norms of the community. According to Herring (2004) *Netiquette* encompasses a moral and political dimension. The rules of netiquette vary according to the values and judgments of the groups of users. Using this interpretation, there might be websites

where posters would not mind the word *retard*, but Wrongplanet seemed not to be one of these namely because one of the site's purposes is to question stereotypes about disabled (more specifically autistic) individuals. A site with such a purpose would not likely have the word *retard* in its list of acceptable language. In addition to exemplifying criterion #5, this example also seems to meet the criterion of conflict resolution (criterion #4). It also seems to provide evidence that there are certain rules and a hierarchy (criterion #6). Posters who have posted many messages over a lengthy period of time are given more credence than posters who post once or twice, and in this case, seem only to want to stir up controversy.

It seems clear from the above examples that autistic individuals do, in fact, create community and participate in self-advocacy online. This study is important because there exist many prevailing stereotypes about individuals with autism and what they are capable of achieving. One such stereotype is that they are not interested in social interaction. My study disputes such a claim, at least for those individuals who participated on the two message boards I studied. Another stereotype is that individuals with autism cannot communicate well with others. Again, this is not true. In fact, many of the individuals with autism online seemed to wish nothing more than to be accepted as they are with their limitations and their strengths. Most of them believe that autism is not a disease to be cured, but a difference to be accepted, maybe even celebrated.

Many of the stereotypes exist from observing *children* with autism who seem different from *adults* with autism. Unlike the children, the adults may have had the chance to learn how to adapt to their environment. As mentioned previously, a Google search of the terms *autism treatments* yields many more entries, more than two million,

than the search *autistic adults* which yields about 1/4 million, suggesting that there exists much more information about treatments for autistic individuals (usually referring to children) than about adults per se. It is only relatively recently that attention to the case of the autistic adult has become more popular.

Historically, diagnosis of an autism spectrum disorder (ASD) typically occurs before the age of three. In fact, it has only been recently that diagnostic measures have been developed to diagnose autism in adulthood (e.g., AQ and DISCO) (Leekam, et. al, 2007; Ben-Sasson, et. al, 2009). In order to receive a diagnosis of autism, one must exhibit a series a behaviors that began in childhood. My study demonstrates that autistics have not vanished from the earth once they become adults. To the contrary, there seems to be a thriving online community of adults with autism who wish to be heard and taken seriously.

Synthesis across research questions.

Upon cursory analysis of the threads categorized under Support and the threads categorized under Advocacy (See Table 4.3), I noticed that the discourse used in the Support threads tends to be more polite and emotionally supportive whereas threads categorized under Advocacy employ much more information sharing. Some threads had become emotionally heated. Although my quick analysis is suggestive of some interesting insights regarding some connections across the three research question, I leave it to future research to explore this relationship more fully.

What one can conclude about the online community building is that individuals with autism who participated on the two message boards discussed topics that were

related to ASD as well as topics that were mundane and everyday. Some posters employed politeness strategies and humor particularly when dealing with a difficult topic. There is evidence of self-advocacy in many of the posts. One theme that stood out is that these individuals wanted to be treated with respect particularly with regard to whether they receive treatment or not. They expressed wanting a voice in the conversation about autism. Some individuals seemed to want to be a collaborator in their education and job prospects. Their comments could be interpreted as expressing that they recognize that they have challenges, but many individuals on the boards felt as though their unique characteristics (e.g., extreme attention to detail) are strengths to be nurtured rather than deficits to be ameliorated.

Many individuals on the boards expressed a desire for friendships and relationships. Some individuals seemed quite interested in cultivating romantic relationships, and many individuals on the boards seemed interested in contributing and being part of a greater ASD community offline, as evidenced by posts expressing a desire to meet in person at ASD retreats.

Limitations of the Study

All studies have characteristics that limit generalizability. Mine is no exception. The participants in the study will not represent every possible way to be autistic. My study was designed to examine the community building and communication style of autistic individuals who participated on one or both autistic-run websites Aspiesforfreedom and Wrongplanet. No attempt to generalize to all autistic individuals was made.

Another limitation is that participants were selected by their self-proclamations of an autistic identity on a relatively anonymous forum. However, based on the degree of their commitment to the boards, one can confidently surmise that they are sincere. This self-selection of participants to communicate via message boards limits generalizability by design because it only examines those autistic individuals who participated on message boards, limiting the generalizability so as not to include all autistic adults.

Another limitation involves the difficulty I had securing participants who were willing to be interviewed separately from their online presence to triangulate the meanings of their online communications. This is a common difficulty in research, but perhaps more so given the population I was studying. Reflecting back, I see that I could have started a thread soliciting participants, but then I would have had to start a second thread. I wanted to keep from influencing the threads so I limited myself to just one thread creation which was the one where I introduced myself.

Implications for Practitioners

This study will contribute to a deeper understanding of autism by demonstrating how autistic individuals communicate online. There is an increasing number of college-bound young individuals with ASD (VanBergeijk, Klin & Volkmar, 2008). My study demonstrates that there exists a group of autistic individuals who communicate primarily online and who might benefit from an alternative method of educational delivery. By analyzing patterns in the ways in which the message board participants choose to express themselves, a curriculum could be designed to capitalize on the strengths of these autistic individuals rather than trying to force them to conform to traditional forms of educational delivery that only showcases their weaknesses.

Individuals with Autism and College. The first autistic children who received services as a result of the Americans with Disabilities act, are now college-aged and are entering college in record numbers (Nevill & White, 2011). Briel and Getzel (2009) stated that “educating young adults with autism in postsecondary education settings is an emerging trend in the field of higher education and disability” (p. 189). As Autism Spectrum Disorders (ASD) become more well known, universities’ disabled service providers such as counselors, advisors, professors, administrators, and staff who work in disabled student services have all taken notice of the increased number of students with autism on their campuses as well (Prince-Hughes, 2002). As more academicians focus their attention on how best to educate autistic college students, there has been an increase in acknowledging and sharing insights about how to meet the educational needs of this

relatively new population. An English professor (Jurecic, 2007) stated her thoughts thusly:

We have arrived at a historical moment, however, when those of us who teach at colleges and universities must examine our unease, because we are about to see a change in our student population. Increasing numbers of students with Asperger's Syndrome, autistic, and other disorders from the spectrum will soon arrive in our college classrooms--if they are not there already. Students who entered college in fall 2005 were likely born in 1987, the year in which the third edition of the DSM-III broadened the definition of the pervasive developmental disorders, thereby widening the concept of infantile autism (p. 421).

With more individuals with autism entering college, it is important to think about what online communication has done for autistic individuals that is similar to what sign language has done for the deaf. One way that schools can assist the autistic student is through technology.

Technology can be utilized in many ways such as having autistic individuals learn how to use word processors for papers and design-oriented software for the completion of course projects. More importantly, online communication can provide a comfortable social outlet for many of these students, particularly those who find in-person social interaction unmanageable. In fact, Robertson and Ne'eman (2008) suggested that instructors could choose to allow autistic college students the opportunity to post to an online course forum to satisfy class participation requirements. Boundy (2008) and Brownlow and O'Dell (2006) all suggested that autistic students be allowed to take courses online rather than face-to-face.

Autistic individuals have a myriad of sensory challenges (Ben-Sasson et. al, 2009) such as hyper sensitivity to light and/or sound. An online environment would mitigate

these challenges by allowing the autistic student to control his or her environment in a manner that is comfortable and most conducive to learning. An autistic student might benefit from being able to choose what color the website background is for the purposes of adjusting the amount of light emanating from the screen.

Although it is possible for autistic college students to regulate and control their sensory environments by engaging in online and virtual environments, they may not be so fortunate when offline. Due to the differential ways in which autistic individuals tend to process sensory information as compared to non-autistic individuals, offline environments pose particular challenges because one cannot simply turn off the sun when the light gets too bothersome. Some autistic individuals have hypersensitivity whereas others may be hyposensitive.

One way autistic college students are served uses the campus-based transition model, that allows autistic students to attend college with peers in a safe, supportive environment while still enrolled in high school (Adreon & Durocher, 2007; Zager, 2006). Other ways that universities can help ease the transition from high school to college is by providing accommodations. Some of these accommodations are mandated by the Americans with Disabilities Act (ADA) such as allowing students to audiotape lectures, to take exams in quiet and less distracting environments, and to have extra time for exams available. Although other accommodations are not required by law, they might prove very helpful to the student with an ASD.

In order for autistic college students to take advantage of these accommodations, they must initiate asking for them. There are many websites of autistic people communicating with each other. On one such site,

www.users.dircon.co.uk/~cns/index.html (University students with autism and Asperger syndrome), Howlin (2004) summarized the information by providing a detailed list of advice given by autistic college students to other autistic individuals considering a university education.

Further research

Ideas for further research might include developing an online curriculum and testing its efficacy with autistic individuals who communicate online. How do autistic individuals who communicate on message boards fare in terms of completing coursework successfully in an online course as compared to their Neurotypical peers? Another study might work like a usability study whereas an online course design is created. What type of feedback do autistic students provide on the online course site? Another study might be designed to examine a different type of online communications such as listservs or blogs. Do communication styles differ on listservs or blogs as compared to message boards? If so, then how?

Conclusion

This study might provide alternatives to commonly held stereotypes about what autistic individuals are capable of accomplishing. Self-advocates tend to favor a social model of disability that conceptualizes disability as being largely the result of a lack of social accommodations to human difference instead of a medical model that "pathologizes" disability by describing in terms of the physical and cognitive disorders of individuals (Silverman, 2008).

This study will also contribute to a deeper understanding of autism by demonstrating how autistic individuals communicate online. By analyzing patterns in the ways in which the message board participants choose to express themselves, a curriculum could be designed to capitalize on the strengths of these autistic individuals rather than trying to force them to conform to traditional forms of educational delivery that only showcases their weaknesses. This study might also provide alternatives to commonly held stereotypes about what autistic individuals are capable of accomplishing.

The autistic individuals I studied seem to want to be seen as having a difference not a deficit. They acknowledge their struggles, but posit that they have strengths that are uncommon and are currently being under utilized by society. Their use of internet demonstrates how autistic individuals are capable of communicating about a wide variety of topics. In many ways, they are like the Neurotypical (NT), they seek mates, want friends and most of all, want respect.

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