REWIRING DIFFERENCE AND DISABILITY: NARRATIVES OF ASPERGER’S SYNDROME IN THE TWENTY-FIRST CENTURY

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ABSTRACT

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This dissertation explores representations of Asperger’s syndrome, an autism spectrum disorder. Specifically, it textually analyzes cultural representations with the goal of identifying specific narratives that have become dominant in the public sphere. Beginning in 2001, with Wired magazine’s article by Steve Silberman entitled “The Geek Syndrome” as the starting point, this dissertation demonstrates how certain values have been linked to Asperger’s syndrome: namely the association between this disorder and hyper-intelligent, socially awkward personas. Narratives about Asperger’s have taken to medicalizing not only genius (as figures such as Newton and Einstein receive speculative posthumous diagnoses) but also to medicalizing a particular brand of new economy, information-age genius. The types of individuals often suggested as representative Asperger’s subjects can be stereotyped as the casual term “geek syndrome” suggests: technologically savvy, successful “nerds.” On the surface, increased public awareness of Asperger’s syndrome combined with the representation has created positive momentum for acceptance of high functioning autism. In a cultural moment that suggests “geek chic,” Asperger’s syndrome has undergone a critical shift in value that seems unimaginable even 10 years ago. This shift has worked to undo some of the stigma attached to this specific form of autism. The proto-typical Aspergian persona represented dominantly in the media is often both intelligent and successful. At the same time, these personas are also so often masculine, middle/upper class and white. These representations are problematic in the way that they uphold traditional normativity in terms of gender, race and class, as well as reifying stigma toward other points on the autistic spectrum.
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INTRODUCTION

This dissertation explores cultural representations of Asperger’s syndrome, a condition that is most often described as a high functioning form of autism. Specifically, I am textually analyzing cultural representations with the goal of identifying specific narratives that have become important about this diagnosis in the public sphere. Beginning in 2001, with *Wired* magazine’s article by Steve Silberman entitled “The Geek Syndrome” as my starting point, I wish to demonstrate how certain values have been linked to Asperger’s syndrome: namely the association between this disorder and hyper-intelligent, socially awkward personas. Narratives about Asperger’s have taken to medicalizing not only high intelligence or even genius (as figures such as Newton and Einstein receive speculative posthumous diagnoses) but also to medicalizing a particular brand of new economy, information-age genius. The types of individuals often suggested as representative Asperger’s subjects are stereotyped as technologically savvy, successful “nerds,” as the casual term “geek syndrome” suggests. On the surface, increased public awareness of Asperger’s syndrome combined with the representation has created positive momentum for acceptance of high functioning autism. In a cultural moment that suggests “geek chic,” Asperger’s syndrome has undergone a critical shift in value that seems unimaginable even 10 years ago.

I believe this shift has worked to undo some of the stigma attached to this specific form of autism. The proto-typical Aspergian persona we see represented dominantly in the media is often both intelligent and successful. At the same, these personas are also often masculine, middle/upper class and white. These representations are problematic in the way that they create uphold traditional normalcy in terms of gender, race and class, reify stigma toward other points
on the autistic spectrum and create certain stereotypic expectations of what Asperger’s syndrome is for those with the diagnosis that may not always reflect their life situation.

In this introduction, I will begin by providing an overview of the diagnoses of autism and Asperger’s syndrome and then discussing the contemporary understanding of autism in the context of an epidemic. I will then turn to a discussion of how I will use disability studies theory in this dissertation, paying particular attention to the critical interrogation of normalcy it provides. Next, I will turn my attention to how I will use language related to disability because I feel as though it is particularly crucial to make clear the deployment of language in this dissertation. Following that section, I provide a brief examination of the importance of understanding representation in terms of how it relates to the autistic spectrum. Finally, I will provide a short chapter breakdown.

INTRODUCING AUTISM

In discussing Asperger’s Syndrome, it is important to look at it in the context of its current diagnostic understanding as well as the current medical view of autism in general. As with many developmental disabilities recognized today, autism is a relatively recent historical classification. Autism has been traditionally defined as a life-long developmental disability that first manifests itself in children under three years old, where it begins with marked delays in the areas of language utilized in social situations, social interaction and imaginative play. Autism was first identified and described as Early Infantile Autism by Dr. Leo Kanner in 1943. Kanner identified many of the traits still popularly associated with autism: limited social ability, repetitive behavior, obsessive behavior, etc. Initially, autism was wrongfully linked with such disorders as schizophrenia and it was always assumed that those afflicted (and it was and in
many ways is popularly thought of in terms of affliction) with autism had relatively few treatment options and would live a severely limited life.

Autism is today professionally regarded as a continuum, known as the autistic spectrum or sometimes as a set of diagnoses known as Pervasive Developmental Disorders. The concept of the autistic spectrum is based upon the idea that there exist certain autistic traits. While these traits can be expected to be differently distributed across the general population, the pronounced prevalence of key traits in combination in an individual can result in a diagnosis of autism.

The spectrum reflects a number of different manifestations of autism, from those who are seen by others to be largely socially dysfunctional and impaired (what we might conceive of as “classically autistic”) to those who possess a number of autistic traits but are significantly more functional. While those on this spectrum are often divided into the two labels of “low functioning autistics” and “high functioning autistics,” the autistic spectrum represents the current scientific view that there is a range of manifestations of autism. In short, there is no longer any “real,” singular autism as had been thought, but rather many different autisms. This is recognition that autism will affect different people in potentially different ways.

The particular range on the autistic spectrum I’ll be talking about is called Asperger's syndrome. Asperger’s syndrome takes its name from the work of Vienna psychologist Hans Asperger. In 1944, Asperger wrote of his work with children who demonstrated many autistic tendencies. These included severe difficulties in social adaptability and uncanny skills at building and understanding systems, memorization and specialization of knowledge. Asperger's work was virtually ignored in his lifetime. It was not until 1981 (a year after Asperger's death), that his work was finally brought to the forefront by autism expert Dr. Lorna Wing. Asperger's
syndrome was not recognized formally in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) until 1994.

The 1994 DSM IV includes five Autism Spectrum Disorders. These are: Classical autism, Rett Syndrome, Childhood Disintegrative disorder, Asperger’s and PDD-NOS, which is a pervasive developmental disorder not otherwise specified. To qualify for a diagnosis of Asperger’s syndrome, a child shows qualitative impairment in social interaction, as manifested by at least two of the following: multiple nonverbal behaviors, a failure to develop appropriate peer relationships, a lack of spontaneous seeking of shared enjoyment, interest or achievements with other people, a lack of social or emotional reciprocity, restricted stereotyped patterns of behaviors, inflexibility, repetitive mannerisms and preoccupations. Also to qualify for an Asperger’s diagnosis, the child must not demonstrate a lack of clinically significant delay in language, cognitive developments, environmental curiosity or the criteria for another specific developmental disorder.

As the above criteria demonstrate, Asperger’s syndrome, like classical autism, is always diagnosed through behavior; there is no genetic test or any other physical means of detecting the condition. Furthermore, there is no uniform diagnostic screening, instruments or criteria for assessing Asperger’s syndrome. Diagnosing autism is fraught with contentions and complexity at the professional level. These complications trickle down to the popular understanding of the diagnosis.

This complexity is one major reason why, for this dissertation, I have chosen to focus solely on representations of Asperger’s syndrome rather than the autistic spectrum as a whole or the other pervasive developmental conditions related to autism. My argument is that this study
must be limited to Asperger’s for many reasons; chief among them is that I feel autism in general would be too large a scope for this work. Additionally, every point along the autistic spectrum is unique and therefore, I believe, worthy of specific academic attention. I hope to demonstrate that a cultural understanding of Asperger's syndrome is very distinct, while at the same time relatable to larger issues, such as classical autism and disability.

Having taken that into account, Asperger’s syndrome is by no means a small topic. As an emerging diagnosis, part of what the media calls the autism “epidemic,” the potential directions a cultural studies project concerned with Asperger’s syndrome are nearly endless. The cultural material available to work with is vast when you begin to closely examine it. As of now, I wish to limit myself to looking at representative texts of popular culture. As it is impossible to survey the vast array of materials, I will limit my discussion to cultural texts that demonstrate discursive trends.

THE AUTISM EPIDEMIC?

The result of medical professionals expanding their view of autism from a single disease entity into a spectrum has been the simultaneous expansion of the possibility of who can be labeled autistic and the possibilities of what life can be like for those diagnosed. Evolving alongside this expanded view of autism have been the rates of diagnosis. To claim that the rates of autism diagnosis have risen dramatically in recent years is an understatement. In the ten years between 1993 and 2003, rates of autism rose over 800%.\(^1\) We are inundated with commercials proclaiming that autism occurs in 1 of 150 children. These numbers have resulted in autism

being referred to frequently as an “epidemic,” fueling a great deal of public anxiety to explain
the cause.

There is an ongoing debate over whether this rise can be accurately talked about as an
epidemic or if this is the result of a change in diagnostic criteria. If it is a disease epidemic, then
it stands to reason that there is a physical cause, such as, as some in the public believe, mercury-
based thiomersal in vaccinations or environmental toxins, though no scientific evidence supports
these beliefs. Millions of dollars are raised in the search of a possible cure for autism, which in
commercials is placed next to disease entities such as cystic fibrosis, cancer and diabetes.

However, since there is no way to diagnose autism (as of yet) through genetic or physical
examination, a behavioral criterion (which can and does vary between professionals) is
contingent upon time and culture and numerous other factors which are far from stable. A belief
in an autism cure is in the present hypothetical. Autism scholar Majia Holmer Nadesan says that
the public reporting of research in this area is inadequate. In translating and creating a
knowledgeable debate around the scientific research of autism, autism becomes “increasingly
reified into a thing unto itself, whose secrets will ultimately be unveiled.”² Until we can look
into the metaphorical microscope and find autism, the disease narrative is misleading and
inadequate.

As Oliver Sacks says: “The ultimate understanding of autism may demand both technical
advances and conceptual one’s beyond anything we can now even dream of.”³ The fact that we
lack such technology or conceptions may one day change. But for now, the conceptualization of

autism as a disease in the absence of concrete understanding has a real impact in how people with autism are treated.

For instance, we can attack a disease, remove a disease or declare war on a disease. How do we, at present, do these things with autism? A disease narrative assumes an intact personality separate from the condition. Is there such a thing as a personality separate and apart from the autistic person? Autistic self-advocate Amanda Baggs says:

Autism is not a peripheral feature that I can discard. Autism shapes my mind, my personality, my senses, my values, my goals, and my dreams. Autism is the source of my difficulties and my strengths, and of the unbreakable ties between them. Autism is a significant, dominant, and irrevocable part of what makes me, and my closest friends, unique.4

For Baggs, there is no way of sifting through her mind to remove the autistic parts, returning her to a healthy state. Yet, as I will delve into in more detail later, there is this reoccurring idea of a normal child “stolen away” or “trapped” in an autistic “shell.”

By this logic, these children and adults need only to be cured and reached for the “real” them to be returned or to emerge from the shell. As I will discuss below, these kinds of beliefs rely on an uncomplicated and uninterrogated conception of normality. This conflict is complicated by the recognition of a spectrum, with “milder” forms of the condition assisting the swelling numbers of autism cases.

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Anthropologist Richard Grinker grapples with questions of the epidemic in his book *Unstrange Minds*. For Grinker, newer, higher and more accurate statistics on autism are what is responsible for this so-called epidemic. For example, autism as a category for children in special education programs in the U.S. has only existed since the 1991-1992 school year. In the school year that followed the recognition of autism by special education, cases of autism tripled. In that time, the chance of a child being diagnosed with autism in the early nineties was approximately one in 3,333. Today, the same chance is approximately one in 150. Grinker writes that 50%-75% of the increases in diagnoses are simply coming from the creation of new categories. Additionally, many more doctors are familiar with and willing to give diagnoses. Furthermore, we are seeing a part of the stigma of the diagnosis lifting off parents, particularly mothers. There are also more much needed resources available that make seeking a diagnosis more attractive. The Asperger’s syndrome ”label is important for my child because it qualifies him for support and services at school, and helps his fellow students understand his brain differences” as one parent wrote in *Newsweek*.

Grinker, the parent of a child with autism, says that the autism “epidemic” is created through the redefining of social definitions of disability. For example, Grinker notes that special education services for generalized categories such as “retardation” and “learning disability” declined in 47 states from 1994-2003. In 44 states, the drop *exceeded* the rise of autism. In short, the belief is not that there are more autistic children, just that there are more children being diagnosed with autism. Grinker uses the example of fetal alcohol syndrome to prove his point.

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No one over the age 40 officially has it, he claims, but 1 out of every 500 children today does. Naturally, no one assumes that pregnant women just recently began drinking alcohol.7

Similarly, based on the sheer magnitude of the number of cases of autism documented each year, we can assume that many people, particularly those labeled as “high functioning” autistics, would not have been labeled as autistic in the past or would have not received any diagnosis or medicalized labeling in the past prior to the creation of autism, perhaps being labeled as “eccentric.” This term “high functioning” is a modern invention and likely wouldn’t have made much sense in the old model of understanding autism as a condition with little to no social capital. The increased recognition of autism as a distinct category is a major contributor to the increase in cases of autism, but also a contributing factor is the current consensus within the medical community that this distinct category of autism cannot be regarded as narrowly defined.

Yet Asperger’s syndrome is often talked about as a narrowly defined point on the autistic spectrum. But as Marianne Kaplan, who directed a film about her Asperger-diagnosed son says no two kids have the same symptoms.8 Understanding Asperger’s syndrome itself as a variety of behavior is an idea that is critically overlooked. Though autism is often talked about as “invisible,” in reality, it is also about performance and the values attached to those performances. Discussing her son with autism, Nadesan talks about the common practice of having to stress her son’s maladaptive behaviors for the social services agent and her son’s high intellect to his teachers.9 In essence, for each “audience,” she highlights certain characteristics of autism.

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9 Nadesan, 2.
Advocating for or being autistic seems to be mired in confronting the social consequences of how one’s everyday behavior will be valued in terms of normality and benefits. Consider, for example, the behavior associated with autism (including Asperger’s) known as “stimming.” To stim means to engage in a repetitive physical behavior, such as leg tapping, flapping of the arms, humming, clenching of the teeth, staring at a variety of objects or the compulsion to touch a certain kind of object or adopting a certain stance or posture, among many other examples. Not all of those with Asperger’s stim, some will stim in a way that is viewed as mild and others will stim in a way that is viewed as maladaptive. For instance, I contend that the social costs of seeing one flapping one’s arm repetitively are not the same as teeth grinding, which is a phenomenon more associated with (more normative) stress than with (visibly autistic) stimming.

Consider also that highly specialized interests manifested with autism can have very different social values attached to them. As I will talk about repeatedly in this dissertation, the stereotype of those with Asperger’s as gifted in the technology field is very prominent. These gifts have obvious social value, but not all interests are going to be valued equally or seen as socially acceptable. An article in the *Wichita Eagle* puts it very well:

> When an 11-year old boy can rattle off the earned run averages of every pitcher in Major League baseball, you might not flinch. When he can tell you everything about an ocean liner that sank in 1912—from its dimensions to the number of lifeboats onboard to the number of people who died—it seems a little more, well, unusual.10

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From a social and cultural perspective, there is no way to understand Asperger’s syndrome as a diagnosis that manifests itself equally. This dissertation is concerned with discussing a few of the endless variety of ways in which Asperger’s as a cultural force can affect individuals. The emergence of Asperger’s as a relatively recent diagnosis indicates that a large number of those people today living with Asperger’s (and virtually all of those of adult age) were diagnosed later in life, rather than in childhood. For some of these individuals, this has meant that their status of “normalcy” has recently been called into question. In some cases, this could mean that what may have been thought of as simply eccentricity, talent or a vital component of their personality is now something to be diagnosed or “treated,” representing a critical shift into a culture of the medicalization of traits such as genius, talent or personality.

Of course, in other cases, a diagnosis might be seen as that positive moment of “sense making,” enabling one to give order to a particular aspect of the self that was previously seen as negative. For instance, someone who may have seen themselves as socially inept through what is interpreted as personal failing may gain a new understanding of their behavior. And for others, perhaps with a more visible lack of social functioning or heightened comorbidities, a formal diagnosis of AS may indicate the end of a journey through an array of different diagnoses, ranging from severe to mild, with the varied social costs these diagnoses entail. And what of those who have never been diagnosed or have remained misdiagnosed? And these questions do not begin to address the younger generations of Asperger’s patients, diagnosed so young, who have come of age in the last decade: what is their experience like and how has a diagnosis or lack thereof affected their life?

These questions are the tip of the iceberg. As diagnoses continue to climb, these questions will multiply further and few answers seem to be forthcoming. The closer one looks at
the work of Asperger’s syndrome in culture, the more complex it appears. I believe a cultural studies approach to this syndrome can be helpful in unpacking some of these ideas.

DISABILITY STUDIES

In this section, I will discuss the theory and methodology I will be using in this dissertation. Disability Studies has been an emerging and rapidly growing field in academia for a number of years. As many have noted, disability studies has gained ground in recognition of the relative silence and inattention given to cultural perspective of disability. Disability as a concept was largely thought of as unquestionable and self-evident in academia as it was outside of academia, despite the political, cultural and historical forces that shape it. As one scholar says, there were once very few distinctions between the academic narrative of disability and the cultural narrative surrounding it.11

Claire Tregaskis in *Constructions of Disability*, states that addressing disability discrimination needs therefore to be seen as equitable with other forms of social oppression, such as racism. The main perspective of most disability scholars is that attitudinal and structural barriers must be addressed simultaneously in order to make sustained and timely progress, rather than assuming that either structural change or attitudinal change alone will end discrimination against disabled people.12

Disability, like all identity categories, is complicated and intersectional, but in its own unique way. For example, many efforts to critically engage with oppression depend ultimately on there being a core identity. For example, the slogans "black is beautiful" or "we're here, we're

“queer” depend on a recognizable coherent grouping. Disability studies does use this kind of reasoning of group identity, but because of the nature of disability and the complications that arise through the consideration of developmental disability, there is a challenge to the idea that there exists a “real” body, mind or self in which to build a coalition. This type of discursive strategy doesn’t always work for all oppressed groups, if for any of them.

The further fragmentation and even denial of core identity is problematic and complex. In academia particularly, where the intellect is so strongly cherished and centrally positioned, the recognition of intellectual disability raises questions in an environment that quantifies, qualifies and standardizes the mind. With that in mind, one important element of disability studies that I have found indispensable to my discussion of Asperger’s is the critical approach that the field brings to the concept of normalcy.

Normalcy and disability are mutually constitutive categories. Leonard Davis says in *Enforcing Normalcy* that our conceptions of disability are based on the entrenched idea of normalcy, which is neither natural nor even recent, saying it is important to “defamiliarize” normalcy. Another scholar, Rosemarie Garland-Thomson uses the word “normate” rather than “normal” to call attention to the constructedness of normality and its existence almost as a kind of mythology. Nadesan agrees, stating that “pathology rests on the mythology of normality. In my mind, there is no such state of brain or mind as normal. There is no normal brain. There is no normal genome.”

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15 Elizabeth Ross, “Rethinking Autism” (Presentation, UNC Chapel Hill, 29 November 2005).
Shelley Tremain’s text *Foucault and the Government of Disability* uses Foucault to argue that the invention of the statistically average, or normal, individual was the foundation for bourgeois society in Europe. According to Tremain, standardization of production, reinforcing national narratives through imperial adventurism requires a social norm that must be enforced and reiterated. The disabled person then is a “constitutive feature of the regime, a figure of bodily or mental deviance against with statistical values of the average or normal could be contrasted.”\(^{16}\) Normality then is a fiction supported by logic steeped in medical discourse. This conclusion is one that child and adolescent psychiatrist Dr. Elizabeth Berger agrees with, saying "There is something unexamined in our thinking when we elevate the need for normalcy to a state of spiritual grace, and live under a constant anxiety that we fail to measure up to its demands."\(^{17}\)

Stressing normalcy in the case of autism constitutes a moral problem for Nadesan in that it “preserves the status quo from critical interrogation: for example, bullying behavior is ‘normal’ but specialized and encompassing interests are pathological.”\(^{18}\) Most of the work done in disability studies has focused on the social costs of bodily disabilities and not developmental disabilities. Though the distinction between “mind” and “body” disabilities is tenuous at best, the distinction does matter and it is crucial to demonstrate how developmental disabilities are socially constructed around this idea of normalcy. The push toward legitimizing normalcy by intervention implicitly condones oppressive practices, both official and unofficial.

Much of the theoretical work of challenging the concept of normalcy is accomplished by pointing out the failure of individuals to meet these demands is not individual failure, and hence

\(^{16}\) Davidson.
\(^{18}\) Nadesan, 202.
disability is not an individual problem remedied through medical or psychological interventions, but one that requires systemic change. Disability must be therefore be redefined as something apart from the individual. Scholars Richard Devlin and Dianne Pothier usefully define disability as not simply a question of “impairment, functional limitations or enfeeblement”, but “social values, institutional priorities and political will.”

Scholar Mike Oliver coined the term “social model of disability” to analyze this distinction. In using the term “impairment” we refer to specific physical or cognitive conditions that lead to a limitation or reduced capacity in some avenue of life. Disability, on the other hand, refers to those social facts that exacerbate impairment, limit opportunities and create barriers. A common example used to explain this is that paralysis of the legs could be considered the impairment. The lack of wheelchair accessibility, condescension or discrimination creates a disability.

Nadesan, Stuart Murray and many other scholars have used philosopher Ian Hacking’s idea of “indifferent and interactive kinds” of people and objects to talk about how this distinction occurs. As Hacking spoke directly about autism in terms of a niche disorder, I have found his perspective invaluable. For Hacking, “indifferent kinds” are things that are classified that are not affected by their classification. “Interactive kinds,” on the other hand, are directly impacted through the ways that they are categorized. In Hacking’s ‘words:

I have long been interested in classifications of people, in how they affect the people classified, and how the affects on the people in turn change the classifications. We think of many kinds of people as objects of scientific inquiry. Sometimes to control them, as

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prostitutes, sometimes to help them, as potential suicides. Sometimes to organise and help, but at the same time keep ourselves safe, as the poor or the homeless. Sometimes to change them for their own good and the good of the public, as the obese. Sometimes just to admire, to understand, to encourage and perhaps even to emulate, as (sometimes) geniuses. We think of these kinds of people as definite classes defined by definite properties. As we get to know more about these properties, we will be able to control, help, change, or emulate them better. But it’s not quite like that. They are moving targets because our investigations interact with them, and change them. And since they are changed, they are not quite the same kind of people as before. The target has moved. I call this the ‘looping effect’. Sometimes, our sciences create kinds of people that in a certain sense did not exist before. I call this ‘making up people’.  

In this way, the classification of people with autism leads to a looping effect. The behavior of people with autism is changed by the classification, research and interaction of them as people with autism. They produce what was classified. Autism or anything else categorized as a disability creates a particular kind of looping in that the research and classification of autism changes. Hacking’s model shows a way in which disability is produced not simply through individual status, but through classification and intervention.

Furthermore, the social model, by denying disability as an individual problem, shows that everyone is implicated where discussions of ability or disability are concerned. Ability status is

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contingent upon how these terms are culturally defined and they are incredibly unstable. As has been said, “Forms of life are always life-forming and realities are always realities becoming.”

Consider that I, like all of us, am a single accident, operation, sickness or psychological test away from my status, whatever it may be presently, changing. It is not only possible, but near certain, that our ability statuses will change in our lifetimes. Disability is not a static, unchanging or immutable condition. Many people who have a disability were not born with it, making it very different from characteristics like gender or race. And even that rare person who cannot think of a way in which disability has affected them must remember that “every single person’s personhood has been shaped by medicine, law and pedagogy.” Even so, as Linton points out, the idea of “all of us being disabled in some way” does not reflect the reality of being presented to the world as disabled and does not make the idea of erasing those lines particularly attractive. Disability scholars typically traverse a fine line between pointing out the universality of disability, but also its status as a particular identity with real social costs.

The notion of disability as a medical issue and/or personal tragedy places people with disabilities within a narrative in which medical accommodation to the impairment is squarely their own responsibility or that of their families. According to Quayson, the medical and social systems are then tasked with corrective, ameliorative, or reprimanding roles, reminding the

23 Linton, 13.
person with disability to “get a grip” and take charge of the process of his or her self-improvement and adjustment.  

In *Critical Disability Theory*, Richard Devlin and Dianne Pothier state that disability theory emphasizes the inevitability of difference, demands the material reorganization of our basic social institutions, and challenges the assumptions of sameness and assimilation in a profound way.  

Above all, according to Simi Linton’s *Claiming Disability*, the field challenges the idea that disability is primarily a medical category.  

Not treating the social processes that constrict the lives of people with impairment, disability is then the social product of a failure to accommodate and include.

Ultimately, as Tregaskis in *Constructions of Disability* argues, the social model approach is profoundly optimistic because it recognizes that to achieve change requires that we expect the best of people in acting in ways that challenge existing oppressive practices.  

One of the challenges in talking seriously about disability as being socially constructed is that the line between impairment and disability is often blurred.  

Ato Quayson, author of *Aesthetic Nervousness: Disability and the Crisis of Representation*, states that impairment is “automatically placed within a social discourse that interprets it and ‘disability’ is produced by the interaction of impairment and a spectrum of social discourses on normality that serves to stipulate what counts as disability in the first place.”  

Making the distinction between impairment and disability still reifies the notion of a disabled subject who does not meet the criteria of normality.

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26 Linton, 2.  
27 Pothier and Devlin, 9.  
28 Quayson, 3.
Tremain’s *Foucault and Government in Disability* looks at how disabled subjects are produced through special education, benefit programs, and other social apparatus and further questions the impairment/disability distinction. In other words, the idea that a disability is constructed but impairment is “really real” is still problematic. Tremain points out how Foucault demonstrates how discourses (both formal and informal) construct individuals as subjects. These individuals are constructed as subject to an outside power through control and restraint. They are also constructed as a subject through their own self-knowledge. The idea of personality as a “distinct and legitimate sphere of investigation” and childhood development as being “fraught with peril” has made it possible to talk about autism, as Nadesan also points out.29 For the past two centuries, the vast apparatuses erected to secure the well-being of the population have “caused contemporary disabled subjects to emerge into discourse and social existence.”30

Ultimately, from a Foucauldian perspective, there can be no meaningful distinction between impairment and disability. Whereas the social model ultimately relies on a celebration of some kind of identity, this kind of Foucauldian analysis looks at everything as part of a problem. While this critique is well taken, I ultimately rely on the social model of disability. For the purposes of this dissertation, I will be taking the idea of impairment, of autism, as being *real*, though with the recognition that it is also constructed. I think in my discussion of high functioning/low functioning autism in Chapter 3, this will be particularly important. Tremain’s book opens by quoting Foucault as saying “My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad.”31 Likewise, the idea of

29 Nadesan, 27, 67.
30 Tremain, 5.
31 Tremain, xi.
impairment as the real marker of identity is not necessarily bad, but seen only in the context of being incontrovertible fact, it can be dangerous.

Having said that, I therefore take the perspective in my research that views Asperger’s syndrome more as a set of beliefs and practices rather than an innate, biological/genetic/psychological “truth.” By taking this perspective I do not wish to caricature the scientific process, but rather the belief that human understandings of such conditions can exist independently of culture. I see this view as being the groundwork upon which a cultural investigation of Asperger’s can be built. As Nadesan says “Although there is a biological aspect to this condition named autism, the social factors involved in its identification, representation, interpretation, remediation, and performance are the most important factors in the determination of what it means to be autistic, for individuals, for families and for society.”32 To me, this is the distinction that makes the social model the best suited as a means of “unpacking” what this condition we refer to as “autism” is.

Having grown up with a family connection to Asperger’s syndrome, I can say that from my experience the truly challenging difficulties that emerge do so from encounters with the social world. I have never met a person with autism who is, in and of themselves, a “problem.” Problems come in the form of ignorance; the forms of this ignorance vary in range from inadequate educational resources to bullies. The sentiment that the problem is social rather than individual is something that I have seen echoed repeatedly throughout my research, whenever I have read of or spoken with people with autism, their parents, guardians, children, siblings and friends. Whatever Asperger’s or autism may be has, in my experience, been less important than the beliefs and practices that comprise it. The work of cultural studies, as I see it, is to

32 Nadesan, 2.
interrogate those beliefs and practices. To talk about a condition such as autism as being socially constructed isn’t to deny the reality of the condition, but rather to call attention to those beliefs and practices that shape the consequences of that reality. Understanding Asperger’s syndrome as a social construction is not to deny the clear realities of a condition that is manifested in the body, but to recognize the accountability of culture’s role in that reality. A social model approach to autism means an acute awareness of those impairments and those disabling features that are a result of the surrounding culture.

LANGUAGE

Kenneth Hall, who wrote the book *Asperger’s Syndrome, the Universe and Everything* stated:

One thing I hate is when people use the word “suffer” and say I “suffer” from autism. It is not something I suffer from, it’s just the way I am. I don’t tell them they suffer from being normal, do I? ³³

Language and how we use it is critical in talking about disability. Therefore I would like to briefly discuss how I will be using language to talk about disability in this dissertation. A Chinese proverb states that “Wisdom begins by calling things by their right name.”³⁴ The importance of using the “right language” in disability studies is crucial in that language has been one of the most important means by which disabled persons have been oppressed.

For instance, language is one key way in which things become understood. I describe the process of how language allows these dominant autistic narratives to be created and sustained. As will be discussed in Chapter Three, I see the *Wired* article “The Geek Syndrome” as being an important article in creating and sustaining ways of understanding Asperger’s syndrome, as well as responding to previous narratives that will be discussed in Chapter Two.

Leonard Davis talks about language of nondisabled people being framed in such a way as to project “imagined bitterness and resentment.” Simi Linton states that terms such as “physically-challenged” or “special,” even used with the best intentions, often “convey the boosterism and do-gooder mentality endemic to the paternalistic agencies that control many disabled people’s lives.” Language is subverted by the disabled to call attention to these inequalities. I have already identified normate as a term that is used with the intention of subverting concepts of normality. Other examples include the term TAB (Temporarily Able-Bodied), which is a term designed to evoke the idea that those who are nondisabled will not always possess that status. Another example is the word “crip,” which has been “taken back” similar to the term “queer” to describe identity. Language and how it is applied to disability is always contextual and always full of complex meanings.

One recent episode demonstrates how complex an issue this is. On March 19, 2009, President Barack Obama spoke at a town hall. In the course of his discussion, he addressed how he hoped his administration would help people with disabilities have more opportunities to work, stating that “we need everybody, and every program that we have has to be thinking on the front end, how do we make sure it’s inclusive.” Later that same night, Obama appeared on the *Tonight

36 Linton, 14.
Show, comparing his bowling skills to “something out of the Special Olympics or something.” Obama was quick to point out his mistake and apologize. Likewise, I do not believe Obama to be insincere is his wish for inclusiveness but believe that his spontaneous remarks show how readily available common words and phrases are that support denigration of the disabled.

In March of 2009, following the Obama remarks, Special Olympics launched a public awareness campaign to draw attention to use of the popular term “retard.” This word is derived from the term mental retardation, which has been used in the pejorative since the 1960s. The word “retard” is in wide use, especially among the young, and used frequently in television, film and music. One can even buy a T-shirt which reads “Political Correctness is retarded.” While this word has been in disrepute, real change is long coming, as many state and federal laws and regulations still use the term within their definitions. The American Association of Mental Retardation only changed its name to the American Association on Intellectual and Developmental Disabilities in 2007 and the Associated Press just replaced the term in its stylebook in 2008.

I mention this word because it so easily and directly evokes hatred towards the disabled when it is used. But if someone were to wish to stop using the word “retarded” to describe someone, what word would I suggest they use to replace it? Dumb? Stupid? Moron? Idiot? All of these terms share a similar institutional background. We literally lack the language to describe inequality in human intelligence without consulting our medical history. From the Social Construction of Disability:

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37 “Political Correctness is Retarded,” Zazzle, http://www.zazzle.com/political_correctness_is_retarded_tshirt-235458141202487168
Explaining human nature has always tended to be a job for the elite…what is true of the substitution story is also true of most street talk: the etymology of words such as fool, idiot, imbecile, dunce, mong, moron and retard shows that abusive language comes not from the streets but from an exceptionally intellectual subculture as an imagining and construction of its own antithesis.  

As difficult is it to talk about any sort of intellectual deficit without relying on elite language, we also lack a completely agreed upon language to talk about disability as a positive. Pediatricians Perrie Klass and Eileen Costello use the term "quirky" to talk about kids in their book "Quirky Kids" to defuse the terror of medical labels. But they admit that such a term is not substitute, as “quirky” will not get one access to the special services you may need. One member of a nonprofit learning institute says that "These are highly specialized minds and to put a syndrome on it and treat it as an aberration does damage to kids and families. There are still challenges there on how to manage it, but why not call it a highly specialized mind phenomenon rather than a disorder? That label alone shapes public perception about uniqueness and quirkiness."  

“Person first language” has been identified as a strategy to the talk about disability without carrying excessive labeling. Person first language was designed to demonstrate that a person is not their disability. For example, I would say “person with autism” rather than “autistic person.” However, disability scholar Tanya Titchkosky disagrees and talks about person first language as being apolitical and “dismembering disability from the self.”  

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40 Ali.
41 Tanya Titchkosky, “Disability: A Rose By Any Other Name?”, *Canadian Review of Sociology and Anthropology* 38, 2 (2001), 125-140.
One way to understand it in Titchkosky’s terms is that an “autistic” is a person whose identity is inseparable from the condition; a “person with autism” has something, something that can be removed. One of the most influential autism researchers of all time, Bernard Rimland, believed that the term autistic child is appropriate, in that autism is who his son is. Person first language has been rejected by many in the deaf community and blind community as well.

For myself, I use them interchangeably. I was originally taught that person first language was the most appropriate, accurate and sensitive way to discuss disability. Today, I now see the preference as individualistic and situational. In *The Science and Fiction of Autism*, Laura Ellen Schreibman similarly states her view that both are understandable and it is acceptable to use both.42 When speaking of others, I have endeavored to use the term they prefer if I am aware of the preference.

**REPRESENTATION**

By looking at media representations for this study, I am concerned with the types of identities, narratives and conventions of Asperger’s syndrome that are framed by the media, often at the expense of other, equally valuable alternatives. This is why examining the narratives that create these stereotypes and the frames that focus them become important to study.

For example, disability media coverage is often dominated by what one author calls the “steady diet of sugar” as opposed to mature and fully realized coverage of people, “steamrolled out of three-dimensional humanity into allegorical flatness.”43 Jack Nelson identifies the seven major stereotypes of disability in his book *The Disabled, the Media and the Information Age*: 1) Disabled as Piti able (ex: Jerry Lewis telethon); 2) Disabled as “Supercrip” (succeeding in spite

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of disability, which other disabled could do if they just worked hard enough), 3) Disabled Person as Sinister, Evil and Criminal; 4) Disabled Person as Better Off Dead (Assisted Suicide); 5) Disabled Person as Maladjusted-His Own Worst Enemy (Bitter, require greater insights about themselves and the world); 6) Disabled Person as a Burden (Tiny Tim); and 7) Disabled Person as Unable to Live a Successful Life. Looking at all of these various, and often repugnant, representations, we see a number of narratives at play. My model of culture is based around the idea that certain narratives, such as those above, emerge and compete with one another based on how they are framed through the media, which is one of the most critical sites for how we make sense of the larger social world. This dissertation is largely about sorting through and identifying dominant narratives and exploring the ways in which they function and, finally, outlining alternate narratives that they may obscure.

The tendency of media representation is to stereotype; to perform a type of shorthand. It is my hypothesis that the term “Asperger’s” has been coded to signify certain types of subjects and narratives. This signification does not always reflect reality. Obviously, there are people with Asperger’s who do fit stereotypical characterizations in the vein of the socially awkward, obsessive genius in one way or another. Yet there are many that don’t fit because of gender, race, class, perceived intelligence, ability, interests or even value to society. It is obvious that there are a multitude of identities and experiences along the autistic spectrum for individuals. But these individuals become invisible through the process of a stereotyping narrative.

There are real consequences, both positive and negative, to the way Asperger’s is represented, not only to those that remain marked or unmarked. While I maintain that that there are more resources available to those on the spectrum today, there is still a deficit of awareness,

44 Jack Nelson (ed.), *The Disabled, the Media and the Information Age* (Westport, CT: Greenwood Press, 1994), 1-23.
funds and understanding of Asperger’s syndrome. Popular representation matters because the knowledge of this disability otherwise can be confined to those who have a disorder, possible guardians, and the medical community. Yet, for change to occur, it must be a public issue and the media are how knowledge of this disorder is made. The media are a site for critical inquiry because we can see how culture views this diagnosis, but also how it responds to it.

For example, as I mentioned previously, it was not possible to register one’s child in special education courses in public schools with a diagnosis of autism (and thus have them receive the appropriate attention) as late as the early nineties. Yet, in 1988, the film *Rain Man*, about an autistic character, was one of the most popular films of the year, winning the Academy Award for best picture. In the wake of marketing the film and the resulting public interest, news coverage, feature stories and documentaries educated the general public about autism. One could argue that the film was at least one factor in increasing public awareness that helped lead to such gains as the recognition of autism in public schools. Yet for all the good the film and the awareness it raised accomplished, it presented only one look at the autistic spectrum. Frequently, we have seen the *Rain Man* idea dominate the public’s understanding of what autism looks like or is supposed to always look like. Over twenty years later, as we begin to see Asperger’s syndrome enter into discourse more and more, what ideas about this aspect of autism dominate the public’s imagination? In what ways will these ideas guide our public response? What messages are contained in the discourse? How do they shape how we see certain groups or ourselves? How does this change how people are able to live their lives?

By focusing this project on media representation, I am not trying to give the media more importance than, for instance, the act of diagnosis or the social experience of those who have
Asperger’s in terms of how it is understood. Rather, I am arguing for its interconnectedness with those things and its importance alongside the multiple ways Asperger’s syndrome is constructed.

CHAPTER BREAKDOWN

In Chapter Two, I will begin by looking at Leo Kanner, Hans Asperger and Bruno Bettelheim. Kanner and Asperger independently identified what we now know as autism in the forties, while Bettelheim, with disastrous results, became the principal framer of autism in the 20 years following the Second World War. Through my discussion of these three figures, I want to introduce the concepts of dominant narratives and explain how the understanding of autism has evolved.

Once we have examined this history, I will use Chapter Three to discuss the recent concept of the “geek syndrome” introduced by Wired magazine in 2001. I argue for its position as a powerful narrative explicitly related to previous narratives put forth by Kanner, Bettelheim and Asperger, but also bringing forth new meaning. While the Wired article was not the first to talk about the idea of a “geek syndrome” per se, it was the first to name it as such and I will make a case for its influence in how we understand and, certainly, idealize this aspect of Asperger’s syndrome. I will be primarily looking at issues of privilege, the question of normalcy relative to other points on the spectrum, representation and discursive strategies. This chapter presents a detailed analysis of how narratives of Asperger’s syndrome have functioned in the media during the time period I have chosen.

In Chapter Four, I take the narratives discussed in the previous chapter and look at their application in other media. Treating these examples like case studies, I examine Aspergian characters on three television series: 24, America’s Next Top Model and Terminator: The Sarah
**Connor Chronicles.** I will compare and contrast these examples to the larger “geek syndrome” narrative. I will additionally be charting their place in the larger arena of Asperger representation.

Chapter Five is concerned with alternate views of Asperger’s syndrome that exist both simultaneously and also contrary to the “geek syndrome” idea. It is my belief that Asperger’s is still unknown enough so that whatever narratives do dominate, they are still not necessarily set in stone. In one example, recent news stories concerning acts of violence by people who are diagnosed have brought with them possibilities of unsettling “geek syndrome” understanding and replacing it with something much darker. Recently, a few have speculated about the Virginia Tech gunman Cho Seung-hui as possibly “having” the disorder. While these types of stories contradict or distort the principal ways we tend to understand Asperger’s, it is imperative to talk about them as Asperger’s syndrome as still “new” enough, in my opinion, to be unstable in terms of its meaning and significance.

Finally, my conclusion will assert my main arguments while placing them within the context of recent developments in the continued evolution of the autistic spectrum. Ultimately, my argument with this dissertation is to demonstrate that narratives *do* matter but also that the further we delve into the topics of ability, cognition, intelligence and capacity, the more these ideas seem to unravel or at least lose some of their certainty.45
In 2001, *Wired Magazine* published an article titled “The Geek Syndrome.” The article was influential for several reasons that will be discussed in the subsequent chapter, such as the titular syndrome becoming a popular nickname for Asperger’s syndrome as well as its explanation for the elevated number of Asperger’s Syndrome diagnoses in Silicon Valley.

This article also addressed one of the fundamental questions raised by the purported autism “epidemic” of recent years. In short, are there more autistic people alive today than in the past or have we only just begun to diagnose them? Has autism been a continuous part of human existence and has it only just been recognized or “discovered” by the medical establishment? Or is autism a strictly modern phenomenon and a new way of sorting people? Explanations for the rise in autism are all fiercely contested.

The most contested of these beliefs is that autism is a direct result of mercury poisoning, particularly mercury-based thiomersal in childhood vaccinations, MMR vaccinations or through vaccine overload. To date, no credible scientific evidence has been found which supports these theories. The chief evidence in support of these claims was a 1998 study linking MMR and autism. In 2010, the author of this study was discovered to have fabricated much of the data.\(^4\) In the wake of this theory, frightening headlines and widespread panic have resulted in numbers of concerned parents withholding vaccinations and a rise in the number of illnesses. The steady rise of autism has been unaffected.

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Others will challenge the “epidemic” as symptomatic of a culture obsessed with the over-diagnosis of its children. Similar to ADD and other diagnoses, this view speaks more to generational anxiety of an “over-medicalized” culture. Many parents express a reasonable and understandable concern that increased medical intervention and the availability of more categories interfere with the “normal” development of their children. Unfortunately, when it is taken to the extreme, one might hear comments such as those made by radio host Michael Savage. In 2008, Savage remarked that autism is a “fraud, a racket...in 99 percent of the cases, it’s a brat who hasn’t been told to cut the act out.” While clearly ignorant, Savage’s comments capture a common bootstrap mentality that maintains developmental disability as somehow resulting from a failure of the parents to “crack down” on their children. As we shall examine in this chapter, this perspective has a very large historical precedent.

Others, however, will argue more convincingly that autism is simply the modern way of explaining those who would have been considered “mentally retarded” or “idiot savants” or even simply “eccentric” in the past. One popular way of exploring this hypothesis is by pointing to history in order to indentify clues of autism’s existence before it was named as such. For example, one idea is that perhaps autism is even the root of the Changeling myths of West European folklore, in which a supernatural being would steal “normal” infants, replacing them with “odd-behaving” and “cold” duplicates. This myth eerily rings of parental testimony of the onset of their child’s autism. Another tactic is to locate famous “autistic ancestors” (such as Albert Einstein or Sir Isaac Newton), posthumously diagnose them and argue that they probably would have been diagnosed with autism had they lived today.

In this spirit of investigating the past for autistic evidence, “Geek Syndrome” author Steve Silberman proposes an interesting scenario at the end of his article:

For all we know, the first tools on earth might have been developed by a loner sitting at the back of the cave, chipping at thousands of rocks to find the one that made the sharpest spear, while the neurotypicals chattered away in the firelight. 48

Of course, even assuming that it was a lone genius that we have to thank for developing that early piece of technology (the spear) we will probably never know for sure his or her identity, let alone their neurological makeup. Of interest here is that not only are we being asked to believe that this monumental achievement could be accomplished by the geek sitting at the back of the cave; we are being asked, in the context of this article, to imagine that achievement was due to the cave person’s autism. This is a fascinating idea, especially viewed in the context of the history of autism, where autistic people have been traditionally seen as contributing very little at best to being societal burdens at worst.

For the moment, let us forget that both autism and Asperger’s syndrome are conditions that are historically and culturally contingent; autism is a term that is meaningless without the linguistic and diagnostic apparatus of our contemporary world to support it. Let us also forget that there is no forensic method of “detecting” such a condition; that autism can only be diagnosed through the observation of behavior and therefore is a virtually meaningless term without modern psychological observation.

Rather, the significance of the caveperson scenario is that it demonstrates that we are at a point where we can be asked to believe that autism was possibly a contributing factor to

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humankind’s development. This brief aside in the article gives us a clue about how we might imagine the past through such a lens. But what is more significant is that this is made possible because this is how we are conceiving of autism in our present. This is representative of a shift in the cultural imagination of this diagnosis.

How we imagine our history very often tells us more about today than the time it purports to depict. Taken by itself, the caveperson story is whimsical and interesting. But we could also consider it as simply an anonymous version of the retrospective (or posthumous) diagnosis that occurs when a famous person from the past is “diagnosed” with an autistic spectrum disorder. Numerous sources suggest individuals such as Einstein, Newton, Andy Warhol, Charles Richter, W.B. Yeats or even the syndrome’s namesake himself, Hans Asperger, may have “had” the disorder. Even contemporary luminaries such as Bill Gates or Steve Jobs have been recipients of speculative diagnoses.

Clearly, autism can’t simply be discussed anymore as a condition that is being stereotyped solely in negative terms, as these are all brilliant and successful people. It is being stereotyped in positive terms as the disorder of the best and brightest as well, so long as the “best” and “brightest” are overwhelmingly male, white, middle/upper-class, high functioning and visible. At a purely surface level, these stereotypes, within the familiar matrix of domination, may be seen to represent positive change for members of a privileged cross-section of the autistic spectrum.

Despite this apparent shift, autism is still viewed as a powerful and frightening word among parents, educators and others, conjuring associated feelings of fear, anxiety and panic. Even more so than the narrative associating autism with genius, we hear about autism in the
context of a disease, a disability, a condition to be “suffering from” or a world to be “trapped in.” Contemporarily, we often hear about autism referred to as an out-of-control epidemic, where one’s child will have a 1 in 150 chance of being diagnosed with autism, according to the Center for Disease Control.

How is it that this “developmental epidemic” can also be credited with providing the spark of progress? How does a “disease” provide so much so-called suffering while providing our “best and brightest?” What role does an organization such as Cure Autism Now serve when the logical outcome of “curing” autism would supposedly threaten our future Einsteins and Newtons? As TIME Magazine suggests “filtering the geeky genes out of high-tech breeding grounds like Silicon Valley, in other words, might remove the very DNA that made these places what they are today.” How can these two ideas about autism, a genius disorder and a dangerous epidemic, function at the same time?

This is a very complicated question. One way to explain it is by making the distinction between Asperger’s syndrome and autism. Asperger’s syndrome has developed a much more visible profile as the high-functioning (and presumably more “desirable”) form of autism over the past decade. With increased levels of awareness, this diagnosis has become associated with very specific ideas and images, most commonly the socially awkward, but highly skilled and specialized persona; the kind of successful “geek,” in short, you might expect to meet in Silicon Valley, according to “The Geek Syndrome.” In a contemporary culture that values both the ability to be successful at social networking and technological specialization, Asperger’s syndrome can be stereotyped as both a disability and as a kind of genetic commodity. Provided that their obsessive interests run to lucrative (usually technological) skills, those diagnosed with

Asperger’s can be represented as ideal workers in an information economy. Autism scholar Majia Holmer Nadesan suggests that the developments of these representations “provide an indication of the beginning of yet another reframing of the culture’s perceptions of the amalgamation of the symptoms we call autism.” These contemporary representations point toward a paradigm shift. In this chapter, to contextualize such a reframing, I would like to examine historically how autism/Asperger’s syndrome has been presented to the public.

The story of autism, as with most disabilities, can most efficiently be organized by tracing the influence of those medical experts who figure prominently in its creation as a category, rather than those people who fall into the category, who would of course probably tell a much different story. I will likewise examine the contributions of some influential experts since it is they who have had the most influence on shaping public discourse on autism. While there are many other people who have also made tremendous contributions to autism research, I have organized my discussion around three only. Specifically, I’m talking about the two individuals credited with simultaneously developing the term autism, Leo Kanner and Hans Asperger. Additionally, it is important to discuss the immense influence of Bruno Bettelheim, who popularized the idea of “refrigerator mothers,” or women who caused their children’s autism. The coincidences of their three stories are jarring. All three men were Austrian psychiatrists who were born and died within a decade of each other. Events within their own lives and on the world stage (particularly World War II) had a significant influence on their work and each contributed a significant amount, for good or ill, to how we understand not only autism, but neurological diversity.

50 Nadesan, 199.
Leo Kanner was born Chaskel Leib Kanner to Jewish-Austrian parents. Originally inspired to be a poet, Kanner abandoned that dream in favor of attending medical school, completing his degree and serving in the Austrian army during the First World War. In 1924, Kanner immigrated to the United States. Only four years later, he received a post at Johns Hopkins Hospital in Baltimore where he worked until his death in 1981. During his career, Kanner became known as the predominant child psychiatrist in the history of the field. A large part of this renown was due to his being credited with the identification of what we would call “autism.”

This discovery took place in 1943, when Kanner published his work with 11 children hospitalized for being “emotionally disturbed” or “mentally retarded.” This monograph was the end result of five years of work, where Kanner recorded symptoms that did not fit the pattern of these children’s diagnoses. Kanner meticulously recorded observations that demonstrated that these children were misdiagnosed. However, no category existed that could reasonably serve as a new classification. Kanner therefore came up with his own classification. He called this new category “Early Infantile Autism.” This term “autism” was identified by Kanner as being a “lack of affective contact, fascination with objects, desire for sameness and non-communicative language before 30 months of age.”

The word itself, “autism,” was not Kanner’s invention, however. Credit belongs to the Swiss psychiatrist Eugen Bleuler, who first coined the term in 1912. Bleuler created the word from the Greek word *autos*, which means “self.” Autism, as conceived by Bleuler, referred to a

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basic trait found in many schizophrenia patients. It referred to an extreme state of withdrawal from social life, with the only remaining interest being their internal world. Freud also used the term; for him “autism” meant roughly the same thing as narcissism.

Kanner adopted the term “autism” and made it his own as a way to describe his patients in his article "Autistic Disturbances of Affective Contact." Using the term differently than Bleuler, Kanner did not feel as if his patients had necessarily “withdrawn” from social life, as the typical schizophrenic was thought to withdraw. Rather, Kanner described these children as having never fully occupied a common social existence in the first place. Some of these children were verbal, others mute; their profound state of autism (or “autistic aloneness”) was a key feature these children shared. Kanner decided that “aloneness” was the most appropriate way to describe children who never withdrew. Extreme narcissism and this aloneness were cast as the two sides of the autistic coin, both having similar manifestations but having very different implications in the popular consciousness. To clarify, Kanner wrote in 1943:

Schizophrenics solve problems by stepping out of the world they are in, while “our children” gradually compromise by extending cautious feelers into a world in which they have been total strangers from the beginning.\(^{52}\)

Kanner’s description of the autistic children resembles exactly what we today call signs of classical autism, early infantile autism or Kanner’s syndrome. While most descriptions of mental disorders of Kanner’s time now seem hopelessly out of date, Kanner’s descriptions of autism are remarkably in synch with what we know as autism in the twenty-first century.\(^{53}\)

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\(^{52}\) Kanner.

\(^{53}\) Grinker, 44.
Kanner had begun the very slow process by which autism was to be seen as a category unto itself, though it would be some time before it was completely divorced from the category of schizophrenia. It would not be until 1980 that it was decided that autism was its own category in the DSM-III. Even so, the identification of this diagnosis and (perhaps more so) the eventual separation from schizophrenic associations was a remarkable achievement.

Part of the impetus for Kanner’s achievements came from his frustrations with the limits of available psychiatric diagnoses and the power with which these diagnoses were reinforced. In Kanner’s time, a psychiatrist working in an institution had very few diagnostic categories to work with. Dementia praecox (which later became known as schizophrenia), manic depressive psychosis, paranoia and a few others were some of a mere handful of labels. The most popular label of all was the category “disorder undiagnosed.” Kanner wished for more available diagnoses to combat the frequency that the patients, many of them children, were rendered undiagnosable, untreatable and relegated to often permanent institutionalization. Kanner disliked labels and the inevitable dehumanization that seemed to come with them. Ironically, the solution to the “label problem” was the creation of more labels.\(^5\)

For Kanner, there seemed to be an emphasis placed on walking the fine line between the importance of describing accurately the symptoms of a patient and crafting a diagnosis, and at the same time resisting the essentialism that grows from diagnosis: the patient’s treatment was a priority and Kanner expressed exhaustion with colleagues who endlessly debated the category of which a particular patient could fit into. The use of the term “autism” as a label to be applied to his young patients was useful to Kanner because it helped provide the most accurate description of their condition and therefore the best treatment.

\(^5\) Grinker, 41.
Kanner’s chief initial frustration was that early infantile autism remained sub-categorized under schizophrenia.\(^{55}\) While “Kanner syndrome” could be separated in daily practice from schizophrenia, the term that would be used to describe most autistic patients remained, nonetheless, schizophrenia. And though Kanner saw autism as distinct from schizophrenia, even he had no way of knowing whether or not autism could be a precursor towards schizophrenia for some patients; his writings on the distinction remain somewhat ambiguous. But nonetheless, autism, in Kanner’s view, was a unique disorder.\(^{56}\) The picture I see of Kanner is of a man at war with the psychiatric establishment, carving out as much nuance as possible from the available jargon.

Being at war with the establishment over labels was one thing; but Kanner’s depiction of autism challenged the establishment in another, even more radical and fundamental way. This was simply in the fact that he believed the condition of autism was rooted in biology; in his words, the children showed “extreme aloneness from the beginning of life.”\(^{57}\)

Believing as he did that these children hadn’t withdrawn in the classical (schizophrenic) sense, Kanner emphasized “inborn disturbances” as the root of the disorder. While Kanner’s work was accepted as a profound piece of clinical scholarship, his contemporaries scoffed at this explanation. Psychiatry, then firmly rooted in the psychoanalytic, could not possibly deal with, let alone treat a disturbance that wasn’t rooted solely in the mind.

After all, if this were true, according to the prevailing psychiatric wisdom of the time, how could it be treated? Or rather, how could it be treated by us? The implication that

\(^{55}\) Nadeson, 11.

\(^{56}\) Nadeson, 78.

psychological illness could be linked to biological causes was an alien idea to the existing psychiatric paradigm.

So strong was the majority opinion within the field that autism was the product of cold and distant parenting, that Kanner himself began to adjust his beliefs and suggested what would be known as the “refrigerator mother” hypothesis. Maintaining that a child’s development will be profoundly affected by the personality and behavior of their parents was a remarkable step away from the idea of “inborn disturbances.” Kanner went against his early instinct and joined with those early “environmental determinist therapists” who viewed autism as the child being emotionally cut off as a result of having an aloof mother. Removing the child from the block of ice in which they were encased by “refrigerator mothers” was a project that psychiatry was equipped to undertake, rendering autism as a treatable condition that has a clear cause as well as people to blame.58

As Kanner worked with these children, he kept records of the behaviors, statuses and demeanors of the parents, almost “as if compiling a secondary archive of evidence relevant to his study.”59 He noted that many of the parents were “unhappy” or “cold.” He even went so far as to describe the mothers of the autistic children (whom he had just named as such) as demonstrating a “genuine lack of maternal warmth” and “just happening to defrost enough to produce a child.”60 But what caused Kanner’s opinion of these “cold” women? One explanation for Kanner’s attitude is that a lack of attachment could be due to the lack of reciprocity in the children. In other words, rather than “cold mothering” causing autism, the effects of a nonresponsive child might influence the mother’s affect. Another reason why Kanner doubted

59 Stuart Murray, Representing Autism (Liverpool: Liverpool University Press, 2008), 171.
his own idea was the fact that there would often be unaffected siblings of the autistic child. If the parenting was causing autism solely, this would not make sense. Then there was also the idea, rooted deep within Kanner’s suspicion of a biological cause, that autism or autistic traits could possibly be hereditary and that this coldness was simply a manifestation of undiagnosed autism or shadow traits. Finally, Kanner’s idea was also conceived of and understood in a culture that understands women as caregivers and men as breadwinners. While the occupations of the father were noted by Kanner, the mothers were singled out and overly scrutinized. Retrospectively, the “lack of warmth” noted in these women could in fact be telling us much more about the researchers than their subjects.

Yet despite this evolution of his thinking, there was still at the core of his belief the idea that autism was a “disease entity”, but one that is susceptible to environmental influences.\textsuperscript{61} This interactionist perspective, mild by today’s standards, was rejected by the larger psychiatric institution in favor of a fully maternal explanation. Just as the severing of the ties between autism and schizophrenia would eventually be overruled by later twentieth century professionals, Kanner’s suspicion of the biological component of autism would eventually be more widely accepted. However, before a biological explanation for autism would be taken seriously as a viable explanation, a maternal explanation for autism would reign as the dominant paradigm in the psychiatric and popular imagination. The figure most associated with this idea was not Kanner, but rather Dr. Bruno Bettelheim.

\textsuperscript{61} Nadeson, 78.
BRUNO BETTELHEIM (1903-1990)

Bruno Bettelheim’s “contribution” to the study of autism was that he strongly positioned the “refrigerator mother” hypothesis as the central explanation for this disability. The destructiveness of this idea is still being felt to this day. One writer describes the experience of having an autistic child during Bettelheim’s heyday thus:

The parents believed what the professionals told them, and the professionals believed Bettelheim. No one questioned his authority. The psychiatrist had ordered her to bring her child in for ‘analysis’ five days a week. The mother was not allowed to sit in the waiting room, so incensed with her was the doctor’s staff. The nurses and receptionists informed her that she could drop the child at the door and wait outside. They never looked at the mother and refused to say hello or good-bye. She had caused this terrible condition in her child, and she merited no human courtesy. She told me that many a day she had stood there — whether in sunshine, in rain, or in sleet — weeping. ‘How did you survive?’ I asked her. “I survived,” she said softly. ‘Some others I know didn’t.’

Bruno Bettelheim arrived in the United States in 1939, escaping from his then Nazi-controlled homeland of Austria. Over the course of the next half-century, before his suicide in 1990, he constructed an enviable, but controversial, public image as a scholar, author, public intellectual and child psychiatrist. Bettelheim’s popularity with the general public distinguished him among his peers. Bettelheim’s rise to prominence can be seen in the context of what Ellen Herman called the “romance” between the field of psychology and the American public. The regulating and explanatory powers of psychological discourse in the post-WWII era demonstrated that a

preoccupation with the mental health of their children should be seen as a prerequisite for acceptable parenting. With his Viennese accent and warm (at least in public) demeanor, Bettelheim fit the stereotypical image of what a psychiatrist was supposed to look like. Likewise, the messages he presented to the public fit the promise that psychology was designed to keep: a “healthy” and “normal” child is possible with parental love and psychiatry’s intervention.

One example of this logic can be found in Bruno Bettelheim’s influential article “Joey: A ‘Mechanical Boy,’” which appeared in *Scientific American*. The article describes Joey, who comes to Bettelheim’s care as a “mechanical child.” Joey had adopted the behavior of a robot, pretending to “plug himself in” before performing certain tasks. He is seen to walk like a machine, eat like a machine, speak like a machine and even toilet like a machine. Through Bettelheim’s intervention, the article demonstrates the process by which Joey becomes a well-developed human being.

Bettelheim’s narrative of Joey is driven by a theoretical argument Bettelheim was known for; beyond being simply a disturbed child, “Joey was a child who had been robbed of his humanity.” And this is precisely what made Bettelheim’s arguments his own: the sense of victimization and of being robbed. A crime had occurred that made Joey “mechanical.” This crime had a culprit and the psychiatrist was in the role of detective, working to find out how this robbery took place. The particulars may change, but any disturbance was the result of the crime of failing to properly love and nurture.

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65 Ibid.
66 Ibid.
In this way, Bettelheim clearly differs from Kanner. The “inborn disturbance” Kanner referred to is very much absent from Bettelheim’s philosophy. To Bettelheim’s logic, such an idea is almost as absurd as a bank which robbed itself. Kanner had been suspicious of the idea of schizophrenic “retreat” from reality, because he saw these children never occupying that social world in the first place. Bettelheim saw the contrary. To him, autistic children were being driven from reality by inattentive and frigid mothering.

“Refrigerator mothers” were just what the nickname suggests: mothers whose emotional frigidity toward their children could directly cause autism. While this seems like an outrageous and offensive idea, it is nonetheless powerful and persistent, even today. As author Stuart Murray says, “it is still intriguing to see how parents are frequently the targets of much of the literature based around ‘treating’ autism.”67 The mother-child relationship remains “pivotal in discussion of autism.”68

I would contend that Bettelheim’s lasting legacy is this very positioning of the maternal relationship as the focus of understanding autism and how one comes to be understood as autistic. Though Kanner first suggested cold mothering as an avenue of exploration, Bettelheim ran with this idea, refined it, sold it and took it farther than it had gone before.

As discussed in the previous section, Kanner had complex and often contradictory ideas about the psychiatric establishment. He had even written a book entitled In Defense of Mothers, in which he urged parents to utilize “common sense” when dealing with mental health professionals, whom he often saw as “bullies.”69 Unlike Kanner, Bettelheim was most certainly

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67 Murray, 15.
68 Ibid.
not conflicted about parents. Bettelheim was known by his staff and patients to be cruel; he often displayed explosive anger to the mothers of his patients. Publically Bettelheim presented a kind demeanor and spoke of “his children.” On-lookers couldn’t help but sympathize with these young children and those parents who abandoned them to an alien existence.70

In short, these children were the product of abuse, according to Bettelheim. Bettelheim’s analogies included referring to parents not only as refrigerators, but as “child-eating witches” or “guards within concentration camps.” Bettelheim stated that children with autism have an “inner reality” comparable to the external reality of the prisoners. The absence of language, he argued, should be recognized as “defense against emotional pain or any further depletion of the self.”71

Bettelheim went on to say:

"I would stress that the figure of the destructive mother (the devouring witch) is the creation of the child’s imagination; though an imagining that has its source in reality, namely the destructive intents of the mothering person….I state my belief that the precipitating factor in infantile autism is the parent’s wish that his child should not exist."72

In reality, the shame and blame most parents of autistic children feel is hardly ever because of their child and certainly not based on a desire for the child to not exist; rather it is the result of a belief, either internal or external, that this is their fault. The belief comes from strangers on the street, friends and family, even their child’s doctors; in essence, the external environment. Bettelheim cannot be said to be the sole proponent of these ideas but he was the most popular purveyor of this belief.

72 Bettelheim, 125.
It is important to point out that the Bettelheim was just that: a popular purveyor. His audience was not necessarily the parents of autistic children. Today of course, there is an industry of prescriptive texts written for parents of children diagnosed with autism. In the fifties and sixties, this would have been a hardly profitable niche audience at best. Rather, Bettelheim’s audience was the parents of “normal” children. The parents of autistic children who were not personally abused by him were bullied or alienated through his rhetoric. Instead he profited from those he could sell his cautionary tales of parents who did not properly love their own children. The parent of autistic child was vilified and made the object of scorn as their children were made the object of pity.

As the parent of an autistic child who was born in 1956, psychologist Bernard Rimland was among the many parents deeply disturbed by this—and not buying it for a second. Unlike most of these parents, however, Rimland’s professional status enabled him to fight back against one of the foremost psychiatric authorities of his day. Rimland didn’t blame himself and particularly not his wife for their son’s autism and he recognized the damage the Bettelheim model was causing. Rimland went so far as to establish the Autism Society of America in 1965: one of the first advocacy groups for parents of children with autism. But perhaps his greatest achievement was scientifically making a hard case for autism as a biological condition. After all, Rimland wondered: how it was that three of the four Rimland children did not have autism if they were such monsters as parents? His 1964 book *Infantile Autism: the Syndrome and its Implication for a Neural Theory of Behavior* (featuring a foreword by Kanner) is regarded as the
principal work that helped to debunk Bettelheim’s work by showing that autism had a
neurological basis, similar to Kanner’s earliest suspicion.\textsuperscript{73}

As Rimland’s work was a direct assault on the Bettelheim idea, Bettelheim countered
with his most well-known book, \textit{The Empty Fortress}, in 1967. \textit{The Empty Fortress}, though
Bettelheim’s most well-known work, is perhaps the last gasp of the cold mother hypothesis in the
scientific community. The tide was beginning to turn against Bettelheim by then. Leo Kanner
referred to \textit{The Empty Fortress} as “The Empty Book.” He emphasized his own initial statement
that autism was an innate disturbance and clarified his own perspective on parenting:

Because I reported some characteristics of some parents … I have been misquoted …

Those of you who have come to me know … I never said ‘parents did it.’ I hereby acquit
you people as parents”\textsuperscript{74}

Kanner’s moment of acquittal was significant though it did not magically create a world in which
mothers were free from blame for autism. The refrigerator hypothesis was further discredited
after Bettelheim’s 1990 suicide. As writer Molly Finn describes:

When Bruno Bettelheim committed suicide in 1990 at the age of 86 he had a towering and
broadly based reputation … within weeks of his death, however, this reputation appeared
to be in danger. Former students accused him in print of having created an atmosphere of
terror in the famous school. Scholars accused him of plagiarism, and stories of falsified
credentials and shoddy research emerged from several sources.\textsuperscript{75}

\textsuperscript{73} Bernard Rimland, \textit{Infantine Autism: The Syndrome and its Implication for a Neural Theory of Behavior} (New
\textsuperscript{75}Molly Finn, “In the Case of Bruno Bettelheim”, \textit{First Things} 74 (1997), 44-48.
Bettelheim’s public identity has been debunked over the past two decades and the distinguished reputation of this controversial and complex man has all but disappeared. Yet, the perception of parental fault still exists. Another parent, author Michelle Dawson, writes:

Bruno Bettelheim is still with us and dictating what we think and do about autism. We know he was a compelling and effective charlatan, but are we aware that he's still calling the shots? Bettelheim's worst and most enduring crime was to create an extreme: to push the pendulum up so high on one side that after its release it swung with a vengeance to the opposite extreme and stuck there. We have progressed from the "Refrigerator Mother" to the "Autistic Person as Poltergeist." Once accused by Bettelheim of being the cause of autism, parents are now seen as its heroic and tragic victims.76

The pendulum from “Refrigerator Mother” to “Poltergeist” that Dawson references hinges upon Bettelheim’s ultimate argument: a lack of knowledge about autism and its causes was tantamount to abandonment and neglect. Love and education were constructed as dependent on one another. In and of itself, this is not a bad thing, as knowledge is a valuable resource for all parents. Dawson’s poltergeist metaphor works doubly well, invoking not just the supernatural phenomenon, but also the classic 1982 film Poltergeist as well. In the story, a family’s love and dedication, more so than the expertise of paranormal experts, results in the rescue of their youngest child from the clutches of the entity that has claimed her. The film works very well as a metaphor for how good parenting in the face of adversity is constructed and celebrated within our culture, particularly concerning the well-being of a child. That a parent would do anything for a child is true. But where the issue becomes complicated is when there is disagreement over

what constitutes good parenting. It is further complicated when we are forced to think about the relation of a “true” self and a “disease entity” (autism) and where and whether a line can be drawn between them. Compared to answering such questions about autism, resolving a supernatural crisis is relatively straightforward. The expectation that to be a good parent is to possess “a love that can counter the destruction that autism brings” oversimplifies the complexity of autism and the roles of parents and creates stakes that are unbelievably high.\(^77\)

A good example of these kinds of stakes can be found in the introduction to actress Jenny McCarthy’s 2007 bestselling book, *Louder than Words: a Mother’s Journey in Healing Autism*. The author of the introduction, Dr. Jerry Kartinzel writes:

> Autism, as I see it, steals the soul from a child; then, if allowed, relentlessly sucks life’s marrow out of the family members, one by one.\(^78\)

In this particular supernatural depiction, autism is decidedly demonic and to counter this force, an equally strong, heroic figure is needed. In *Louder Than Words*, McCarthy, a believer in the theory of immunization-caused autism and that autism can be healed through nutritional intervention, portrays herself as the opposite of the refrigerator mom in many ways—she is a self-proclaimed “mother warrior.” In fact, *Mother Warrior* would become the title of her next book. On a certain level, the idea of a “Mother Warrior” who takes matters into her own hands can be seen as an empowering idea, particularly to the millions of parents who want to be advocates for their children. After the finger-pointing and judgment of the Bettelheim era, such an idea is rather refreshing.

\(^77\) Murray,177.  
\(^78\) Jerry Kartinzel’s Introduction to *Louder than Words* by Jenny McCarthy (New York: Penguin, 2007).
However, there is a way in which the “Mother Warrior” idea is simply the Bettelheim pendulum swinging toward the "Autistic Person as Poltergeist" model. To be a “Mother Warrior,” according to McCarthy, is to wage war on a “life sucking entity.” Again, this is a simplification that depends on conceptualizing a schism between the person with autism and the category of autism. This is a position that is highly problematic in that not all people with autism conceive of themselves in such terms and indeed heavily resist such a conception.

Dr. Michael Fitzpatrick, author of _Defeating Autism: a Damaging Delusion_, refers to the historical link between Bettelheim and modern advocates such as McCarthy:

Yet the concept of the ‘warrior mom’, as McCarthy presents herself in her latest book, is not so much the polar opposite of the ‘refrigerator mother’ as a distorted mirror image. The ‘warrior mom’ is yet another reflection of the culture of mother-blaming and a manifestation of the burden of guilt carried by parents as a result of the influence of pseudoscientific speculations about the causes of autism … Blaming themselves, blaming their doctors, blaming the world, ‘warrior moms’ carry the burden of both causing and curing their children’s autism.79

Bettelheim’s notion of autism is that it is the result of a kind of “crime,” either of action (frigid mothering, vaccinations) or the inaction of failing to “love a child enough” to pursue the appropriate remedies or blame the appropriate causes. When the causes and remedies are contested, as they are today, we see parents yet again in a mode where the rewards for their efforts are often blame and guilt.

Bettelheim’s most enduring legacy, as Michelle Dawson suggests, is the extremism of our available ways to imagine autism: a mother is either a “warrior” or a “victim.” The third and final individual to be discussed in this chapter, Hans Asperger, offers an alternative perspective that may suggest a way to resolve the issue.

HANS ASPERGER (1906-1980)

This chapter began with a discussion of the autistic caveperson as inventor. But the picture we have of autism viewed through the lens of Kanner and especially through Bettelheim does not show us how we can imagine such a person. Autism is, in those views, a disease, a disability, and something to be “defeated.” In Kanner, we have a figure with high institutional esteem and in Bettelheim, a figure who possessed popular prestige. Hans Asperger, on the other hand, was relatively obscure in his lifetime, but his resurgence helps provide the third and final narrative of this chapter, one that offers perhaps a more hopeful vision and lets us see how we can imagine that caveperson as possible.

Though separated from Kanner by a world at war, pediatrician Hans Asperger was doing similar work at the same time with “unusual” children in Vienna, Austria, and is co-credited with the “discovery” of autism. In 1944, Asperger published the article “Die autistischen Psychopathien im Kindesalter” or “Autistic Psychopathy in Childhood.” This work wouldn’t be known except by a very few until after Asperger’s death. One of the reasons why his work was delayed in publishing was that Asperger was not a Nazi party member.

It bears pointing out that in 1944 Asperger did not have access to Kanner’s already published paper nor did Kanner have any awareness of Asperger’s existence. Interestingly, Asperger had in fact already borrowed Bleuler’s term “autism” to describe his patients back in
1938. In this particular case, Asperger used the term “autistic psychopathy.” The word psychopathy was used by Asperger in the technical sense, referring to an abnormality of personality rather than the modern tendency to equate psychopathy with sociopathic behavior. The popular usage of the word “psychopathy” would become part of the impetus to refer to this condition instead as “Asperger’s syndrome.”

Using a similar case studies approach similar to Kanner’s, Asperger published his observations of four young boys, all with similar traits he referred to as “autistic.” Despite both Kanner and Asperger’s use of the label autism, their outlooks differed markedly. Whereas Kanner saw autism as distinct but still as a possible precursor to schizophrenia, Asperger described his patients in a way in which they most likely would not meet Kanner’s criteria for autism, emphasizing the social value of their remarkable focus and ability to devote themselves to various interests. Between the lines, Asperger was making an argument for the social value of autism in a culture “murderously bent on eliminating the unfit.” Asperger saw himself as potentially saving lives through emphasizing “usefulness” in his patients. He romanticized his enthusiasm for their ability, describing their condition as:

… a sort of intelligence hardly touched by tradition and culture- 'unconventional, unorthodox, strangely 'pure' and original, akin to the intelligence of true creativity.

It is partially true, as noted above, that there were life-and-death reasons for doing so. But there was also something more. The patients Asperger worked with all had hit speech developmental milestones, unlike Kanner’s children. In fact, Asperger noted that not only were these children

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81 Paradiz, 68.
speaking, but they were hardly ever quiet! These children were referred to as his “little professors.” He was amazed by their capacity to retain incredible amounts of information about various specialized subjects. Asperger’s staff often wondered how much of a difference there was between the man and his patients. It has been theorized that Asperger may have been recognizing certain personal traits in his patients, as he was seen as socially awkward and had his own obsessive lifelong preoccupations (with the works of poet Franz Grillparzer).

Asperger would later acknowledge the similarities between his “autistic psychopathy” and Kanner’s syndrome—but he believed them to be different as he saw Kanner’s autism as a psychotic process and his own syndrome as a stable personality trait with clear and distinguishable social value. But like Kanner, Asperger considered his syndrome to be genetically transmitted. Also similarly to Kanner, Asperger was very much interested in the parents of the children, particularly their social demeanors and talents.

Asperger was also interested in following his patients from childhood to adulthood. One particular case was his patient “Fritz V”. Fritz V was an 11-year-old boy. This child possessed an extraordinary calculating ability, while possessing very few social skills. Asperger noted that he grew up to be an astronomy professor, one so bright that he identified and corrected a mistake in Sir Isaac Newton’s calculations!

After his initial work was finally published, Asperger was able to create a school for autistic psychopathy, which was a further demonstration of the prevalence of the disorder he classified, since there were enough children to justify a school. Another casualty of war, the school was destroyed during an Allied bomb raid and most of Asperger’s research was lost in the destruction.
What did survive of Asperger’s work was in German and was very rarely translated. Asperger continued to work in relative obscurity, even continuing to work with several of his original patients (such as Fritz). Asperger died in 1980.

Then, in 1981, his work was rediscovered by Dr. Lorna Wing. As one of the most well-respected and influential researchers in the field, she published work which first identified “Asperger’s syndrome” as a way to distinguish a particularly high-functioning form of autism. Asperger’s work was translated into English and slowly Asperger’s syndrome has garnered attention and research. Added to the DSM-IV in 1994, Asperger’s syndrome is now characteristic of a new way of conceptualizing autism as Autism Spectrum Disorders.

Today, in clinical practice, Asperger’s syndrome and Kanner’s syndrome (which is what we conceive of as classical autism) are grouped under the classification of autistic spectrum disorders. In practice, autistic spectrum disorders are defined as pervasive development disorders, which cast a wide net over a variety of traits and diagnoses. Whereas Kanner saw autism ultimately as limited to being associated with schizophrenia and this view was reflected in practice for a long time, the modern conception of autism as being a range of classifications more accurately represents Asperger’s idea of personality traits.

Kanner’s conception of autism was very complicated and was filtered through the dominant views of psychiatry in his time. Kanner was entrenched at the highest level of his profession. Hans Asperger, more isolated in his life’s work, reflects the common trope of the genius, unappreciated in life. As far as Asperger is concerned, ultimately, we know relatively little, except that which Dr. Wing’s research and subsequent others have told us.
In Kanner’s work, we see the origins of the dominant narrative associated with classical autism. The nucleus of what Kanner describes represents the popular, prototypical autistic subject today: language impaired, somehow existing outside an objective social reality. The fact that those labeled autistic have been largely misunderstood, stigmatized, institutionalized and pathologized is not Kanner’s legacy to bear.

Nevertheless, it becomes interesting to speculate then, what if Asperger’s work would have been as revolutionary in its time as Kanner’s or as popular as Bettelheim’s? How would the early view of autism have changed? Would the notion that we have today of a spectrum have arrived earlier? It is impossible to know for sure. What we do see in the 1940s are competing professional narratives of how autism should be seen. One set of narratives, through circumstance, emerged as dominant while the Aspergian narrative would have to wait for popular acceptance.

**CONCLUSION**

In this chapter, I discussed three such narratives associated with Kanner, Bettelheim and Asperger, three individuals who largely created the language that shaped and thus limited how we talk about autism today. Each of these three was representative of a different major paradigm. First, Leo Kanner is co-credited with discovering autism and throughout his long and storied career was able to establish it as a diagnostic and social category unto itself. Secondly, I discussed the tragic and bizarre life of Bruno Bettelheim. Bettelheim’s story displayed the potentially harmful and enormous power of diagnostic language as he became the public face of autism, explaining it to the world as the end result a mother’s failure to succeed at bonding with her children. Finally, the third individual was Hans Asperger, whose work, unlike the others,
was not appreciated in his time. Only relatively recently have large numbers of people been able to have access to the different possibilities Asperger saw for people with autism. These possibilities were informed through a variety of factors, including his initial work in World War II Austria, where he fulfilled his responsibility to emphasize the “usefulness” of his charges.

Where has this emphasis led us? The conception of what autism means and how it could include such people is derived from the narrative associated with Hans Asperger. The emergence of the idea of there being such “value” in such a condition can be traced back to his research. Asperger made a bold argument that autistic people had their place in the “organism of the social community.”

Today, this basic argument serves as the nucleus of a changing idea about the potentials of autism and of disability in general. This chapter has reviewed the importance of three narratives of autism. These stories matter a great deal. In her autobiographical account, *Elijah’s Cup*, Valerie Paradiz, whose son Elijah is autistic, writes:

> Elijah’s identity is encumbered by the paradox that in the moment autism was first identified, it was also loaded up with cultural values produced mainly by professionals. How will I hear my son’s voice if it’s entangled in such a legacy of wartime fear, cultural misogyny, and ideological posturing?”

That is an important question. How we understand autism and those who are classified as autistic depends on how it is that we can untangle these narratives and, possibly, create new ones. In the following chapter, I will demonstrate, through a detailed reading of *Wired Magazine’s “The

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83 Murray, 152.
84 Paradiz, 77.
Geek Syndrome,” how recent narratives about autism and particularly Asperger’s syndrome could be seen as potentially liberating and yet still entangled in the past.
CHAPTER 2
THE GEEK SYNDROME: RE-WIRING ASPERGER’S SYNDROME

“The limits of my language mean the limits of my world.”

-Ludwig Wittgenstein  

I have encountered the above quotation from philosopher Ludwig Wittgenstein in several books on autism. It is a relevant quote to a traditional sense of looking at autism from a medical perspective; the autistic life is often seen as limited due to a lack of language ability. So often because of this limitation, people with autism are metaphorically discussed in terms of their own “world.”

But in another sense, it is also a useful quote to consider from the social disability perspective. The ways we talk about impairment construct disability and essentially limits the mainstream imagining of the possibilities of autism. The subject of language, when someone begins to use it, and how it gets used, is a source of extreme anxiety in diagnosing and treating autism.

I argue in this chapter (and dissertation) that we should be concerned with the ways language about autism frames the possibilities of truly understanding it as a complex biological, historical and cultural phenomenon. In this chapter, I will examine narratives and discursive trends in disability, discuss the modern usage of the term “geek” and the cultural knowledge embedded in that term and complete a textual reading of the Steve Silberman’s Wired article “The Geek Syndrome.”

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AUTISM NARRATIVES

As one scholar, Rosemarie Garland Thomson, writes, “disability always demands a narrative.”86 The Geek Syndrome provides such a narrative by essentially pointing to rising levels of autism diagnoses in Silicon Valley and probing the question of whether or not this can be explained on the genetic level: Can these numbers be explained by the reproduction of the large number of skilled technological workers in that area?

For our purposes, we cannot answer the question of the genetic causes of any autism spectrum disorder. What is interesting in the context of this dissertation is that this theory has elements of a socially positive dimension. Michael Fitzgerald, author of Genius Genes: How Asperger Talents Changed the World, would write: “Psychiatric disorders can have a positive dimension.”87 This is very true, but beyond just having a positive dimension, Asperger claimed that “for success in science and art, a dash of autism is essential.”88

This idea that autism could be considered “essential” to success is a revolutionary idea and, as it turns out, was an idea way ahead of its time. A central question raised by my analysis of Steve Silberman’s 2001 Wired article “The Geek Syndrome” is: Given the history of portraying people with autism as diminished and feeble, how did we get to this point where, without individuals on the spectrum, the “modern world” could be described as “unthinkable.”89 Before discussing this article, I must put it into a context with other narratives that frame and shape this disability.

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88 Silberman.
89 Murray, 37.
As I explored in the previous chapter, I see the genesis of this idea in how Asperger chose to describe his patients. I used Silberman’s analogy of the “loner in the cave” who creates the spear in the previous chapter. This idea clearly is shared by one individual with autism who says “without autism, we might not have fire and the wheel.” Matthew Belamonte argues that autistic behavior can be understood as a narrative drive on the part of the person with autism “to organize reality so that it may be epistemologically ordered and understood,” thus making the person with autism, in a way, “human, but more so.”

If indeed human or more than humangenius have always owed a debt to the autistic spectrum as Hans Asperger claimed, then this is a reality that we as a culture are just beginning to understand in terms of its implications, both today as well as by looking back at the past for evidence of autistic presence.

Autism has been described as both “timeless and totally contemporary.” I find this to be an apt description of this diagnosis because despite the brevity of their “official” existences, autism spectrum disorders, particularly those understood as high-functioning, have a curious habit of being extended backwards (and even forwards) through time. Cave-people “had it.” Einstein “had it.” Warhol “had it.” Bill Gates “has it.” Mr. Spock “has it.” or will “have it,” as the case may be. If we begin thinking about the autistic spectrum as an ingredient necessary for both accomplishing and understanding innovation, then it becomes necessary to look backwards for evidence of its previous existence as well as understand its place in our present and future.

This perspective seems to imply an autistic spectrum that exists separate from the social context in which we understand it today. There is what can be called a diagnostic “precision to

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92 Murray, 11.
the term autism,” that is uniquely tied to our own historical time and place. Yet a whole host of representations, “geek syndrome” included, demonstrate contested meaning. The word autism “has evolved to not simply refer to a specific, clear neurological difference, but a word to describe oddness or even “dangerousness,” which is a subject that will be explored in Chapter 4. Given all of these multiple meanings, scholar Ato Quayson states that the “social treatment of disability has historically been multifaceted and sometimes even contradictory.” Despite any talk of precision or context, the term Asperger’s, autism and other specialized terms acquire new meanings and signification that evolve outside of their specialized usage.

This contested meaning demonstrates that the autistic spectrum is not necessarily “a thing-in-the-world awaiting discovery,” but is perhaps better understood as “a disreputable moral status” filtered through social institutions as a “speakable truth.” Essentially, the “speakable truth” is the diagnostic language that compresses a complex concept into something manageable. The autism we know as a diagnosis is such a “speakable truth,” but so are all of its permutations, such as the “geek syndrome.” This syndrome can be considered as what Ian Hacking calls a “niche disorder.” The niche disorder concept concerns the interaction of biology and culture to effect the creation of disorders that are particular to their time. In essence, Hacking argues, once we identify a type, not only do we look for that specific type, but we begin to examine, treat, market to and generally construct that very same type. The creation of a niche disorder doesn’t indicate that it is solely socially constructed, but rather is culturally expressed in historically specific ways. This is a way to understand how a modern notion of a “geek” might be conflated with a category of autistic spectrum disorders.

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93 Murray, 27.
94 Murray, 9.
95 Quayson, 14.
96 Rapley, 208.
On a surface level, the creation of the “geek syndrome” niche seems to wrest Asperger’s syndrome out of the disability category and places it into the realm of “intellectual difference.” While this is a positive and useful shift, I nevertheless maintain that co-existing with these dimensions are the familiar hallmarks of disrepute historically associated with disability. This syndrome, like many other disabilities, is multifaceted and contradictory.

As a multifaceted phenomenon, the “geek syndrome,” as stated in the previous chapter, is an emerging paradigm but not the dominant paradigm for conceptualizing the disability. The dominant paradigm is still the disease paradigm. This paradigm is based on the medical model of disability, which can be associated more with Kanner’s conception of autism, or, at its worst, Bettelheim’s. Autism in the medicalized model is something to be cured, managed or, as Bettelheim might say, something that one allows to steal one’s children.

This dominant narrative is best represented by the ubiquitous puzzle piece imagery associated with fundraising for autism research. As one individual associated with autism research says, “The puzzle piece is so effective because it tells us something about autism that conforms to our dominant notions: our children are handicapped by a puzzling condition; this isolates them from normal human contact and therefore they do not ‘fit in’.” While the puzzle piece is an effective symbol for fundraising, it is “viewed derisively by activists with autism.” The puzzle piece imagery is more associated with those who “speak for” people with autism; the puzzle piece is derided by those who feel that the puzzle imagery implies that they are somehow missing something. I am not trying to suggest that activists associated with such organization are somehow misguided. Yet, there is a discrepancy of goals between many of those who “speak

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98 Paradiz, 200.
for” autistics and those who often “speak as” autistics. There is an important distinction between autism activists and activists with autism, and in this debate, the message of the puzzle piece is contested. It is perhaps ironic, as has been said, “that the key message of many of these basic education policies is that autism is largely a mystery.” Implicit in the puzzle piece imagery is the promise that autism is a puzzle but one that can be “solved.”

Problematising the medicalized conception of autism as “puzzle” is this “geek syndrome” idea. Taking a developmental disability and reframing it as a valued strength (to say nothing of a product of evolution) raises interesting implications for whether we should be talking about “cures” to begin with.

In our race to cure, manage and hide neurological difference, do we limit or deprive ourselves as a culture of significant contributions or even the best possible life for many of our citizenry? A less dramatic but very relevant question can be posed: Is it possible “to think of autism not as a mental illness that absolutely needs a cure, but rather as a way of life that possesses a deep history and rich culture”? In her account of her son’s autism, Valerie Paradiz says her child, Elijah, “is being framed by a language that cannot shake its negativities, a language so cautiously self-involved with clinical precision that it overlooks the problem of its own ephemeral standards and presumptuous conventions.” Furthermore, she states that:

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100 Paradiz, 12.

101 Paradiz, 68.
In the DSM-IV, there are words that I cannot bring myself to say about Elijah. Words like “lack”, “deficiency”, “impairment”, and “failure”. Condescension litters the DSM-IV and betrays a burdensome psychiatric history.\(^\text{102}\)

This “burdensome” history works to “demand explanation” or “invite correction.” But it is because of how autism, “difficult to identify” and “problematic in its range,” both adheres to and disrupts conventional disability narratives that makes it interesting to see how autism narratives work.\(^\text{103}\) All disability narratives can be shown as multifaceted. But the idea of a spectrum, one that includes low-functioning and high-functioning ends, is particularly useful in showing a multitude of representations, each with very different values attached. The idea of a spectrum does not necessarily resolve the tension between adhering to and disrupting disability narrative, but it does make obvious the reality that there can exist a range of autistic manifestation.

Audiences have indicated that they are interested in engaging with autism, as the condition features prominently is a variety of popular media. Films such as *Rain Man* or novels like *The Curious Incident of the Dog in the Nighttime* have fascinated audiences by offering them windows into autistic experience. These texts, far from simply entertainments, have been called by Stuart Murray autistic “events,” breakthrough cultural moments where audiences felt as though they were receiving special insight into the condition.\(^\text{104}\) The “events” educate those audiences with little stake in the diagnosis and help guide their expectations of what autism is should they encounter it in their lives. As well, these “events” also educate people with autism and their loved ones as to the possibilities of their own lives and the ways in which they are likely to be perceived by others. Representations matter a great deal to the autistic community.

\(^\text{102}\) Paradiz, 67.
\(^\text{103}\) Murray, 3.
\(^\text{104}\) Murray, 12-13.
I argue that *Wired's* “The Geek Syndrome” is also such a defining event. While without the kind of fame that comes with popular fiction, this article does have a steady presence on the Internet. Furthermore, the inclusion of the Autism Spectrum Quotient (AQ) test, a diagnostic tool, still invites audiences to not simply be educated about the spectrum but also to evaluate *themselves* in the spectrum. The Geek Syndrome both invites both the spectatorship reviled by many disability rights activists and also presents the possibility of *inclusion*, for good or ill.

Moving beyond *Wired’s* readership, which skews toward young and technologically savvy, links to the AQ test (now also known as the “*Wired* test”) can be reposted, linked to and pasted in blogs. Examples of AQ questions include: "I prefer to do things with others rather than on my own," "When I'm reading a story, I can easily imagine what the characters might look like," "I usually concentrate more on the whole picture, rather than on the small details," and "I am good at social chitchat." The questions are answered using a Likert scale: one can answer “definitely agree, slightly agree, slightly disagree and definitely disagree.”

As audiences read this article and take the AQ test, I wonder if they ask themselves: would I rather be the neurotypical caveperson blathering away by the fire or would I rather be the spear-maker? In other words, would they rather be the stereotypical jock or the stereotypical geek? On a forum discussing the AQ, one recipient of a high AQ score triumphantly said “I knew I had something in common with the really smart people!”

This, of course, is an artificial choice of constructed, non-mutually exclusive categories. On the Internet, self-diagnosis via self-administered tools such as the AQ or sites such as WebMD is often derided as an epidemic of a kind of on-line Munchausen syndrome.

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But at the same time, another perspective could be witnessing the democratization of diagnostic power. One autistic writer says “It was through the internet that I discovered AS and the whole concept of neurological differences.” And another Asperger’s diagnosee said that “It allowed me to make sense of everything through a new lens.” And if the Internet is described as a “kind of autistic Greenwich Village,” how does a “geek syndrome” change the way in which its denizens choose to see themselves? One website described the article as such:

It created an enduring notion popularized in the media and self-help books that "Geek Syndrome" equals Asperger syndrome and precipitated a rash of self-diagnoses in part because it was printed alongside Simon Baron-Cohen's 50-question Autism Spectrum Quotient Test. Like some people with Asperger syndrome, geeks may exhibit an extreme professional or casual interest in computers, science, engineering, and related fields and may be introverted or prioritize work over other aspects of life. However, no determination has yet been made of whether the "Geek Syndrome" personality type has a direct relation to autism or is simply a "variant normal" type that is not part of the autistic spectrum.

I am not qualified to answer this question or to assess the reliability and validity of Baron-Cohen’s test; rather, I am fascinated with the investment Internet users have attached to it and to this article. For instance, an on-line list of “Aspergian Wikimedians” (those who contribute to

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Wikipedia) featured an accounting of those Wikimedians who identify as having Asperger’s. Out of the list of 75, 14 referenced the AQ test (and score) as their point of diagnosis.¹¹¹

Despite the contested nature of the self-diagnosis, the “Geek Syndrome” offers a new way to understand Asperger’s syndrome as a valued human difference, an ideal long prized by many scholars, activists, families and people on the spectrum. The narrative of the “Geek Syndrome” sets up Asperger’s syndrome as a potentially valuable or attractive option.

However, any potential value of Asperger’s syndrome and the autism spectrum has to be aligned with “a normal world and understood in a way in which it adds to the majority culture.”¹¹² Ultimately, the “Geek Syndrome” does not represent an upheaval of the medical model of disability and does not represent a change in the status quo. Autism has been historically understood in the contradictory context of trauma but culturally represented as the “holy innocent/eternal child” stereotype. This common stereotype treats the disabled as being compensated for their condition by being blessed with a strong, interior wisdom or some type of special insight.

These ideas of trauma and gifts sit together uneasily; one is a reason to panic, the other represents a collective wish for human objects of fascination.¹¹³ I am arguing that “The Geek Syndrome” is a new permutation of this “holy innocent/eternal child” idea, one that is not quite as othered, but more mainstream and acceptable and more subtle. In short, we have moved or are moving from “Rain Man” (as Dustin Hoffman’s character is popularly and alienatingly

¹¹² Murray, 38.
¹¹³ Murray, 94.
referred to) to Bill Gates as the prototypical (and, it is noteworthy, publicly undiagnosed) autistic subject of fascination.

With its discussions of cures and causes and spectatorship of the diagnosis, “The Geek Syndrome” does ultimately fit within the context of a medicalized model of thinking about disability. However, it is a model that invites the reader to consider themselves as potentially a subject rather than strictly as a spectator. When considering the readership of *Wired* magazine, which is largely made up of technologically savvy, hip and (perhaps most interestingly) communicative consumers, it is not a surprise that the article was widely distributed and has had such a long life.

Writing for such an audience also creates new ways to conceptualize the diagnosis. When most of the autistic narratives stress personal and family trauma, what is often missing from autistic narratives is the idea of potential quality of life or *pleasure*. The qualities that are described as part of the syndrome, such as systemizing, are in synch with qualities that Wired’s audience would likely be interested in. The idea of experiencing pleasure as part of the diagnosis is antithetical to most depictions of disability; Wired provided a space where we can understand a more multifaceted view. While the disease narrative does figure strongly in the article, Silberman’s “The Geek Syndrome” does begin to open up the idea of taking pleasure in neurological difference, which is itself a radical act.

As mentioned in the introduction, the two main perspectives disability scholars refer to are the traditional/medical and the social/progressive perspectives. How disability is framed can be divided into those two distinct perspectives. The traditional/medical model focuses on the

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114 Murray, 49.
disabled individual’s differences from others in society. Newspaper coverage of those with disabilities has been criticized as being “stereotypical, paternalistic and inaccurate” in the areas of “issue coverage, role portrayal and language.”\textsuperscript{115} Traditional models of disability tend to view persons with disabilities solely as individuals facing individual problems: this is easiest discussed in terms of the medical model, where disability is an illness, dependent upon professional care for management.

On the surface level, this idea often strikes many as common sense and appropriate. After all, don’t many people with disabilities require medical care? Don’t many people with disabilities need special assistance? And indeed some of these frames help to drive fund raising, breakthroughs and therapies that have positively impacted lives.

At the same time, the way language itself is used is very important in that it can affect individual lives in a less-than-positive sense. For example, to talk of a person as confined to a wheelchair frames the condition in accordance with the victimization model; to talk of a person who uses a wheelchair assigns agency that the previous language sought to take away. This is largely a question of power. Words like “confining”, “suffering” and others frame impairment in such a way that it portrays the impaired as victims.

Who then is granted agency in this particular frame? That is easy: it is the doctor who can treat the condition, the scientist who can find the cure, the worker who builds a ramp or the person making the donation or simply treating the disabled person with the respect and kindness that an unimpaired person doesn’t even need to ask for.

What are disallowed in the framing of disability are socially-produced inequities impacting the disabled. As Stuart Murray says “the dominant arc of most disability narratives is a movement from the representation of impairment to the overcoming of the difficulties that are seen to come from it.”

One frequently used example of this model is what is known as the “SuperCrip” model. In this model, the media frames disability stories as uplifting narratives which call attention to those individuals who achieve amazing feats in spite of particular impairments. This is not to downplay the success of those individuals featured in such stories. But SuperCrip stories highlight the deviance of the disabled. The person then is represented solely in terms of the disability and how hard they work in overcoming it. The SuperCrip story is analogous to the addendum of someone referring to another as being intelligent “for a woman,” talented “for a black person” or athletic “for a homosexual.”

At the heart of this criticism of how disability is framed is the idea that there is a level playing field if only an individual works hard enough, rendering social inequality and ableism a non-issue. Examining the social apparatus that creates disability can be therefore framed as irrelevant or at least secondary. Economically, the traditional/medical model frames economic concerns such as support for the disabled as not a right, but a gift of charity for the passively vulnerable.\(^{116}\)

The social or progressive viewpoint focuses less on the impairment and more on how the society constructs and then understands and treats disability.\(^{117}\) In the progressive model, the limiting aspect of disability lies in society’s inability to adapt its physical, social or occupational

\(^{116}\) Clogston, 47.
\(^{117}\) Clogston, 46.
environment to accept those with impairment. For instance, rather than as “confining,” a wheelchair can be understood as a liberating technology that enables the person to traverse their environment. The disabling element is the environment; in this case, the stairs or lack of accessible ramps creates disability. On a less visible level, a culture that encourages those with disabilities to be seen derisively as “retards,” “cripples” or objects of pity creates the disability. Disability rights advocates adopt a minority/civil rights model and a culturally pluralist perspective in which the person with a disability is given their due as a “multi-faceted individual, with no undue attention being paid to disability.118 One example of how this is manifested is through “person first language.” For example, a “person with autism” is preferred over an “autistic person.” Though the value and effectiveness of people first language is contested, this is a critical example of how language matters to disability. Language is integral to understanding how a population is largely described as powerless and constantly struggling.

This particular narrative of powerlessness is so dominant that it seems as though there is no alternative. After all, if those with disabilities aren’t powerless and don’t struggle, then what is their story?119 This is a good question, because portraying the disabled as victims appears to be the only frame the mass media and public institutions have at their disposal. Moreover, the progressive model, which recognizes complexity, does not lend itself easily to simple narratives.

This can be a serious problem because frames set agendas. The mass media, simply by paying attention to some issues and neglecting others, will have an effect on public opinion, creating the agenda in a sense. The agenda for disability has been traditional. For autism, in recent history, the shorthand has been to label it as the epidemic, a subset of disability invoking

118 Clogston, 47.
119 Murray, xvi.
panic, in need of a cure. But autism, as a spectrum disorder, is a lot more complex. For example, autism has been described as a compressed concept.\textsuperscript{120} This essentially means that it is in fact a large and multifaceted biological and social phenomenon. Thus the frequent shorthand does the complexity of the concept a disservice.

Stuart Murray, author of \textit{Representing Autism}, wrote of creating a Google news alert for the word “autism” and how the vast majority of hits he received showed individuals coping with autism and families needing resources. Of course, there is truth and heartache related to this experience. But yet, as Murray notes, the most numerous stories were personal stories of triumph and heartbreak that are readily consumable narratives. These were followed by stories that focused on the medical investigation of the autism “epidemic” and treatments available: the “puzzle piece” narrative in short.\textsuperscript{121} Murray identifies a strange kind of “social narcissism” that suggests that autism can only be understood through “external parameters focused on majority concerns,” like a mother coping or a marriage coping.\textsuperscript{122} For all the well-meaning reports, most of the alerts Murray received showed a population of “victims” being cared for by “victims.” This is the same basic story the Bettelheim narrative used but with a much nicer sheen. In short, the public discourse on autism is being framed in much the same way it always has been.

The type of framework used to discuss “The Geek Syndrome,” as we shall see, is not radically different from the above discourse, but shares more in common with the progressive model in terms of giving more agency to people with autism (as well as to their parents, etc.) and communicating the increased complexity that the subject deserves. One such progressive model that might be able to help communicate the complexity of the diagnosis is the concept of

\textsuperscript{121} Murray, 2.
\textsuperscript{122} Murray, 15.
neurodiversity. In many ways, the idea of neurodiversity, in which neurological difference is seen as a natural and possibly welcome phenomenon, complements the social model perspective of disability. The term first started appearing in conferences, chat rooms and communications around the year 1998. Credit for the first use of the terms is usually attributed to an Australian graduate student and autism activist named Judy Singer. Singer herself says that she’s not sure if she coined the phrase or whether it was simply “in the air.” Indeed, it was no accident that this term first was “in the air” at a moment when we have the technology for many people on the spectrum to communicate with each other instantly over vast distances. We have many terms available to us to describe disability; neurodiversity is one of the few generated largely within the population it is meant to describe.

GEEKS?

Is the “geek syndrome” concept fully compatible with the ideal of neurodiversity? The answer is a bit ambiguous. As pointed out earlier in this chapter, the geek syndrome has not been a true counter-narrative but rather is a narrative that modifies existing traditional discourses of disability. As many scholars who have worked with the subject have noted, autism is a subject that is met with both fascination and pathophobia. Fascination with autism is usually directed toward the image of the autistic savant. In the case of Asperger’s syndrome, savant genius has given way to the “geek” stereotype, framing this fascination in synch with contemporary cultural values. As one article states:

It was *Wired* magazine, the high-tech bible, that coined the term Geek Syndrome for the Silicon Valley autism explosion. Not long ago it would have come off as a school-yard...

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slur. But the computer revolution made geek chic -- not to mention wealthy, powerful and proud.\textsuperscript{124}

It is true that not so long ago, to be called a “geek” was usually taken as an insult and the idea of a “geek syndrome” would have been viewed as a widespread insult towards an entire community. In fact it is hard to imagine such an insult appearing in a major magazine such as \textit{Wired}. Why then is the Asperger’s syndrome called the geek syndrome? Why is this not taken as an insult? How did \textit{geek} become \textit{chic}?

The term “geek” is possibly a variant of the word \textit{geck}, which meant a fool, dupe or simpleton. In the U.S., the historical basis of the word is largely associated with a carnival or circus performer, one who participates in acts such as biting the heads off chickens or eating live mice. In this way, the etymology of the word could be seen as always showing a combination of foolishness and specialized (though macabre) skills.

The advent of “geek culture” has greatly reduced the use of the term as a pejorative. The change of the term from a primary school putdown into a self-applied identity appears to be wrapped up with the development of an information-based economy and a shift in what constitutes valued skills. As author Neil Feineman writes in 2005:

\begin{quote}
Geek: A member of the new cultural elite, a pop culture-loving, techno-centered Community of Social Discontents. Most geeks rose above a suffocatingly unimaginative educational system, where they were surrounded by obnoxious social values and hostile peers, to build the freest and most inventive culture on the planet: the Internet and World Wide Web. Now running the systems that run the world. Tendency toward braininess
\end{quote}

and individuality, traits that often trigger resentment, isolation, or exclusion. Identifiable by a singular obsessiveness about the things they love, both work and play, and a well-honed sense of bitter, even savage, outsider humor. Universally suspicious of authority. In this era, the geek Ascension, a positive, even envied term. Definitions involving chicken heads no longer apply.125

The September 2005 TIME magazine article entitled “The Geek Shall Inherit the Earth” further states:

It's as if the economic hegemony of the geek in the 1990s, when high tech and the Internet were driving the economy, has somehow been converted into a cultural hegemony.126

The celebratory tone of these pieces suggests a revolution of sorts, a “revenge of the nerds” scenario with utopian images of the web as a space where boundaries cease to be important. However, virtually all cyber scholarship today suggests that inequality due to identity still exists on the Internet. By saying they no longer matter, these utopian beliefs help to reinscribe the privileges of race, gender, etc.

Gender privileging is articulated by Sidney Eve Matrix, author of Cyber Pop: Digital Lifestyles and Commodity Culture, who discusses the change in fortunes for the term “geek” as resting on the idea of “technomasculinity.” Matrix sees today’s proliferation of images of heroic and successful “geeks” as being rooted in traditional ideas of masculinity in the guise of technomasculinity, where the “geeks” are the ones who possess the power (technoliteracy) to

manipulate “the central commodity of digital capital culture, which is information.”127 In this way, the geek figure can be associated with power, demand and success but still be seen as the underdog.

Perhaps the best cultural representation of this idea of technomasculinity is in Apple’s “Get a Mac” advertising campaign. In this campaign, actors Justin Long (“I’m a Mac”) and John Hodgman (“I’m a PC”) engage in a series of skits, the purpose of which is to showcase the superiority of Apple to Microsoft. In a typical ad, the casually dressed and soft-spoken Mac will be revealed to be superior to the fussy, stodgy, suit-and-tie clad PC. Justin Long, often cast in geek roles in films such as Galaxy Quest and Live Free or Die Hard, is the perfect portrayer of this technomasculinity: his coolness and confidence is contrasted with PC’s dork-like lack of mastery. Mac is allowed to be both a geek and cool. What we see here is the placement of “geek” qualities as being desirable.

However, that desirability is only possible through the denigration of PC. A hierarchy of what constitutes “coolness” is being created and the Mac-level geek is not at the bottom of geek hierarchy. This point is reflected on a popular T-shirt design, which reads:


Many on-line stores sell such merchandise, based upon the thesis that geeks “get it done.” You will notice that in the geek conception, the emphasis is on creative and intellectual power, rather than the passive (the Nerd who merely understands and collects) or cluelessness (the confused Dork.) The appropriation of a marginalized status and celebration of differences depends on a

hierarchy; Mac is only cool if PC is seen as a dork. It would seem that even if we live in a “geek world,” there will (unfortunately) always be someone getting stuffed in a locker.

Infused with this idea of technomasculinity, the term geek is even celebrated on Geek Pride Day on May 25th of every year (paying homage to the anniversary of the beginning of the Star Wars saga). This newfound celebration of “geek pride” is especially critical in the way it marks a shift towards establishing the personal value of workers in an information society. I believe the cultural work of this geek renaissance has been reasserting traditional ways of understanding power within an information-age context.

What is significant is that the advent of “geek chic” has taken Asperger’s syndrome along for the ride, conflating the idea of geek chic and this diagnosis. Temple Grandin, a best-selling author and scientist with Asperger’s syndrome, states:

We wouldn't even have any computers if we didn't have Asperger's. All these labels -- 'geek' and 'nerd' and 'mild Asperger's' -- are all getting at the same thing. The Asperger's brain is interested in things rather than people, and people who are interested in things have given us the computer you're working on right now.128

What is coming across from Grandin’s idea is both a reiteration of the value that neurodiversity has to our culture but also a blurring of the lines between these terms: the heavily medicalized Asperger’s and the more amorphous and flexible geek idea. That Grandin, as a brilliant woman, is speaking these words demonstrates that the often-expressed emphasis on the technomasculine is not the inevitable result of this conflation.

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128 Tracy Mayor, “Asperger’s and IT: Dark secret or open secret,” Computerworld Management, 2 April 2008.
Of course, there is also a visible tension in Grandin’s statement, which is between the conflicting ideas revolving around technological skill and an interest in *things* to the exclusion of people. Autism scholar Majia Holmer Nadesan discusses the tension inherent in savant fascination, of the person with autism’s capacity for being represented as somehow “machine-like” or “scary.”[^129] The prospect of an autism “epidemic” has been theorized as the “medical hysteria rooted in our collective fears” at a time when computers make us feel “less than human.”[^130]

Might Asperger’s syndrome, that mild variety of autism as Grandin puts it, be that cyborg entity, a blend of the person (normative) and machine (autistic) mediating the tension and fear created by the autistic epidemic? If one considers Asperger’s syndrome to be the “geek syndrome,” then the twenty-first century representation of the geek replaces that machine-like terror with Mac-like confidence and authority.

Now far from being scary, this geek reframing makes it more possible for more people to understand the contributions of autistic people. One welcome example might be the rise of celebratory themes. A cursory look at larger book stores reveals not only the expected self-help books for parents of children of autism, but books for the children themselves, some written by people on the spectrum, such as *All Cats Have Asperger’s Syndrome* and *Different Like Me*, a children’s book which looks at Thomas Jefferson, Andy Warhol, and Albert Einstein as idols for Asperger’s kids. In *Different Like Me*, a child says:

> Sometimes I wonder about all the autistic people who lived before, though. Most probably never met anyone else like them. They must have thought that they were the

[^129]: Nadesan, 216.
only ones who ever cared more about trains, or music, or the planets, than about making friends. They probably assumed that every person on earth but them knew the secret to fitting in. Did they wonder why they weren’t like everybody else? And how did they turn their unique abilities into something great? It’s hard to say for sure, but there are even some famous people who I think may have been different like me …”

Here we see a “hidden history” of autism being uncovered. Retrospective diagnosis is, as Stuart Murray says, “a fraught process that is all too open to the abuse of the lazy claim, it can also be a radical critical intervention that is enlightening in extending the parameters of how we understand and read disability.” While autism spectrum disorders such as Asperger’s are ultimately products of their time, the making of an autistic history can be seen to be empowering. It is hypothetically empowering to a child who might have been told, even just a generation ago, that their best hopes lie in dependent, hidden existences, that their obsessions and interests are an embarrassment. This same child might now be taught to celebrate these differences. All the while, the great thinkers, artists, scientists are offered as role models.

Hans Asperger referred to his young patients as “little professors” and one occasionally will hear Asperger’s syndrome referred to as “little professor” syndrome. But that term hasn’t “stuck” in the same way that the “geek syndrome” has. The cultural capital of a “professor” is today eclipsed by the capital of the cyber world. To be the little professor might be understood and being quant and childlike; to be a geek is understood more and more to have power. Silberman’s “Geek Syndrome” is a representation of such a niche disorder, one that is very particular to our technomasculine cultural moment.

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132 Murray, 51.
The first line of Silberman’s “The Geek Syndrome” reads simply:

Nick is building a universe on his computer. He's already mapped out his first planet: an anvil-shaped world called Denthaim that is home to gnomes and gods, along with a three-gendered race known as kiman. As he tells me about his universe, Nick looks up at the ceiling, humming fragments of a melody over and over.¹³³

It appears that this article is beginning with an idea of the autistic child in their own world. This is the arguably the most common trope in all of autistic representation; people with autism, particularly children, are set apart in a ‘strange and sad world.’¹³⁴ Amanda Baggs later said in a separate interview with Wired, “I’ve said a million times that I’m not trapped in my own world. Yet what do most of these news stories lead with? Saying exactly that.”¹³⁵ While trading in the spectacularized language of the “lost child,” consider the difference between being “trapped” and how Silberman presents his subject: Nick is not necessarily “trapped.” Rather, I refer to Nick as “world-building.” In the “trapped” idea, the autistic child is portrayed as isolated in their own experience. It might be a positive world they are trapped in, perhaps, but nonetheless, they are without agency. When the autistic (usually) child is portrayed as world-building, on the contrary they are actively creating.

A famous fictional example that is on the border between being trapped and world-building is Tommy Westphall, the fictional child from the television series St. Elsewhere. In the final episode of that series, it was revealed that the entirety of the series took place in the

¹³³ Silberman.
¹³⁴ Paradiz, 90.
imagination of the autistic Tommy as he gazed into a snow globe containing a replica of the titular hospital. This is a romanticized version of world-building which calls on an audience to gaze with wonder at the brilliant but solitary autistic mind.

The difference between Tommy’s conjuring of *St. Elsewhere* and Nick’s conception of Denthaim is that Nick’s universe depends on his real-world skills, which are used to build this place on his computer. Tommy, who existed in the mind of the creators of the show, dreamt the show in a way only he could experience. In the world-building paradigm, we can all enjoy Nick’s universe. Nick’s computer skills are valued and can be commodified. Nick is building a universe that we all can live in rather than living in one of his own, or being “trapped.” Nick is being framed like a typical autistic child, except, like our T-shirt example from earlier; Nick is being fixed on top of the “geek hierarchy.” Technomasculinity depends on the ability to act as creator and receive credit for the creation, not the more passive dreaming of Tommy.

Following Nick’s introduction, the article presents a brief history of autism. After portraying Nick with more agency than one typically sees in such articles, the original patients of Asperger and Kanner are described as seeming to “withdraw into iron-walled universes of their own”, establishing the article as a place where traditional ideas of disability mingle with ideas of autistic agency. Describing Asperger’s syndrome as a “milder version of the condition Rain Man had,” we are told that there is “no miracle drug, no cure.” Even while the article is asserting the social value of certain aspects of Asperger’s syndrome, it does so by invoking the particular style of writing about autism associated with the medicalized narrative. We are told that “something dark and unsettling is happening in Silicon Valley.” Silberman writes:

> Autism's insidious style of onset is particularly cruel to parents, because for the first two years of life, nothing seems to be wrong. Their child is engaged with the world,
progressing normally, taking first steps into language. Then, suddenly, some unknown cascade of neurological events washes it all away.  

One parent in the article says that onset of autism was like "watching our sweet, beautiful boy disappear in front of our eyes." While the article ultimately sympathizes with these parents rather than demonizing them in true Bettelheim fashion, the idea of the “child washed away” is nonetheless associated with Bettelheim’s writing. Like the child in their “own world,” this is a common example of how autism is talked about in the media. A great example of this idea is present in Jenny McCarthy’s narrative of her own experiences in *Louder than Words: A Mother’s Journey in Healing Autism*. She writes of her experience of hearing her son’s diagnosis:

I almost felt betrayed, like I didn't know this child standing in front of me. Everything I thought was cute was a sign of autism and I felt tricked. I guess the doctor sensed this from me because he turned my head back toward him and said, "He is still the same boy you came in here with."

No, in my eyes he wasn't. This was not Evan. Evan was locked inside this label, and I didn't know if I would ever get to know who Evan really was. All the behaviors I had thought were personality traits were autism characteristics, and that's all I had. Where was my son, and how the hell do I get him back?  

What we see happening in this quote is a common scene from many parental accounts: the moment of diagnosis. In this instance, McCarthy describes her son, in essence, as now

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136 Silberman.
137 Ibid.
“missing” and her effort turns to rescuing him. As described in the previous chapter, in the Bettelheim paradigm, it is the mother who is responsible for her child’s autism; in the post-Bettelheim paradigm, the mother is responsible for the cure. It is crucial to remember that such reactions to autism, no matter how strongly felt, are nonetheless socially produced. A large part of that production is the result of the types of lives that we can imagine for people with autism. When I hear the reactions of parents, it is often with a projection of fear over what the future holds or doesn’t hold.

Of interest is how, even while trading in established tropes, in “The Geek Syndrome” Silberman counters this fear by pointing to other possibilities for future lives. Autism (of a high functioning variety) still is seen as a label to be “locked inside.” The “geek syndrome” presents a wider variety of possibilities. This is in essence the Asperger paradigm as opposed to the Bettelheim paradigm. Rather than the medicalized idea that states that only professional intervention can ameliorate or change the person’s condition, success might result from that condition itself. Intervention is not being taken off the table, but rather the key to success is the nurturance of abilities that may come with certain points on the autistic spectrum.

Silberman also problematizes the “bad news” of autism. He quotes one expert who asks a simple question, of a child, “How much eye-to-eye contact is normal?” This is an interesting moment that raises questions of the social dimension of disability, that “how much” of many kinds of behavior is arbitrary and socially constructed. It brings to mind just how problematic it is to operationally define normal. Ian Hacking’s idea of looping is relevant to this problem. “Looping” essentially refers to the idea that the types of people scientists wish to study will be the types of people they end up producing. Hacking uses as an example of this the idea of a “flat” speech affect. In the early days of autism, both Kanner and Asperger stressed the
relevance of flat affect as a feature that was strongly identified with autism. Today, the flat affect is no longer as significant diagnostically. The types of people being “made up,” to use Hacking’s term, are not the same.

This line of reasoning constructs the basis on which Grinker and others argue that the rising numbers of diagnoses are the result of new diagnostics. But at the same time, the article only goes so far with this idea, quoting one source: "Anyone who says this epidemic is due to better diagnostics has his head in the sand."\textsuperscript{139}

Silberman largely uses the biological explanation of positive assortative mating (to explain the rise of autism in Silicon Valley. The basic idea of this assortative mating is that when two beings that are similar to themselves mate with one another, they will increase the likelihood of increasing the range of variation. In terms of Asperger’s, the article argues that an environment that attracts and then financially and socially rewards traits associated with the diagnosis will result in more children being born with Asperger traits. Of course, one thing that almost all researchers in the field agree on is that genetic predisposition plays a crucial role in laying the neurological foundations of autism in most cases.\textsuperscript{140} What emerges in the “Geek Syndrome” is that there is an interactionist perspective combining the biological and the socio-historical, very similar to Kanner’s interactionist conception. Consider the following excerpt from “The Geek Syndrome”:

The bad news from Santa Clara County raises an inescapable question. Unless the genetic hypothesis is proven false, which is unlikely, regions with a higher than normal distribution of people on the autistic spectrum are something no researcher could ask for:

\textsuperscript{139} Silberman. 
\textsuperscript{140} Ibid.
living laboratories for the study of genetic expression. When the rain that fell on the Rain Man falls harder on certain communities than others, what becomes of the children?

The answer may be raining all over Silicon Valley. And one of the best hopes of finding a cure may be locked in the DNA sequences that produced the minds that have made this area the technological powerhouse of the world.141

The interactionism of Kanner, the “bad news” of Bettelheim and the valorization of traits associated with Asperger can all be seen represented in this above section. We might see all the historical forces behind the label “autism” appearing in this article. From my perspective, I see Asperger coming through this article the strongest. From Nick’s world-building to the example of the caveperson to the “best minds” of Silicon Valley, we see the strong sense of intellectual privilege and valorization associated with autism.

Yet at the same time, the other paradigms are present enough to present tantalizing contradictions. Observe the ways in which Silberman’s article is categorized: “It was the Silicon Valley connection that led *Wired* magazine to run its geek-syndrome feature last December. The story was basically a bit of armchair theorizing about a social phenomenon known as assortative mating.”142 This assortative mating has led another writer to describe the article as “Another hint that the brightest weren’t supposed to mate.”143 From “The Geek Syndrome”:

141 Ibid.
142 Nash and Bonesteel.
The chilling possibility is that what’s happening now is the first proof that the genes responsible for bestowing certain special gifts on slightly autistic adults – the very abilities that have made them dreamers and architects of our technological future – are capable of bringing a plague down on the best minds of the next generation.\textsuperscript{144}

This is a crux of the article and with it the central problem: a community whose very genius comes with a price. Of the three major figures we identify, Asperger most strongly argued against a disease-mentality to understanding autism, focusing instead on the talents of his patients. “The Geek Syndrome” can then be seen as a modern reiteration of the Asperger thesis.

But it can only be understood in a context of a disease narrative. Which explains why “The Geek Syndrome” can be heralded by some as a celebration of valuing autistic identity, but at the same time be the recipient of a Cure Autism Now award in 2002. Cure Autism Now is a pro-cure organization reviled by many autism self-advocates. There is a large contradiction at play here, as quarters with radically divergent ideologies both have praised the same article. A news piece about an autism fundraiser, titled “Stars CAN do about defeating autism,” illustrates this same contradiction:

And computers and computer "geeks" may hold the key is solving the autism puzzle.

Genetic arguments have particular cache in Silicon Valley, bolstered by recent marked increases in the birth of children with autism and a milder related form called Asperger's syndrome. Investigative reporter Steve Silberman broke this disturbing trend in Wired Magazine late last year. And that makes the Facing Autism event potentially more powerful than ever. High-functioning people with mild autistic traits find the mechanical

\textsuperscript{144} Silberman.
precision of computer programming a welcome one because they often thrive on tasks that demand order and continued close attention. They may read, create, and decipher complex computer language more easily than unravel the subtle social cues and facial expressions most of us learned to read in early childhood. Concentrate these "computer geeks" who may have a few of the 20 or so autism genes in a tight geographical area and they'll be far more likely to meet others just like them and raise children —- explaining the area's rise in Asperger's disease. At least in theory. In short, the very people who rule Silicon Valley may have a dedicated workforce that involves autistic abilities and disabilities, the interest to back research, and the collective computing and programming power to accelerate genetic research to new levels. "If more people understood how close they were to finding out what causes this, they'd be more likely to jump in and provide more money," says Robinson. "All these possibilities make Silicon Valley pretty exciting and a very encouraging place to be for this event. We are getting closer to a cure, and that will really be something."\(^{145}\)

It is really something, especially when we consider that we are talking about the theoretical possibility of a population essentially curing themselves of a condition using the very skills that they hope to remedy. As Silberman writes, the “ultimate hack for a team of Valley programmers may turn out to be cracking the genetic code that makes them so good at what they do.”\(^{146}\)

But what about the wife of a Silicon Valley software engineer who claims that her Asperger's son represents the fourth generation in just such a lineage of genius?\(^{147}\) Here we see again this contradiction at the heart of this discussion. Are we discussing autism as a collection

\(^{145}\text{Mike Falcon, “Stars ‘CAN-do’ about defeating autism,” } \textit{USA Today}, 10 April 2002.\)

\(^{146}\text{Silberman.}\)

\(^{147}\text{Nash and Bonesteel.}\)
of behaviors (positive and negative) or strictly as disease? If we understand this as a disease rather than a collection of behaviors, those who argue for autism as a way of being and identity see the cure discourse as a clear threat to their existences. This is similar to the debate over cochlear implants resulting in the diminishment if not outright destruction of the deaf community. Intervention at some level can be understood from certain points of view as a destructive act. David Anderegg, author of *Nerds: Who They Are and Why We Need More of Them*, addresses this issue directly:

Okay, maybe the term "genocide" is too strong a word, but if nerdity is a condition that, like homosexuality, is thought to be biologically based and still (unlike homosexuality) officially an "illness" of some kind, then we have to decide whether or not we want to cure it … But, as Silberman points out, if the problem really is genetic, are people really going to look to a bright future when we have selective breeding to produce more people with great eye contact and melodious voices and fewer people like Thomas Jefferson or Bill Gates? Would we expect nerds and geeks to participate in their own genocide?

But, if there were a nerd genocide, it would need to be endorsed not only by parents of nerds-in-utero but also by nerds themselves. In this case, the genocided would have to be invented and carried out by the very people it might seek to extinguish.¹⁴⁸

So-called “nerds” or “geeks” erasing themselves is a disturbing proposition. Far more immediate however is the reality of how this disease narrative affects other points on the spectrum. Genetic counselor Kathleen Fergus writes of the possibility of future prenatal screenings for autism:

Termination of fetuses with Down syndrome is routine today; given the fear that autism inspires in parents, why wouldn't it follow? And what would our world be like without autism? The vast differences among individuals on the spectrum make the notion even thornier: will parents start demanding to know whether their fetus will be low-or high-functioning? But it's also impossible to ignore the parents who say they'd do anything to free their children from isolation and pain. Some feel so hopeless so much of the time, they do wonder in private if their children would have been better off not born. And who can blame them?149

It is hard to not be reminded of Bettelheim’s theory of the parent’s wish that the child “should not exist.” Silberman quotes Bryna Siegel, an autism researcher described as like “the children whose mysterious world she navigates, Siegel prefers to march to her own drummer,”150 Siegel, a student of Bettelheim’s, disagreed with her famous teacher on numerous things (to put it mildly), including the question of biochemical markers in autism. Ironically, Bettelheim had the opinion that proof of the existence of such markers would work to dehumanize children, creating in essence a genetic underclass. Siegel questions whether a "cure" for autism could ever be found and comes to a conclusion similar to Fergus’:

"The genetics of autism may turn out to be no simpler to unravel than the genetics of personality. I think what we'll end up with is something more like, 'Mrs. Smith, here are the results of your amnio. There's a 1 in 10 chance that you'll have an autistic child, or the next Bill Gates. Would you like to have an abortion?'"151

151 Silberman.
In Siegel’s hypothetical example, the possibility and implied value of the “next Bill Gates” is weighed next to the perceived danger of the (presumably lower functioning) autistic child. Silberman quotes Dan Geschwind of UCLA who states: "In the parents, who carry a few of the genes, they're a good thing. In the kids, who carry too many, it's very bad." Dr. Eileen Costello, a pediatrician, further illustrates this idea saying that:

The sort of stereotype of the Asperger’s child is that they’re all going to go to MIT and be Bill Gates and start Microsoft and be millionaires and who cares how weird they are. And, you know, that’s true for a small segment of this population, but it’s just too appealing to think that’s where they’re all going, because it just isn’t true.  

Here the notion of a spectrum is revealed in terms not simply of range of experience, but also of a spectrum of culturally valued traits. This idea uncovers a fundamental truth of the geek formulation: high-functioning autism cannot exist without simultaneously understanding other kinds of autism as inferior or less valuable. Majia Holmer Nadesan cites Silberman’s “Geek Syndrome” and subsequent articles in *Time* and *Newsweek* as the beginning of a kind of de-pathologizing of high-functioning autistic difference:

The writings provide an indication of the beginning of yet another reframing of the culture’s perceptions of the amalgamation of the symptoms we call autism. Although these affirmative representations of high-functioning autism tend to standardize, homogenize, and stereotype the intellectual strengths and weaknesses of all those who bear the label of AS, they do de-pathologize the disorder and offer parents and people with high-functioning autism a strategy for reframing behavioral oddities in ways that

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may, at least partially, valorize, rather than pathologize, their eccentricities. At least, these new formulations lessen cultural stigmatization by deflecting attention from the “developmental” limitations of a medicalized disorder without invoking the morally inflected baggage of the personality disorder.¹⁵³

Nadesan goes on to say that the result of this reframing is the heightened argument of autism advocacy to regard high functioning autism as more of a “cognitive style” as opposed to a developmental disability. Nadesan places “The Geek Syndrome” in a prominent position in this contestation over the divisions between cognitive style and disability. While the vested interest in pro-cure advocacy groups remains in treating autism like a disease entity, both pro-cure and anti-cure interests can be seen to agree on one goal: elevating the social value of high-functioning autism, particularly Asperger’s syndrome. A parent of a child with autism says:

As much as I believe in self-determination—the right to be different—for adults with cognitive disabilities, it may be unrealistic to ask parents of severely impaired kids to refrain from trying to “fix” them. But lowering barriers? There’s a battle cry that parents and self-advocates should be able to all get behind.¹⁵⁴

This is a very understandable position that I have read expressed by many parents, particularly those whose children require services: lowering barriers while not forsaking clinical intervention. Unfortunately, the ways in which individuals (both children and adults) are framed in discussions have little to do with their reality but more to do with the essentialized understanding of autism, where either the autistic is severely disabled and requires curing or possesses “compensatory gifts” and is only marginally autistic. This idea is understandably very offensive to many people

¹⁵³ Nadesan, 199-200.
on the spectrum, but the logic serves a political goal of making autism into something that 
always has to be corrected or cast into doubt.

Elevating high functioning autism in terms of its social value and lowering barriers is 
vitally important and worthwhile. Yet, emphasizing high-functioning autism as a “cognitive 
style” in order to reassert autism as a disease entity re-pathologizes those whose skills are not 
valued or recognized by society. In this way, it reasserts the traditional model of disability 
through the creation of a hierarchy.

Autism rights activist Amanda Baggs, for instance, has been accused numerous times of 
not having “true” autism. As someone who has been defined professionally as low-functioning, 
one once she started to express herself in more conventional ways and was understood by observers 
as therefore intelligent, she could no longer be truly autistic. Some have claimed that she was 
either faking it or perhaps brought the condition, whatever “it is,” on herself, perhaps through 
drug abuse. We learn very little about the actual Amanda Baggs from this kind of discourse, but 
we can certainly see the various ways her reality is being framed for us. Baggs becomes 
problematic because she cannot neatly fit anywhere; first she is disappeared through her 
disability and once she takes a platform again, her critics attempt to take away even the position from which she speaks. Writer Cal Montgomery states that the high/low distinction seems very 
often to be a fight over the kinds of lives made available to autistic people, such as Baggs.
Montgomery further states:

Awareness, of course, is a standard goal of almost every book, article, lecture, and 
documentary about disability: the intended audience is obviously nondisabled, is 
Obviously curious about disability, and cannot be insulted by the suggestion that maybe
they're a bit voyeuristic. Nope, they just want to be aware, to understand, to become educated about the sort of people we are. Not the sort of things that are done to us, but the sort of people we are.155

Nadesan agrees, stating that the simultaneous elevation and denigration of “high-functioning” autistic characterizations speak more to cultural preoccupations than they do to the “essential” autistic personality.156 This article is a representative text of current cultural preoccupations with autism because of how, with the catchy name “The Geek Syndrome,” it represents the ambivalent, complex and contradictory understanding of autism as both a gift and as a disability. Thus on one hand we see the “geek syndrome” idea working to help create a hierarchy, and on the other working to elevate status and potential in the public eye for people with Asperger’s syndrome. It’s a fascinating concept because one can see so much good in it, but at the same time see how it fits into a context where traditional notions of disability are being reinscribed. I am not being critical of Silberman, per se; clearly he is a skilled writer knowledgeable of the subject, who portrays autistic people with more agency than one would find in most mainstream articles. I am instead being critical of the available means by which we have to understand disability and the unconscious byproducts of framing an issue even in an overtly more positive way. Ato Quayson states, “It is important to bear in mind that attitudes to people with disabilities at any historical conjuncture are often multifarious, even in contexts that appear more enlightened and progressive.”157

Though often multifarious, Silberman’s the “Geek Syndrome” does represent an evolutionary step towards more neurological inclusion and tolerance. Echoing Hans Asperger,

156 Nadesan, 6.
157 Quayson, 36.
Silberman once told a laughing audience that "I think we're all living somewhere on the spectrum."¹⁵⁸ To again quote Rosemarie Garland Thomson, disability always demands a narrative and the Geek Syndrome is likely to continue to survive and reproduce long enough to become a dominant narrative in our understanding of Asperger’s syndrome.¹⁵⁹
From *Rain Man* forward, screen representations of autism, both in film and television, have been important to educating the public and it is therefore very worthwhile to interrogate those representations. *Rain Man*, featuring Dustin Hoffman’s acclaimed performance as an autistic savant, is widely considered to be the central text that begins discussion of filmic representations of autism. *Rain Man* helped to bring the word “autism” to audiences unfamiliar with the term. However, it also established savant skills (the rare cases in which the disabled individual displays amazing brilliance in memory or other skills) as a baseline for mainstream understanding of the condition. As I demonstrate, new representations of the autistic spectrum, particularly Asperger’s syndrome as the “geek syndrome,” are both broadening the representations as well as conforming to old models of narrative. Similarly, though autism and Asperger’s are typically seen as a masculine diagnosis, examining representations of female Aspergian characters opens up our understanding of how autistic characters are used in media representation. I am not necessarily interested in exploring how these representations conform to or deny traditional representations about women and how we might recognize them in a feminist framework. Rather as anomalies in the “traditional” narrative of disability, they offer insight into basic elements of autistic narratives. I choose this tactic because visual representations of autism, as Anthony Baker says, have a strong *definitional* power. This way of defining and setting the context for public understanding is considerable. Notably, this definitional power is
often at odds with the real experience of persons on the spectrum. I will limit my discussion of representation to three television programs. Prior to this I will provide an overview of important issues in understanding both gendered autistic representation and the autistic presence in media such as television and film. This topic is obviously large enough to form the basis for its own dissertation, but I feel it is important to talk about how ideas like the geek syndrome manifest themselves in ways that reach larger audiences.

“AUTISM MADE PALATABLE”

Disability identity, according to Rosemarie Garland Thomson, is largely constructed around the explanation of why “my body is different from your body”; in terms of developmental disability, this would be the why or how or to what extent one mind is different from another. Disability narratives are more often than not generated by nondisabled people, presenting a vision “saturated with deterministic thinking and characterized by maudlin and morbid sentiments projected on disabled people’s experience.” Disability representation tells us much more about Hollywood’s attitudes toward the disabled rather than actual disabled experience.

For example, in the popular comedy Tropic Thunder, actor Kirk Lazarus (Robert Downey, Jr.) gives fellow actor Tugg Speedman (Ben Stiller) advice on playing a disabled character:

Check it out. Dustin Hoffman, 'Rain Man,' look retarded, act retarded, not retarded.

Counted toothpicks, cheated cards. Autistic, sho’. Not retarded. You know Tom Hanks,

161Linton, 67.

Though it is degrading way of saying so, the “going full retard” idea may nonetheless be the most honest and straightforward discussion Hollywood has ever had in regard to its own way of portraying disability. In other words, success is determined by making the performance of disability palatable; blending the maudlin and morbid into a narrative that is undisruptive to the viewing audience.

The Geek Syndrome narrative, as discussed in the previous chapter, can be interpreted as providing an even more palatable counter-narrative to the “maudlin and morbid” stories we tell ourselves about autism. However, as was discussed in the previous chapter, the Geek Syndrome does not abandon those traditional stories completely; it is also a projection of the familiar, simultaneous fear and fascination often projected by narratives of autism.

Though it is tempting to look at narratives of disability as simply belonging in categories of “good” or “bad”, it has been said:

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162 Tropic Thunder, DVD, directed by Ben Stiller (Dreamworks Video, 2008).
It is too simplistic to talk about “negative” compared with “positive” images because although disabled people are in general fairly clear about what might constitute the former, the identification of “positive” is fraught with difficulties.\(^\text{163}\)

That representation of autism is widely considered by those intimately familiar with it as being largely negative is of no surprise. People who are intimately engaged with disability are rarely encouraged by what they see and understandably so. But as stated above, it is not easy, nor maybe even desirable to sift through representations as positive or negative. Perhaps it is better to talk about how these stories work and how they impact public discourse.

For example, there have been a number of non-fictional films made about autism. Some of these documentaries present autism as complex and multi-faceted phenomenon; others present it in more simplistic terms. But the initial challenge to all films and especially fictional representations is that autism is presented so monolithically because the autistic spectrum cannot (by definition of it being a *spectrum*) be captured at any single point in time. Ato Quayson agrees that the use of narratives preclude the possibility of a “pure articulation of the autistic spectrum.”\(^\text{164}\) Quayson explains the challenges of spectrum representation:

In filmic representations of persons with autism, a composite definition of autism is deployed that includes features such as extreme discomfort with the unfamiliar, echolalia and monotonic speech, difficulty understanding social cues, unusual preoccupations, pronounces lack of affect, and auditory hypersensitivity. However in real life autism has a broader symptomotology and is diagnosed on the basis of abnormalities in the areas of social, adaptive, and communicative development and


\(^{164}\) Quayson, 157.
imagination, together with marked repetitive or obsessive behavior or unusual narrow interests.165

Narratives rely on conventions and simplifications. Although narratives can point to a spectrum, as I believe the Geek Syndrome sometimes does, they can never, as Quayson suggests, truly represent a spectrum.

The idea of never going “full retard” then refers to the public desire for representations of disability that match a cultural set of desires and limits. As an object of public fantasy, disability in popular media is more often not an accurate representation of the private lives of disabled citizens. As autism scholar Mark Osteen writes, “Rather than providing a stage on which to celebrate or at least explore autistic unity and agency, movies have placed a screen between their audience and any authentic sense of life with autism.”166 As the autistic spectrum is an unfilmable concept, autism is often portrayed as metaphor. Quayson says that “Another dimension that complicates the literary representation of autism is the degree to which metaphorical discourse, or indeed metaphor itself, undermines the assumed verisimilitude of representations of the condition.”167

Metaphor has long been a principal way in which fiction has deployed disability. In classic examples from literature such as Captains Ahab, Queeg or Hook, disability works to draw “on the prejudice, ignorance and fear that generally exists toward disabled people” and “will evoke certain feelings in the reader or audience.”168 Disability works in this way as narrative shorthand to communicate ideas about a character or situation. Martin Norden’s identification

165 Quayson, 151.
166 Osteen, 30.
167 Quayson, 155-156.
of the “High Tech Guru” stereotype, in which fictional computer experts are often portrayed as wheelchair-users, is an example of such shorthand; a disability such as paralysis is used in a particular way to emphasize a character’s technical skills.\textsuperscript{169} It is rare in fiction, particularly in film and television, for disability to simply “be there” without comment; rather disability is always made to work to communicate a specific message to the audience to serve a narrative end. Existing as stock characters for the most part, characters with autism are “always packaged for a certain kind of consumption.”\textsuperscript{170}

As Stuart Murray points out, prior to \textit{Rain Man}, knowledge of autism was largely the province of educational and medical establishments and families, making the film “the foundational text for all the various contemporary representations of autism.”\textsuperscript{171} But at the same time that \textit{Rain Man} educated, it also, through the force of its popularity, led to presumptions of what autism was: \textit{Rain Man} established savant skill as the baseline.\textsuperscript{172} Certainly, the roots of the stock character were thrust to the forefront of public consciousness with Dustin Hoffman’s Academy Award winning performance in \textit{Rain Man}. One poll said that 43% of people believed that autism granted special abilities similar to Hoffman’s character.\textsuperscript{173} For a spectrum, it is odd for autism to have such a “consistency of presentation,” especially in regards to such rare gifts.\textsuperscript{174}

The savant skills so integral to these presentations carry a specific kind of fascination for audiences and in the over-twenty years since the release of \textit{Rain Man}, an autistic formula has

\textsuperscript{170} Murray, 46.
\textsuperscript{171} Murray, 84.
\textsuperscript{172} Murray, 88.
\textsuperscript{174} Murray, 22.
emerged. Anthony Baker identifies this formula as follows: we begin with a hero who is non-autistic and serves as the audience’s point of entry into the narrative. We are then introduced to a character who exhibits clear, visible behavioral traits that can be read as autistic. These autistic characters must be “cute” or “attractively quirky.” This character also must have their vulnerability established through their dependence on caregivers. Often these characters have savant skills or near-superhuman powers. The major theme of the narrative revolves around the separation of the person with autism from their parents or parental figures. The person with autism must be in some kind of danger or be involved with some conflict, the resolution of which allows the “normal” hero to bond and perhaps even assume the parental role.

Such autistic narratives are meant to be reassuring, comfortable and palatable. The wish for audiences is for autism to be “difficult and challenging but conquerable yet also spectacular and beyond comprehension.” In so doing, looking at Baker’s formula, we see the narrative functions for the “normal” (the presumed audience surrogate) character to be transformed through the interaction. Overall autism fiction operates as “voyeuristic engagement from a majority, non-disabled audience.”

We saw in the previous chapter how the Geek Syndrome narrative both challenges and affirms traditional narratives of autism. We can also see how Baker’s formula is evocative of those more traditional ideas. Autism is almost always seen in these representations in highly medicalized, institutional terms that place the individual with autism almost in a prop-like role. Looking at the frequent roles of parental figures as absent, figuratively or literally, it is difficult not to think back to Bettelheim.

175 Murray, 92.
176 Murray, 14.
The Geek Syndrome of course problematizes this formula to an extent through implicit
delineation between high function and low functioning autism. Aspergian characters have been
featured in films such as Mozart and the Whale, Adam, Mary and Max; television series such as
Boston Legal, Grey’s Anatomy and Degrassi: The Next Generation and have been a plot point on
such shows as Law and Order: Criminal Intent, The Closer and House M.D. Conceptually, the
typical Asperger character, as we shall see, tends to be portrayed as much more independent than
the so-called classical or savant character. And yet the Aspergian character does have a
counterpart to the savant fascination in most other autism stories: this would be the intelligence
and skills associated with the diagnosis. We almost always see Asperger’s represented in terms
of fascinating gifts. My belief is that we have seen a rise in Asperger portrayals not just because
of a rise in diagnosis, but because it is seen as that more palatable portrayal of autism.

For instance, Boston Legal featured an explicitly diagnosed Aspergian character named
Jerry Espenson, played by Christian Clemenson, who won an Emmy for the role. His brilliance
as a trial attorney is contrasted with his social difficulties and behaviors that others find bizarre.
Jerry was a popular and engaging character on the show. Dramatically, the Asperger’s syndrome
of this character allows a lot more social maneuverability than if Jerry was shown in terms of a
low-functioning stereotype.

In addition to explicit Asperger’s characters, there are those characters whose diagnoses
are purely speculative. Similar to the way real-life figures such as Einstein or Newton are
diagnosed in the popular imagination, fictional characters are diagnosed as well. Sheldon, a
character on the popular program Big Bang Theory was even the subject of an article in Slate
Magazine as being a representative Asperger’s figure, despite his fictional nature and lack of
diagnoses within the context of the show. Another area of interest is in speculative character
studies of fantastical figures such as Spock from *Star Trek* and Data from *Star Trek: The Next Generation*, who are Vulcan and android respectively.

Whether through a Spock or Sheldon, the Geek Syndrome narrative idea allows us, like with the Autism Spectrum Quotient, to do diagnostic work ourselves and to speculate on the neurology even of fictional characters. As Stuart Murray said, autism is both “timeless and contemporary.” I think of all the characters in past and present fiction that have characterizations that depend upon missed social cues and eccentricities, from absent minded professors to geeky programmers who fit the mold of possibly being on the spectrum. We have been conditioned to understand Asperger’s as a disability along the traditional lines of tragedy, illness and crisis; looking past these dire narratives, a world of alternative representations open up to us.

For instance, in Valerie Paradiz’s *Elijah’s Cup*, Paradiz remarks upon her son’s fascination with Laurel and Hardy and their “missed cues and sophisticated social transgressions.”¹⁷⁷ As Paradiz says “To deny the relationship between autism and humor is to deny it a basic humanity.”¹⁷⁸ In other words, if we solely see autism as tragic and humorless, is it any wonder why people with this condition are treated as categories instead of people able to express themselves in numerous ways?

We are moving away from very strict imaginings that constitute “recognizable” autism and moving to a much more liberal interpretation of autism that doesn’t always “look like” autism, which leaves room for reflecting the diversity that is present along the spectrum. One new way in which autism is being recognized is through the growing attention being paid to diagnoses of females, who have been overlooked for some time.

¹⁷⁷ Paradiz, 170.
¹⁷⁸ Murray, 49.
WOMEN AND ASPERGER’S SYNDROME

At the same time as the spectrum is extended to fictional and historical figures, it is important to address the inequities of who precisely is being diagnosed in our present day reality. Since the earliest days, the diagnosis of patients within the autistic spectrum, including Asperger’s syndrome, has reflected basic social inequities. White, middle to upper class children are and always have been diagnosed earlier and more often than minority children or those from a lower socio-economic background. The rates of diagnosis therefore reflect structural inequities of all minority groups and the lower number of cases of autism within these groups can be seen as evidence of fewer resources, education and medical care. For example, Frederika C. Theus discusses barriers to diagnoses of Asperger’s syndrome in the African-American community as indicative of a social and historical legacy of racism and discrimination.

While there are implications of race and class and other identity categories related to Asperger’s syndrome, that subject is deserving of its own project and is much too large for our purposes here. However, it is integral in terms of how autism is mapped in the public consciousness to explicitly talk about the category of gender relating to the geek syndrome.

Autism affects many more boys than girls; often this figure is reported as only 1 girl being diagnosed for every 10 boys. Earlier, I talked about the construction of the geek syndrome as a technomasculine cognitive style, and it would be a mistake to not address the issue of gender as it relates to this.

179 Grinker, 13.
One writer states that “Men are not a model of anything … so much as a model of everything.” Discourses of disability depend on the fiction of a “normal” body and mind, which are typically imagined as male. The relevance of this idea is particularly pertinent to thinking of the geek syndrome as well as the larger autistic spectrum. Multiple theories have been put forth to explain the larger number of autistic males. Essentially, the choices come down to believing either a) boys are biologically more likely than girls to develop autism spectrum disorders, b) boys are socially more likely to be identified as having autism spectrum disorders than girls are or c) some combination of the two.

Typically, conventional descriptions of autism describe it as a), in disease terms. When boys are reported to have greater rates of autism than girls, it is assumed that whatever autism “is” on a biological narrative, boys just naturally are more likely to have it. According to prominent autism researcher Simon Baron-Cohen, creator of the AQ, males are “hard-wired for understanding and building systems” and women are “predominantly hard-wired for empathy.” If autism is a male brain pushed to its masculine extreme, according to Baron-Cohen’s perspective, the focus on the masculine attributes of the higher-functioning Asperger’s syndrome is “even more pronounced,” even in girls.

The idea of understanding Asperger’s syndrome in terms of thinking about “extreme male brains” is not new. Hans Asperger himself said the “autistic personality is an extreme variant of male intelligence.” Baron-Cohen’s idea harkens back to Asperger’s cultural

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182 Baron-Cohen, 1.
183 Murray, 140.
184 Murray, 155.
assumption and modern understanding of sex hormones and brain development, which in the view of his critics, is still largely contested and speculative.\(^{185}\)

In thinking through this, my mind returns to Hacking’s idea of looping: the very idea of a male disorder creates more male diagnoses, not to mention white diagnoses, middle-class diagnoses and so on. If we compound this reality with the essentialist understanding of “boys=systematizing” and girls=empathizing,” this understanding further leads to more male diagnoses. Should a young girl be referred to a doctor, many times, doctors will not even begin to look for it.\(^{186}\)

Of course, hypothetically something about male physiology could be shown to be the reason for the large number of male diagnoses ratio, but even in the unlikely event that such a fact will be proven to everyone’s satisfaction, it is impossible that the social costs of male-centered autism research will not have a negative impact on women, who have been described as “research orphans.”\(^{187}\)

In his book, Baron-Cohen is very quick to point out that innate sex differences don’t imply one sex is inferior overall. He states that the potential controversy was not lost on him and he in fact held off on his finding for as long as possible since the topic was just too politically controversial, and that he needed to wait for a moment when psychological sex differences could be talked about “dispassionately.”\(^{188}\) Baron-Cohen believes that this work is not stereotyping

\(^{185}\) Nadesan ,129.
\(^{187}\) Murray, 164.
\(^{188}\) Baron-Cohen, 11.
since “stereotyping reduces people to an average whereas science recognizes that people fall outside the range.”\textsuperscript{189} One reviewer of \textit{The Essential Difference}, who took issue with this, states:

So, to clarify the baseline of this debate: Baron-Cohen is in the company of the majority, not an oppressed minority. His attempt to win over his audience by claiming to be a lone voice crying some sort of truth against the constraints imposed by misguided feminism of the last three decades comes across as insincere.\textsuperscript{190}

Renowned autism expert Tony Attwood, however, explains several ways in which to possibly explain the gender discrepancy without discussing innate differences. First, young girls have the same profile of abilities associated with autism as boys but will often manifest subtler expressions of characteristics. Parents, Attwood points out, are much less likely to seek a diagnosis if they see a child coping “reasonably,” asserting that “Asperger's manifests differently, less obviously in girls, and that factor is also causing them to slip through the diagnostic cracks.”\textsuperscript{191}

Secondly, in social terms, boys are much more likely to be identified as aggressive and are more likely to be referred to professional. After all, “the quiet, daydreaming girl staring out the window is not a problem for her school teacher, so there is less concern about her erratic scholastic achievements.”\textsuperscript{192} As a result, many girls go undiagnosed well into adulthood.\textsuperscript{193}

Likewise, girls are socialized from birth to act (and will be identified by authority figures) as more passive. Girl peer groups are more likely to “mother” at a young age, where

\textsuperscript{189} Baron-Cohen, 9.
\textsuperscript{191} Interlandi.
\textsuperscript{193} Interlandi.
boys are more likely to be overtly predatory toward one who is different, thus alerting adults to the behavior. One woman with Asperger’s stated that "As you move from high school to college, or from one group of friends to another, you have a whole new set of rules to learn."  

Attwood’s clinical experience leads him to believe that girls are more motivated than boys to acquire these rules and social skills in order to blend in.

Attwood’s description explains the gender discrepancy in terms of gender socialization, which makes a great deal of sense. Many of these “missed diagnoses” may continue to struggle through life, never understanding why they feel so different and why they find many things difficult.

For those women identified on the spectrum, they may face a different reality and a number of different obstacles, and representation is prominent among them. Catherine Faherty, the writer of Asperger’s Syndrome in Women, talks about the importance of “seeing one’s place”; it is vital that people with autism see other people with autism. Women therefore experience challenges as a minority within the spectrum.

REPRESENTING THE GEEK SYNDROME ON TELEVISION: THREE CASE STUDIES

What is fascinating about the three television figures I will discuss in this chapter is that they are all female representations and hence automatically atypical in the discussion of autism. As one author notes, even as males outnumber females on the spectrum, the ratio of males-to-females in the genre of autistic autobiographies is fairly even—publishing houses are more

194 Interlandi.
196 Andrea.
interested in unique (but still palatable) perspectives. So too, I would argue, are television creators and their audiences.

Even so, typically we are conditioned to see autistic qualities in representations of males rather than females. For example, sitting in a movie theater one evening, I saw a trailer for the 2009 film *Adam*. Directed by Max Mayer and starring Hugh Dancy and Rose Byrne, *Adam* is a romantic comedy about Adam, a young man with Asperger’s syndrome who falls in love with a young neighbor named Beth. *Adam*’s trailer had many of the conventions of both a romantic comedy but fused with a traditional autistic narrative discussed earlier in this chapter (Beth “learns a lot about herself” through befriending Adam, and Adam is able to overcome some of his social disability through her intervention). Though the trailer sells us on a formula, there are some intriguing self-referential moments, which hint that the film is going to play with conventions: at one point Beth offers Adam a box of chocolates and Adam replies “I’m not *Forrest Gump*, you know.”

Immediately following the preview for *Adam*, I saw the trailer for a Sandra Bullock romantic comedy entitled *All About Steve*. Though not explicitly about Asperger’s syndrome, *All About Steve* seemed on the surface to have the same basic story as *Adam*: a brilliant but socially awkward person (Sandra Bullock’s character of Mary) pursues a relationship with an ideal mate who learns a lot about himself in the process (in this case, Bradley Cooper’s character of Steve). Juxtaposed, these two movies have a great deal in common with one another but it was also interesting to see how an autistic presence changed the tone. Both movies are marketed as romantic comedies, but Adam has a lot more dramatic weight due to the autism discussion; at

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198 Andrea.
199 *Adam*, DVD, directed by Max Mayer, (20th Century Fox, 2009).
one point, Beth’s father says “He lives in his own world … you don’t need to make that kind of compromise.”\textsuperscript{200} All About Steve is a lot lighter in tone; Mary’s behavior is meant to be seen as quirky and charming. Says Steve: “She sees things that other people don’t. She doesn’t pretend to be somebody that she’s not.”\textsuperscript{201} Scholar Jenny Morris says that women “do not have to be portrayed as disabled in order to present an image of vulnerability and dependency,” because they are already being stereotyped as these things, hence most disabled characters in film and television tend to be men. The disability serves to explain their ineffective masculinity.\textsuperscript{202}

Now when we see female representations of autism in television and film, it often plays upon the contrary relationship between Aspergian “maleness” and stereotypical femininity. On the popular television series Grey’s Anatomy, there is a character with Asperger’s named Dr. Virginia Dixon (Mary McDonnell). Dixon, a brilliant surgeon with social difficulties, was introduced to the show for a multi-episode arc. Some of the reactions among people on in the Asperger’s community: “They showed us a character with Asperger’s who wasn’t portrayed as a patient or someone who needed help. Dixon is a bright capable woman who has quirks. And don’t we all.”\textsuperscript{203} But there was also criticism of the character: “Instead of a brilliant cardiac surgeon who happens to have Asperger’s, Dr. Dixon is a very impaired Rainman-like stereotype of autism.”\textsuperscript{204} I wonder if some of the criticisms of such portrayals of women with autism so often strike many as somehow wrong simply because we are not used to seeing female representation at all.

\textsuperscript{200}\textit{Adam.}

\textsuperscript{201}\textit{All About Steve}, DVD, directed by Phil Trail, (20th Century Fox, 2009).


For example, the film *Mozart and the Whale* was based on the real-life relationship between Jerry and Mary Newport, two individuals diagnosed with Asperger’s syndrome. In an interview after the release, Mary Newport has this criticism:

“They changed things … They have me as a little one-dimensional, always going: Hah! I don’t do that unless I’m being really sarcastic and I laugh in different ways … It covers part of my personality, but it really leaves out a lot. They weren’t really willing to get to know me. They just wanted to get to know Jerry.”

Autistic representation is on some level all about the Steves and Adams and Jerrys of the world. Because of the Geek Syndrome narrative’s reliance on masculinity, I have decided to base the remaining discussion of Asperger’s and filmic and television media on three female characters on television that are atypical and challenge conventional assumptions.

The first character I would like to discuss is from the Fox Network’s *24*, about the adventures of an agent named Jack Bauer who saves the world in “real time.” *24* premiered on television in November of 2001. This premiere was rescheduled from its planned debut earlier because of similarities between its subject matter and the 9/11 terrorist attacks. Since that beginning, the program has always found itself occupying a space in which contemporary debates over such issues as torture and homeland security were writ large over an action-orientated canvas. *24* has been one of the programs most discussed in terms of culture significance in the post-9/11 United States. One of these contemporary elements that makes *24* such a representative show of its time is its depiction of a larger-than-life modern workplace in

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which technological specialist deal with extreme variations of workplace problems while hurrying about in support of (or, often, secretly working against) the hero.

For a show with such a high body count, the very survival of these supporting characters on 24 is greeted with some excitement by fans communicating online. One such character is Chloe O’Brian (Mary Lynn Rajskub) who serves as, in short, the resident tech expert at the fictional Counter Terrorism Unit (CTU). First appearing in Season 3, Chloe has survived through Season 9, which is a near eternity for a program with such a high mortality rate. Second only to Jack Bauer, Chloe has arguably become the most popular character still alive. She is the character that Jack depends upon for hacking access codes to government facilities, shifting satellites to spy on terrorists or even figuring out how to disarm a tactical nuclear warhead in less than three minutes. In short, aside from her gender, her character is perfectly consistent with the Geek Syndrome narrative.

While Chloe is portrayed as having an uncanny success at helping to save the world from her computer console, she is also at the same time portrayed as having a difficult time with her co-workers due to her tendency to be seen as overly blunt or rude. Once, when one character asked her if she had a minute, she didn’t even look up when answering “No.” Chloe has emerged as a fan favorite for television viewers, in a large part due to the blend of her amazing skills and her abrasive personality. Chloe is often the closest 24 comes to having comic relief, which is needed in a show that frequently is very bleak in tone. Her character has resonated with the fans, some of whom have begun to write on-line about her as being nearly indispensable to the success of the show as Jack. Fan Stephen King, writing about the suspense inherent in a show that will
routinely kill off major characters, added a caveat regarding Chloe when he warned the producers: “If you hurt the little lady, you’re gonna answer to me.”  

An Internet commentator reviewing the premiere of Season 6 enthused: “And praise the gods, Chloe is back with her unique brand of potato-faced Asperger’s Syndrome and technical wizardry.”

That Chloe is a “technical wizard” is her character. Referring to her as “potato-faced” has precedent originating as a critique on Rajskub’s frustrated facial expressions. For our purposes, the most interesting aspect of the quote is the reference to her “unique brand” of Asperger’s syndrome. The assumption that Chloe has Asperger’s or the debate over whether or not she might have it, has been a recurring element of on-line discussion about the character.

As mentioned earlier, a character with Asperger’s is, while noteworthy, not unheard of in prime time television characters in recent years. But what is particularly interesting is that attributing Chloe’s persona to this diagnosis does not come directly from a storyline or even a passing snippet of dialogue. Instead, it is the fan community who seems to be making the connection between Chloe the character and Asperger’s Syndrome.

In short, they are making an AQ-like “armchair diagnosis,” which I believe illustrates many of the ongoing elements present in the public discourse concerning Asperger’s. Opposed to the explicit representation of Asperger’s in a female character such as Dr. Dixon from Grey’s Anatomy, Chloe’s neurological status has emerged from consumers of the program. Her Asperger’s syndrome has never been mentioned, let alone subjected to “disease of the week.”

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style stories; perhaps an undiagnosed character is the best way to represent a population that is so often misrepresented. Through a lack of diagnosis, Chloe escapes the narrative conventions of disability. Her trust is earned and her skills are respected by other characters without the shadow of paternalism. The question of whether or not Chloe really “has it” is not really what is at stake; rather it is the connection people are engaging with in terms of her behavior and personality and her appeal as a role model.

Chloe makes “sense” to viewers as having Asperger’s syndrome based on her lack of social skills and her genius with technology. That she shares traits with the behaviors and personality of how we understand Asperger’s syndrome is clear, but an interesting tension results from the ways in which she does not conform to the stereotype. I speak mainly of her gender, which becomes the one thing that problematizes her status as Aspergian.

On an Asperger’s discussion forum, one individual wrote, “I have Asperger's Syndrome - what's generally termed a light case of autism (24's Chloe, especially in Day 3, is a very good representation).” 208 This individual points to Chloe to explain her condition, which is significant, as this same individual is the one making the diagnosis in Chloe. What is also significant is the emphasis on “Day 3” (aka Season 3) Chloe.

Chloe and her Asperger’s are always discussed in reference to recent developments with her character. As Chloe has become more popular, she has been given increased screen time and more characterization. For instance, the writers have contrived to have her go into the field, where she has managed to both kill a terrorist and taser a guy at a bar that annoyed her while she was trying to find a WiFi connection. In Season 5, we were re-introduced to Chloe waking up in

bed next to a fellow CTU employee (who later turned out to be a mole). And, it was eventually revealed, Chloe has an ex-husband, who now works at CTU. Later, she would reunite with her husband and have a child, successfully balancing both motherhood and anti-terrorism. Professionally, she would receive her due by assuming temporary control of CTU at one point and receiving the support of no less than the President of the United States.

Throughout these life-shifting developments, much commentary has occurred regarding the level of make-up Chloe now wears or her new hair style. The “potato face” comment mentioned earlier originates from Chloe’s affectionate nickname on the popular website *Television Without Pity*, referencing Rajskub’s consternated facial expressions. Chloe’s first few appearances on the show were met with hostility by many active fans and the name stuck. As her popularity increased by the end of her first season, the name was used by those few hold-outs resisting the character. Now, if she must be referred to as a potato on-line, she has become known as “Hot Potato.” In an issue of a magazine called *Geek Monthly*, Mary Lynn Rajskub appears on the cover and in a pictorial, wearing a number of sexy, spy-themed costumes.

This transformation of Chloe into “Hot Potato” has not been welcomed by all. One contributor, responding to the potential of Asperger’s syndrome and Chloe stated: “But I must admit I was a bit disappointed when Chloe was in bed with the mole. She looked almost pretty AND sexy. It just didn’t work for me and that character.”

Another contributor demanded “Bring her back to her Asperger roots!” in an on-line petition to drop Chloe’s current storylines, which included romance. Another stated that “‘maturing’ Chloe seems to be just another way of making her just like all the other women on

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the show—which is to say, less than memorable. Please, don’t turn my Chloe--our Chloe--into just another bland stereotype of a woman.” And another pleaded “Please give us back the blunt awkward Aspie that has become one of the most popular characters on television.” On another site, this one not centered on 24, a user writes about the once-role model of Chloe: “Tip: watch some early episodes of 24 with a really terrific Aspergian character called Chloe. They tarted her up for later seasons, but when I saw her in Season 3 I fell in love.”210 The Chloe that individuals “fell in love with” seems incompatible with the Chloe we have today. Despite the core components of Chloe’s personality being intact, the relationships, the make-up, the new hair styles and the family seem to have alienated many who originally identified with her and engaged her as Aspergian. What is interesting here is that Chloe’s perceived Asperger's, her gender and the perceived sexualization of her character are seen as being mutually exclusive categories. What is at stake for the fans in this argument occurs to me to be that the sexualization seems to threaten the uniqueness of a brilliant female character who, unlike most women in television, is not defined primarily through her sexuality.

The logic of this discourse seems to be that Asperger’s is incompatible with certain sexualized performances of gender. While the notion of the spectrum seems to be liberatory in making room for many identities along a continuum, it is remarkable how far we seem to have not come, in terms of giving characters with a disability a sexual identity. The question of Chloe’s diagnosis will be linked to how well she performs it, which in turn is linked to how she performs her gender.

In the aforementioned issue of *Geek Monthly*, in the accompanying interview, the question re: AS was finally posed to Rajskub, who was vague.

**Question:** There’s a theory on the net that Chloe has Asperger Syndrome …

**Rajskub responds:** I’ve heard about this—let’s just say I’m a genius and leave it at that. And that I can talk to dolphins.²¹¹

As no “official” answer seems to be forthcoming, Chloe’s character remains a space in which the public plays out the stereotypes and performances of gender and disability against one another. But Chloe also is a character who is smart, strong, and in the minds of many, *decidedly* on the autistic spectrum. The character provides an interesting space where the viewers claim the diagnostic label themselves. This is in essence the Geek Syndrome ideal: the smart, capable though socially awkward professional for whom the label of Asperger’s syndrome comes after the fact. The lack of an official diagnosis is no roadblock to membership; her gender seems to be the only obstacle between Chloe and her “Asperger’s roots.”

While Chloe’s “tarting up” challenged the perception of her as an accurate portrayal of Asperger’s syndrome, the next television personality I wish to discuss had no choice but to spend a lot of time in hair and make-up.

This individual was 21 year old Heather Kuzmich, one of the contestants on the ninth cycle of *America’s Next Top Model*, Tyra Bank’s competition-based reality show. The fact of Heather’s Asperger’s diagnosis was featured prominently throughout the show. Though she was not the winner (placing fourth in the competition), she has been enormously popular with the fans (voted “Cover Girl of the Week” by the fans an amazing nine weeks in a row). Reading the

message boards, YouTube tributes and fan pages, the words “best,” “favorite,” “inspirational,” and “real winner” are all attributed to her. In *Reality TV: The Work of Being Watched*, Mark Andrejevic wrote that the:

... promise deployed by reality TV is that submission to comprehensive surveillance is not merely a character-building challenge and growth-experience, but a way to participate in a medium that has long relegated audience members to passive spectators.\(^{212}\)

Just as the fiction of reality television promised, Heather was presented with the opportunity to participate in this medium of reality television, to submit to this surveillance, ostensibly to build character and to grow. Obviously, on a show entitled *America’s Next Top Model*, she was also there to display her skills as a model.

Yet as viewers of reality TV well know: to be beautiful or skilled is often not enough for success. There also needs to be a narrative hook of some kind to capture audience interest. Setting Heather’s story apart was the way in which the show constructed Heather’s Asperger’s syndrome. Heather’s participation on the program presumably introduced many of its viewers to Asperger’s syndrome. This introduction, on a show populated by female models, could not have been more of a turn-around from traditional masculinist narratives of Asperger’s if it tried. Of course, reality television does not always reflect reality but does *construct* an understanding of reality in a way. For once, on this particular show, Asperger’s syndrome was mediated through a non-fictional woman embodying a narrative that audiences wanted to cheer on, with the old trope of succeeding in spite of a disability.

Needless to say, *America’s Next Top Model* is a unique presentation in which to look at narratives of autism. Heather is recognizable as fitting the criteria of Asperger’s in her self-described “awkwardness” or “geekiness” but, very clearly, does not fit into the stereotype in other ways; on the basis of her model persona, her gender and her visibility on this television show.

Just as Chloe problematized her status as an Aspergian role model through her gender and sexuality, Heather’s identity as a model and her identity as Aspergian are often at odds with one another based on cultural stereotypes of what a model is supposed to be and what someone with Asperger’s syndrome is supposed to be. Heather said:

I was worried about being defined by it. At the same time I was just thinking, you know, there were very few people, examples who really were myself when I was a kid and I wanted to change that. I wanted to. If there was going to be another girl, or kids out there who were like me, I wanted someone to have a better experience than I did when I found out. So I just … I just did what I was taught to do, a selfless thing and just come out with it and hope for the best.”

A narrative of selflessness, serving as an example to others and being oneself is evocative of the “SuperCrip” narrative but when Heather, so often picked on and excluded as a child, says with such earnestness that “This is going to be the thing that makes me strong,” it is hard to not want

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to root for her, to buy into her arc on the show. “She wants to show that Asperger’s doesn’t define her” her mother later said, calling it Heather’s “redemption time.”

Asperger’s doesn’t define Heather, but in the context of the program, the expectation was that she would define it for others. On America’s Next Top Model, it was assumed that many viewers would be introduced to Asperger’s syndrome through Heather, so it was explained to the audience several times. In the first episode, Heather explained Asperger’s to Tyra and the judges. In the second episode, one of Heather’s co-stars asks her to explain her Asperger’s while sitting by the pool:

Contestant 1: What is it? Aus-bergers?


Contestant 1: So, do you see the world differently, from, like, me?

Contestant 2: Yeah, explain it. Because we don’t know.

Heather: We just think differently, I guess. We don’t pick up on social norms and that sort of stuff.

Another contestant (via voiceover): She does seem a little weird from far away, but I think I’m really, really open minded and I give everyone a shot.

This exchange encapsulates some themes in terms of how Asperger’s syndrome played out as a topic on the show. In this brief exchange, we see a) a desire for more information, b) a heightened, not-so-subtle confrontation, e.g. the more insistent “Explain it,” c) assessment of

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Heather’s behavior (“seems a little weird”) and most importantly, d) the insistence of appearing liberal-minded, the idea of “giving everyone a shot,” even if they seem a “little weird.”

Early on in the show, Heather achieves great success in the competition. Her photos win praise. This praise evolves into a source of contention as several contestants begin to attribute Heather’s success to her disability. This attribution takes the form of a) her success being described as “natural” or the function of her Asperger’s syndrome serving to help her succeed “without trying” and b) “pity” taken on her by the judges because of her disability. The question of “Does Heather have a disadvantage?” eventually gives way to “Does Heather have an advantage?”

In a post-show interview, Heather was asked what she was hoping to achieve by “bringing up” her Asperger’s syndrome. Said Heather “I was hoping to be a role model to girls who were told they weren’t beautiful and had problems.”216 A theme on the show and in queries to Heather after the show involves Heather’s success in serving as a representative of Asperger’s syndrome and what potential advantages and disadvantages it offered. In an interview with the popular Asperger’s syndrome-centered site, WrongPlanet.net, Heather stated:

Umm, yeah I was. I mean they didn't make it seem like I had so much of a problem where it hindered my ability to do, like, the show but at the same time they did show that I had some problem and that it was there. 217

217 Plank.
And yet, the tension on the show as edited together was based around this idea of Heather’s unfair (?) advantage. This mostly played out in Heather’s contentious relationship with another cast member, Bianca, who was constructed as Heather’s nemesis. Said Bianca of her rival:

Heather. I think her disability gives her a lot of leg up. She gets a big pity call from everyone and I don’t know if she deserves it.

And later:

Everybody in the house babies Heather and I treat everyone else the same and I refuse to be the girl who treats her differently because she has a disability (rolls eyes) of some sort.

Bianca is often shown as being mean to Heather: “I wish I could get the joke,” Heather says in one memorable exchange. “You’re the joke” replied Bianca.218

What is interesting is that Heather downplayed this quarrel later on in the press, claiming that she and Bianca were actually fairly close and at worst “bickered like old women.”219 Even if the relationship was not as troubled as it appeared, the producers sought drama from it. Whether or not the drama was real is inconsequential; the show used footage to tell a story about the limits of advantages from disability.

This narrative is underscored during the judging sessions on the show. Unlike a reality program such as American Idol, where popular votes determine elimination, America’s Next Top Model is a show in which Tyra Banks and her judges decide who stays and who goes.

As a result, the judging has the feel of a professionalization exercise rather than a popularity contest. As lay people, we viewers may or may not openly disagree with the

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219 Plank.
decisions, but Tyra Banks and her judges are constructed within the show as an *authority* within the modeling profession. This is a critical point because, in the authoritative role, Banks and the judges help define the role of Asperger’s syndrome in Heather’s success on the show.

Heather’s Asperger’s syndrome was a topic the judges were keen to address. For instance, one memorable moment was when Heather had difficulty remembering lines during a challenge. The following is a transcript of the judges’ (Tyra Banks, Nigel Barker, Jeffrey Chu and Twiggy) response to Heather:

**Tyra:** Mr. Jay said that when fed lines one at a time, you were not able to mimic the performance and you just totally struggled ... I'm going to be hard on you because this is a fair competition ... We're not going to say, "Oh my God, Heather, you needed to remember it all." We understand. We invited you into this competition. We know that you have Asperger's and we know that there's ADHD and we know that there's other things. So then your lines get thrown at you. So that's a little favoritism that I'm sure some of the girls are like, "That's not fair." So if he's delivering you lines, then every line should have been fantastic.

**Barker:** You've got to focus. Even if you're not getting it right, make sure to get the things that you can do right. (Later) It was disappointing to see Heather's performance this week. I think Heather was disappointed with herself. I think she's allowing herself to conquer herself.

**Chu:** Don't make a funny face. If you don't hear, "Cut," assume that the camera's on you.
Twiggy: She looks gorgeous. I love her look. But I don't know if she'd be able to hold it together if she got a job with a major client.  

Heather, ultimately, is eliminated in another episode because of this inability to “hold it together” but not before all above have made it clear that they have taken every step to make it a fair competition.

Heather then, in “conquering herself” as the judge puts it, absolves these judges, the program, and the audience of any responsibility for her elimination and supports the very logic in which we construct disability as an individual obstacle rather than a social construction. This is an essential criticism of the medical model of disability: disability is an individual problem and therefore everyone can deny any responsibility for the construction of that which creates a disability in the first place.

These episodes of America’s Next Top Model are very interesting in that the behavior of the judges, contestants and the way in which the show is packaged are all very much in line with the problematic, traditional portrayal of disability. However, despite this, Heather as an individual comes across as very positive and unique in terms of a representative of the Asperger’s community. Stuart Murray says that:

If the creators of commercial cultural products wish to represent autism within narrative for consumption by a large audience, it is not in their interests to present the condition as a complex overlapping of stark and subtle behaviors, itself bound into a specific personality.  

220 “The Girls Go to Shanghai”
221 Murray, 22.
Though reality television is anything but, Heather’s complexities were still very much on display, despite the way in which they were presented. Although I see Heather as a very positive representation of a real person that challenges some preconceptions, it is important to note that this characterization is ultimately an anomaly. Surrounding her are still many of the same old narratives that remove “the agency of the individuals” on the spectrum.222 One blog post disturbingly illustrates this point:

Heather is an excellent model, but only when she isn't moving. If we could get a taxidermist to stuff her and find an animatronics expert to install some circuitry in her face to simulate facial expressions, she'd be the winner of this thing hands down.223

For better or worse, the Geek Syndrome “democratizes” the medical gaze. It is interesting that someone would choose to describe Heather in terms of needing to be “stuffed” and “wired”: this brings to mind the ways in which the denial of agency of people with autism has often been couched in cyborg rhetoric. This also segues into the discussion of my third and final autism representation: the character of Cameron (Summer Glau) on the program Terminator: The Sarah Connor Chronicles.

Cameron is not quite like the other women discussed in this chapter, primarily due to the fact that she is not even human but rather a killer cyborg from the future. She becomes a particular point of interest for this dissertation due to the fact that in a second season episode (titled “The Tower is Tall, but the Fall is Short”) a therapist, unaware of Cameron’s true nature, reports her robot-like behavior as possibly being due to Asperger’s syndrome. This was not a major plot point, rather a throw-away line that nonetheless many people took notice of.

222 Murray, 46.
Set after the events of the film *Terminator 2: Judgment Day*, the show tells the story of Sarah Connor, a woman who protects her son John, who is destined to lead the human resistance against intelligent machines in the future. The blog *Stuff Asperger People Like* describes the plot of the show (through an Aspergian lens) as follows:

“Terminator: The Sarah Connor Chronicles” is a popular television series on Fox involving a robot that displays many Asperger traits. The whole gist of the story is this: Sarah Connor (Lena Headey) has a son, John (Thomas Dekker). John is being pursued by a Terminator that wants to destroy him. They recruit Cameron, a Terminator played by actress Summer Glau, who has been reprogrammed to help instead of hurt John (Good Terminator) and off they go running from the Bad Terminator and trying to figure out how to stop him. In between plots, there are love stories, adolescent angst, and plenty of robots getting blown up, shredded, burned, then putting themselves back together in a strange Humpty-Dumpty fashion and reactivating themselves to chase after John again. Pretty typical life for a teenage boy. Cameron, the Good Terminator, follows John wherever he goes, including school. Although she is beautiful, it’s not long before John and everyone else who interacts with her realizes that she is a little bit “different.” She is supposed to be able to blend in and interact with real humans better than the other robots, but she has her, um, moments.224

Cameron is further described again on another site:

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Personality-wise, Cameron still has a ways to go, recently having been professionally diagnosed with mild autism. But like all Terminators to come before her, she’s a sponge for information. She’s been reading the Bible, watching TV and observing the kids around her to get a grasp on all the latest hipster lingo. It doesn’t always come out quite as it should, but she’s learning from her mistakes.225

Cameron also has a heritage that includes many science-fiction characters that grapple with their lack of understanding of human culture, such as the aforementioned Spock and Data from the Star Trek franchise. There is often a role in popular science-fiction for the “outsider,” who must learn about humanity.

Autism is again both “timeless and contemporary”: if Cameron can be labeled mildly autistic today, then there would be no shortage of previous science fiction characters that could also carry this label. The way that these “outsider” characters’ journey of enlightenment often functions is to serve as a way to reinforce the value and goodness of human traits or to highlight human shortcomings and foibles. This discovery is often a two-way street, as humans often learn valuable lessons from their less-than-human counterparts. This is exemplified in Terminator 2: Judgment Day, when Sarah Connor remarks that “if a machine, a Terminator, can learn the value of human life, maybe we can too.”226

The equivalent of this trope in traditional autism narrative is the “normal” character learning lessons about the self through interacting with a person with autism, such as in Rain Man. As Baker points out, this serves to spectacularize autism and removes agency from the

character with autism. It is also yet again another way in which the character of the autistic serves as a prop for “normalist” enlightenment.

Describing people with autism as "machine-like," "cold," “inhuman,” or “overly efficient,” not only places certain values on people with autism, but also defines “normality” as the antithesis. A Terminator is not real (at least not yet) and thus represents no one, but through the imaginative acts that we engage in the geek syndrome era, the fictional and the real often receive the same diagnosis. The categories “fictional” and “nonfictional” leak onto one another, and in some ways, the idea of autism as machine intelligence is the result of the stories we tell ourselves about machines.

Differences between what is considered normal and autistic are often explained in terms of what is called the theory of mind, which is the capacity of a person to attribute different perspectives or emotions to others. One common perspective is that this so-called “mind-blindedness” is the root of the lack of social skills and a lack of duplicity in people with autism. As will be discussed here and in the next chapter, this lack is interpreted by the non-disabled in a multitude of ways, sometimes with anxiety and fear of autism. Or, this can be presented as charming or funny on a show such as The Big Bang Theory, as the behavioral quirks and missed cues are often the source of the humor.

However, in more dramatic fiction, this mind-blindedness also can be understood in terms of the autistic’s questionable morality or amorality. This is an idea that is at play with Cameron on The Sarah Connor Chronicles. Unlike a human character, let alone a female character (who is often perceived as having a much greater capacity), Cameron does not have empathy, sympathy or any understanding of human emotions save for those who assist her in
completing her missions. Cameron is the “good” Terminator only because of her programming and if she returned to her default self, she would be no different than the Terminators who are bent on the eradication of humanity. Drawing the parallel from Terminator-to-autism, only through the intervention of normal humans enables Cameron to learn to become human herself. The idea that autism, high-functioning or otherwise, is close to this frightening machine intelligence suggests that what is privileged as normal and human is the opposite of autism with its reputed scary Terminator-style intelligence. As one observer writes of Cameron, “She’s got no instincts for how human interaction works, so she has to simply memorize the mechanics. The Asperger’s diagnosis was not far off the mark.” In that comment we can see the way a Geek Syndrome can take on darker meanings. Maria Holmer Nadesan writes on the subject of Asperger’s as artificial intelligence:

This tendency to link or equate autism with artificial intelligence holds troubling implications. Despite the tendency to use the computer to make sense of human cognition, there remains a recognized gap between artificial and human intelligence. The irremediable gap between actual computers and human brains typically situates in the fundamentally human capacities of sociality (love, desire, sympathy, empathy) and spontaneous imagination (play, aspirations, fantasy), and in reflexive “self-consciousness” (whose nature remains ambiguous). The general public and academics are well aware of this gap, which is the subject of much interest in the science fiction genre, despite publicized efforts to create ever more sophisticated models of artificial intelligence. Consequently, the semiotic equations across autism, technology/science, social deficiencies, and lack of personal reflexivity contain the potential to dehumanize

autism and the people associated with this label. They are dehumanized in their renderings as cyborgs.\textsuperscript{228}

The same basic elements that can be spoken of in a celebratory way in the geek syndrome are easily tweaked into this cyborg rendering or “terminator type” that Nadesan finds dehumanizing. An article in \textit{Wired} magazine examined the appeal of the Terminator mythos and illustrates this point:

\begin{quote}
But the secret of their success is the same as Arnold's: implacability. Bells and missiles aside, we want the same unblinking Asperger's case—the flesh of the face half-ripped away to reveal the silvery endoskeleton beneath—shooting its way calmly through a mall in steady pursuit of a target or jerking expressionlessly as the LAPD pesters it with yet another fruitless fusillade.\textsuperscript{229}
\end{quote}

Here Asperger's syndrome is not reflecting a person either literally or figuratively. Rather, within the same magazine that gave birth to the term “geek syndrome,” we see Asperger’s reflecting a range of traits that can be used to describe and explain, on one hand, the intelligence behind mastering machines or, on the other, a frightening machine-intelligence, both sides of the same coin.

But is it necessarily true that the association of machine intelligence and autism has to be self-evident or even undesirable? In the article, “Learning from Temple Grandin, or, animal studies, and who comes after the subject,” Cary Wolfe writes:

And then there is the case of Dawn Prince-Hughes, a sufferer of the form of autism known as Asperger's Syndrome, who claims that her disability enabled her to have an

\textsuperscript{228} Nadesan, 131.
unusually keen understanding of the nuances of the social interactions and communications of a group of zoo gorillas. And as with Monty Roberts, this was crucial for the evolution of her own self-understanding, enabling her to move from being 'a wild thing out of context', living on the margins of society, to completing a Ph.D. in anthropology, and eventually to becoming an author and editor. Gorillas, she says, 'taught me how to be civilized'.

Here the story of Dawn Prince-Hughes takes on a different tone from the autistic-as-cyborg idea. It is Prince-Hughes’s Asperger’s syndrome that is credited with allowing her to understand nuances and understanding in a gorilla community, skills clearly not availed to her under the concept of mind-blindedness.

As Mary Lynn Rajskub joked about her character being able to talk to dolphins, this closer-to-nature idea could be another narrative; a case of the pendulum swinging the other way. This demonstrates that the autistic as machine is not the only available narrative and more importantly is not the only way for people, males or females, with Asperger’s syndrome to see themselves.

CHAPTER 4
FROM GEEK SYNDROME TO GEEK DEFENSE: BACKLASH AND COUNTERNARRATIVES

When I first began this project, I expected to see two main narratives about Asperger’s syndrome dominantly represented in the media. The first that I expected were traditional narratives of disability that offer a medicalized view of autism. Secondly, I also anticipated the narratives of socially awkward but valued intellects associated with the so-called “Geek Syndrome.” I found plenty of both these narratives but what surprised me the most during my research was the presence of narratives about “deviant-autistics.” These stories targeted Asperger’s syndrome for open ridicule and even equated it with crime and criminality. While these narratives are not nearly as prevalent as the others, the relative public unfamiliarity with Asperger’s syndrome can be seen as a concern, as the proliferation of the kind of ignorance and panic that has often accompanied such stories about disability in the past, such as the cold mothering hypothesis, which depend on mass ignorance. Asperger’s syndrome is of course increasingly well known but it is rare in news coverage that it is not defined for its audience. Asperger’s syndrome is defined and redefined by every article, telecast or other media representation in which it appears, presumably because the assumption is that most of the audience will be unfamiliar with it. The context of these appearances will shape the ways in which new audiences understand the condition. Therefore the stakes of negative representation are especially high. These stories of deviant autistics attempt to undermine the idea behind Zoisa Zaks’s argument that “autistic children and adults need to see reflections of success and achievement, no matter how small the increments or how much learning is left to do.”

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Representation always matters, but it is perhaps because of this need for positive influences that representation of Asperger’s syndrome particularly matters.

These types of negative Asperger stories were developments that I did not anticipate and it is important to acknowledge these narratives and think about some of the ways in which they function. I posit that much of this backlash arises out of some misperception of “privilege” to the exclusion of other factors that accompanies being diagnosed as an “Aspie,” as well as anxiety over the “otherness” of the Aspergian mind. I see these developing narratives as relating to the “Geek Syndrome” in a particular way: these are accounts that rely ultimately on the specialized skill sets and social awkwardness of their subjects. Whereas the geek syndrome narrative depends on us seeing these qualities in terms of value, the stories mentioned within this chapter invite us to see them solely in a negative light.

It is worth remembering here that the dominant cultural view of Asperger’s syndrome is still ultimately that of most disability representation: that it is best understood as evidence of a biological, physical or mental inferiority, rather than being the result of continuous cultural production. As discussed in previous chapters, the geek syndrome narrative offers a partial counter-narrative against this idea by asserting the contemporary social value of Asperger’s syndrome. At the same time, however, I have argued that this narrative also simultaneously places high-functioning autism within traditional frames of disability by its constitution of other places on the spectrum as occupying a lower position on a socially constructed hierarchy. The geek syndrome, in short, offers radical new ways of conceptualizing disability. But at the same time, as is often the case, the narrative cannot erase within itself traces of alternate narratives that reiterate harmful stereotypes that have little to do with the well-being of those they affect.
From examining narratives such as the geek syndrome we learn much more about cultural preoccupations with autism than we necessarily do about any innate qualities of the diagnosis. The availability of cultural narratives of autism have not led to increased understanding and knowledge but rather reveal, in Stuart Murray’s terms, the “complex desires of a society that wishes to be fascinated with a topic that seems precisely to elude comprehension.”232 Viewing Silicon Valley as the “world’s largest incubator of high-functioning autism”233 and the geek syndrome as the product of that incubation speaks more to contemporary wish fulfillment for this fascination than anything else. Similarly, the presence of negative stories also tells us a lot more about the desires and wishes of the larger culture, unfortunately, than it does to tell us about the condition itself.

DANGEROUS DIAGNOSES

In the United Kingdom, a controversial 2009 Action for Children advertisement was broadcast, portraying an animated monster rampaging through a city. Within the monster’s mouth, a child is visible. This child has not been eaten by the monster, but is rather simply present within the monster as a spectator. The child is named Dan and the monster is meant to represent his autism. Dan says via voiceover:

I used to lash out if something pushed my buttons or I wasn’t able to do something. Things that wound me up were if they’d insulted me I would physically hurt that young person. My parents sought out help with my autism because it was becoming a pain in the bum. I went to an Action for Children school. I started feeling a bit more friendlier with other people. Thanks to the carers, I was able to correct a lot of errors in my behavior and

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232 Murray, 4.
233 Schuler.
become a better person. Well I feel a lot more confident thanks to them. I feel at peace with myself.\textsuperscript{234}

The image of autism as the “monster” the child is trapped inside harkens back to the Bettelheim paradigm. Through that specific paradigm autism is constructed as a shell that the child, the so-called “real child,” is trapped within. This “real child” is rescued only through professional intervention and is able to “become a better person.”

What is interesting about this commercial is that, rather than being aloof in a solitary world, the child is shown as rampaging through “our” world. This is noteworthy because the most stereotypical depiction of autism has historically always been understood in terms of distance and aloofness. But increasingly, autism and Asperger’s are discussed as the contributing factor found in more aggressive maladaptive behavior in children and adults, even in violent crimes. According to autism researchers:

\begin{quote}
Although there is little evidence of an association between autism and criminal offending, occasional and sometimes lurid publicity has led to suggestions that there may be an excess of violent crimes among more able people with autism, particularly those diagnosed as having Asperger’s syndrome.\textsuperscript{235}
\end{quote}

The contention is that speculation on a correlation between people with autism and violence is “likely to increase the stigma and distress of those affected and their families.”\textsuperscript{236} Writer Lisa Jo Rudy agrees, stating “Could these headlines be having a negative impact on our children with

\textsuperscript{234} Dan’s Story, (Action for Children UK, 2009).
\textsuperscript{236} Howling and Goode, 235.
autism? My guess is that the answer is "yes." Ultimately, studies have found that there is no difference between offenders with autism and without. However, these concerns are still well-founded, not because there is any real association between autism and violence, but because the perception of this association with violence seems to be a growing phenomenon. A realistic fear is that such depictions will be the initial point of contact for much of the public. For example, as one article states:

Last week was the first time many people ever heard about Asperger's, when John Odgren, 16, was accused of stabbing a classmate to death at Lincoln-Sudbury Regional High School. His attorney says he has this disorder.

If Asperger’s syndrome can be perceived as causing such behavior, then the association with Asperger’s and violence also reaffirms the medical model of disability as the only viable alternative which would be curing or managing “infected” individuals. As one blogger writes:

How many stories of violent deaths allegedly at the hands of autistic teen males will we have to read before the world either A) embraces treatment for autism as a medical ailment or B) paints all autistic males as dangerous killers and locks them away a la 1955?

This writer represents the view of many who are disturbed by the construction of the autism spectrum as dangerous. Another writer gives voice to another sentiment, in which

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“neurodiversity ideologues” wish to discourage any perspective which emphasizes medical management, even at the cost of a “reality” of autistic violence:

In recent days and weeks two severely autistic young men have been implicated in homicides. In one case, a young man with autism has been implicated in the death of his mother who publicly professed her deep love for her son and the joy that he brought to her …. Neurodiversity ideologues are unlikely to change. Their views are entrenched and tied to their own public careers as professional “autistics” or “enlightened” autism parents. The truth is that they discourage society from addressing the harsher realities of autism by effective therapy, treatment or cure. They help keep members of the public from understanding the full nature of autism, particularly as it affects the most severely autistic. Theirs is a movement whose aim is to keep everyone from facing autism reality. Theirs is a movement which wants society to keep our heads in the sand and ignore autism reality.241

In the above two examples, we see alternatives to medicalized narratives dismissed as either unrealistic or dangerous. Here, autistics seem to be portrayed as powder kegs of potential violence. Asperger’s syndrome in particular has been wrongly associated with heinous, violent acts through pointing out the symptom of lack of emotional responsiveness or so-called sociopathic tendencies within some Aspies. Several articles have been published which describe Asperger’s syndrome as a potential link between a variety of murderers including Jeffrey Damher or the Unabomber, Ted Kaczynski. The authors argue that:

Psychological phenomena of central importance to understanding serial killers such as deficits in empathy have frequently been explained as originating from a psychopathic

241 Leitch.
core” thereby missing the possibility that deficits in empathy may also be due to autistic psychopathology.242

This is a twisted mirror of the retrospective diagnosis often employed by geek syndrome narratives, in which we imagine Jefferson, Einstein and Newton as Aspergian. Despite such theorizing, as stated previously, there is ultimately no evidence to support this idea that autism contributes to the likelihood of committing violent acts. The reality is that the nature of being on the spectrum means that one constantly is seen as representing the spectrum, i.e. if a person with autism commits an act of violence, then the autistic spectrum is seen as the cause. Author William Stillman claimed “What makes me so mad is that when these things happen, the autism, or the Asperger's, is taking the rap.”243 The emerging reality is that, yet again, Asperger’s syndrome is understood as a zero sum game: if it is believed to be present, then the diagnosis is burdened with essentially explaining everything about the person in question. Asperger’s, in each of these cases, is essentially “put on trial” alongside the defendant.

Wired magazine, besides coining the term “Geek Syndrome,” used the term “Geek Defense” in 2008 to describe the “strategy” of using Asperger’s syndrome as a possible explanation for a defendants’ wrongdoing. Slate magazine also discussed instances of the “geek defense” in an article, claiming:

That was more or less the tactic used by the team representing Robert Durst, a real estate heir who killed and dismembered his neighbor in 2001. Durst was charged with first-degree murder, but a psychiatrist testified that his actions were the result of emotional

deficits and impulsive behavior associated with Asperger's—so the crime could not have been premeditated. The argument worked, and Durst was acquitted. Most judges and juries have been unconvinced that Asperger's can explain or excuse violent behavior, though. Last month, a judge in the United Kingdom sentenced a 22-year-old woman with Asperger's to life in prison for beating her mother to death, saying her lack of empathy didn't reduce the gravity of the crime.244

While the Durst verdict seems to be the exception rather than the rule, the positioning of Asperger’s as a way of explaining these crimes is problematic. Can Asperger’s be a contributing factor to such an incident? Of course, but that could be said of any personality trait and it is highly unfortunate to imagine that Asperger’s syndrome in particular could be singled out as the cause of such an event. As one article put it:

If people with Asperger’s, as a group, lack the natural social skills that most of us use every day, they also tend to lack some of our darker social habits too: artifice, manipulation, spite. Not, on balance, a bad trade-off.245

This is not to romanticize Asperger’s syndrome; certainly some cases show examples of violence within the Asperger’s community. But what is interesting is the way in which we understand these cases as being instructive about this disability, of using the disability as a way to explain criminally deviant behavior. Another attorney who used this "geek defense" said: "The question is: how can somebody so smart be so dumb? And Asperger's answers that question."246

Recently, a great deal of attention was paid to the legal troubles of Scottish computer expert Gary McKinnon. McKinnon hacked into top-secret Pentagon and NASA computers, causing authorities to fear a cyber-terrorism attack. McKinnon says that he was compelled to hack into government computers in his search for evidence of alien spacecraft and the ensuing cover-up. The threat of extradition to the U.S. for McKinnon has created a space for debating the culpability for someone with Asperger’s.

This debate often involves a constitution or reconstitution of what Asperger’s means. Essentially, the debate over the nature of McKinnon’s autism boiled down to whether we understand the autistic subject as wilfully destructive and deviant, or childlike, innocent and in a world of their own, i.e. the old stereotypes. Notably absent in the proceedings is any room for complexity in terms of there being space between the two ideas.

Simon Baron-Cohen was asked to evaluate McKinnon and stated that it is “important to recognize that his emotional age or social intelligence is at the level of a child, even if his intelligence is systemizing at an advanced level.” McKinnon scored 43 out of 50 points on Baron-Cohen’s AQ test, which is a very high score.\footnote{James Slack, “‘If Gary McKinnon is sent to U.S. I fear he will kill himself’: Top Asperger’s expert warns ‘cyber-terrorist’ will not survive jail,” \textit{Daily Mail Online}, 8 July 2009, http://www.autisticdaily.com/2009/07/08/simon-baron-cohen-describes-gary-mckinnons-aspergers-traits/} Asperger’s cultural work in the McKinnon case largely functions to minimize the crime through constructing the person as childlike, innocent and vulnerable. While McKinnon’s legal problems remain unresolved as of this writing, the arguments have touched a nerve: songs have been written, petitions signed, protests held and celebrities such as Sting have rallied to McKinnon’s aid.

Another incident in which the “geek defense” was deployed was by the attorneys of Hans Reiser, a visionary computer programmer who was ultimately convicted of murdering his wife.
The “geek defense” did not work in this case, either in terms of the verdict or in the attitude which greeted his disability. For example, Reiser explained his tendency to not look people in the eyes, a common autistic trait. The judge in the case merely chuckled and jury members "shook their heads in disbelief." The judge later said of Reiser: "You are rude. You are arrogant. There are not enough words in the English language to describe the way you are." 248

One lawyer, whose client was on trial for murder, used a different strategy to make the courtroom better understand the condition. This lawyer compared his client Anderson to *Star Trek*’s Spock:

He operated on pure logic. He had no sympathy, no empathy, no regret, no remorse. He was civil, but not kind. He was cold, but not bad or evil. He thought differently than others on the ship. But the difference is that Mr. Spock knew of his reliance on logic and that he was different from the others, Mr. Anderson does not know that.” 249

Here the lawyer uses the character of Spock, a beloved alien character, to explain the actions of the defendant. In narratives of violence, Asperger’s often is couched in terms of a biologically based form of narcissism because of a perceived lack of empathy. This becomes an essential point to understanding how these narratives work because in these violent stories as well as geek syndrome stories, a lack of empathy is often what is used to distinguish the Aspergian personality from the so-called normal personality. Therefore, it is important to turn a critical eye towards empathy.

A QUESTION OF EMPATHY

Autism activist Jim Sinclair refers to empathy as a “nebulous term often used to project one’s own feelings onto others.” Sinclair here offers a rare critical perspective on empathy; continuing on that line of reasoning, we might imagine an alternative narrative that sees empathy as a kind of narcissistic imposition of one’s thoughts onto another’s. As several experts have remarked, the difference between a narcissist and a person with Asperger’s syndrome is very simple. The difference is that while a narcissist doesn’t care what others think, a person with Asperger’s would prefer not to hurt someone’s feelings. We could even argue the same for the character of Spock.

Furthermore, even if we can understand empathy in a positive way, we might consider autistic empathy as an earned skill as opposed to an unearned advantage. This is very similar to the way the Peggy McIntosh discusses privilege in her famous essay “White Privilege: Unpacking the Invisible Knapsack.” Qualities such as empathy that many autistics are thought to be deficient in work to the disadvantage of autistic people while being a hidden privilege for those not on the spectrum. The reality is that many people on the spectrum do experience levels of empathy and even in those who don’t they are not precluded from living anything less than a respectful, lawful life.

Ironically, as the “lack of empathy” is painted as an explanation of monstrousness, individuals with autism or Asperger's syndrome who have committed criminal offenses tend to have better performance in terms of theory of mind functioning than their Asperger's counterparts who have not offended, according to an article in the Journal of Forensic

250 Paradiz, 182.
Psychiatry. Essentially, this means that those who commit crimes tend to be more “empathetic” than those who don’t.

For instance, it has been estimated that 90% of kids with Asperger’s are bullied on a daily basis. There are plenty of advice books for parents on how to normalize an autistic child but very little has been said until recently about rehabilitating the bullies. As Nadesan says “it preserves the status quo from critical interrogation: for example, bullying behavior is “normal” but specialized and encompassing interests are pathological.” I am not suggesting that schoolyard bullies should experience the same level of pathologizing. Rather, it is critical to think of the ways that labeling and normalization work to privilege some identities as opposed to others. It is also useful to reframe some of these narratives in ways that are non-oppressive. This is particularly convincing when we hear from people who are actually on the spectrum.

For example, some writers with autism have talked about their functioning as "machine-like" in a positive, empowering way and as helping them to relate to other living things. Dr. Temple Grandin, for instance, has acknowledged her lack of neurotypicality, which helps her see with an "unclouded mind.” Here again we see that there are multiple ways to understand a so-called “machine-like” intelligence. As Cary Wolfe writes of Grandin:

The autistic's body boundary problem is at the core of another remarkable moment in Thinking in Pictures, which dramatizes in an especially powerful way many of the themes I have been discussing thus far. Grandin was hired to redesign a very cruel system used for the kosher slaughter of cattle, replacing it with a chute that would gently hold the

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254 Nadesan, 202.
animal in a standing position while the rabbi performed the final deed. 'It worked best when I operated the hydraulic levers unconsciously, like using my legs for walking,' she writes ….. I would simply like to draw attention to how here, disability becomes the positive, indeed necessary condition for a powerful experience by Grandin that crosses not only the lines of species difference, but also of the organic and inorganic, the biological and mechanical, as well. In a kind of dramatisation of the category meltdowns identified canonically in Donna Haraway's 'Cyborg Manifesto,' disability here positively makes a mess of the conceptual and ontological coordinates that Grandin's own rendering of the passage surely reinstates rhetorically on another level.255

These category meltdowns are inhibited in part by the understanding of the geek syndrome in terms of “technomasculinity” According to Nadesan, she sees the move from disorder to “unique, masculine cognitive style” as emphasizing intellectual strengths on one hand but also not being enough to combat the social marginalization of the person.256 She writes:

“There are two primarily detrimental effects of these assumptions: autistic people are represented as lacking “normal” consciousness and are therefore viewed implicitly as deficient, and autistic people, particularly “intelligent” high functioning autistics, are viewed as possessing an alien, machine-like form of intelligence.257

Terminator: The Sarah Connor Chronicles, discussed in the previous chapter, plays with this idea of category breakdown in a multitude of ways, as a reoccurring element of the show is the struggle of some Terminators, with mixed success, to become more human. Human, in this case, typically is defined in emotional terms such as empathy. Meanwhile, the human characters are

255 Wolf.
256 Nadesan, 200.
257 Nadesan, 126.
struggling to behave more like machines, to deny their human emotions and needs so that they stand a better chance in the upcoming future war. As Haraway said, “Our machines are disturbingly lively, and we ourselves frighteningly inert.”

The relevant thing to the Terminator discussion is that we've moved or started to move away from talking about "damaged" children to talking about "wired" children. This is the anxiety that is being grappled with; if this is inborn and genetic, does the indignation once directed at the parents now move to the children? Whether the geek syndrome is celebratory or dehumanizing, seen as inherently innocent or violent and lacking empathy, it has high stakes in that it is seen as being “wired” into a child’s being, as opposed to a monster that has taken over.

Public fascination and anxiety revolve around the constructed similarities between the autistic mind and the machine. Writer Harvey Blume states that “Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general. Who can say what form of wiring will prove best at any given moment? Cybernetics and computer culture, for example, may favor a somewhat autistic cast of mind.” Harvard professor Jonathan Zittrain urges the technology industry to make their products “less autistic,” implying that the current state of the digital world is wired for a kind of functioning autism. Indeed, it seems very difficult to divorce the subject of autism from debates and anxiousness over the interaction of humans with technology.

Recently, scientists developed a 4.5 million dollar robot named KASPAR that resembles a child’s doll. KASPAR is designed to teach children with autism a variety of social skills, such

as recognizing facial expressions and social cues. Autism research has in fact yielded breakthroughs in the development of emotion-mimicking robots that are in today’s science fiction. Quite literally, our robots are being designed based upon what we understand as autistic intelligence. Looking at KASPAR, do we see a friendly “Data” yearning to become human or a cold, efficient Terminator without empathy? Ian Hacking’s idea of looping comes to mind when considering the technological implications of how we understand autism today and the impact it will have on the future. The existence of a geek syndrome narrative, in some senses, paves the way to building bridges for increased participation for the neurologically different. There is no fate but what we make, as Sarah Connor would say.

SKEPTICISM

As we’ve seen, misperceptions such as the belief that autistics have a dangerous lack of empathy can be roadblocks. As well, there is also a barrier in the form of skepticism towards the idea of the autism, particularly Asperger’s syndrome. Consider the following skeptical quotation from The Chronicle of Higher Education:

Moreover, Asperger's syndrome is a "neurological disorder." It is classified as a disability, along with difficulties in hearing, vision, and mobility, that most universities are required to accommodate … If our hires had permitted themselves to accept a diagnosis of Asperger's syndrome (assuming that was, indeed, their condition), would we

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have been expected to adapt ourselves to the neurological differences that make them obsessive, miserly, rude, and truculent?\textsuperscript{260}

The writer in this case seems to understand Asperger’s as a questionable condition that pushes the limit of what one might call a “reasonable accommodation.” This kind of discussion represents a visibly growing backlash against positive representations of the autistic spectrum. This backlash has evolved alongside the shift in social value of autistic persons; one autistic activist glowingly described those with Asperger’s syndrome as "our visionaries, scientists, diplomats, inventors, chefs, artists, writers and musicians. They are the original thinkers and a driving force in our culture."\textsuperscript{261}

With such a description of Aspergian personas as “thinkers” and “visionaries,” that so contradicts disability, it is unsurprising to see some react with pride. For example, upon the completion of an online Asperger’s quiz with a tentative diagnosis and an urging to consult their doctor, one user proudly proclaimed “I guess I’m ready to join the X-Men now!” referring to the popular Marvel comics franchise about super powered mutants heroically struggling in a world that misunderstands and fears them, attractive tropes of misunderstood talent … of being special, but no one quite understanding you. As Stuart Murray says, this kind of fictional and heroic manifestation of disability representation is “strangely satisfying.”\textsuperscript{262}

This makes me wonder: If fans of the X-Men were to imagine themselves participating in this fictional world, would they want to be merely \textit{human}? I would venture that few would picture themselves as being the fictional helpless bystander during a battle, as typical, powerless


\textsuperscript{262} Murray, 99.
and genetically mundane. It is more likely that they would prefer to imagine themselves as mutants, both powerful and special? In this analogy, Aspergian traits are placed into the realm of the fantastical. Murray goes on to say making a condition an object of fantasy removes so many of the questions of the social dimension, obscuring the costs of a diagnosis. This narrative creates an elite category out of what has primarily been seen as a devalued population, and there is unsurprisingly an incredulous response. As one message board user writes:

People with mental disorders usually don't brag about it like it's a badge of honor, especially a form of autism. It's always worth a good laugh to see every awkward, socially-inept, angsty teenager who has ever gotten beat up by the "jocks" in school claim to have Asperger's Syndrome to justify being an utter loser.

Here Asperger’s syndrome is cynically viewed as part and parcel of a culture of over-diagnosis, eager to market treatment, literature and drugs … or to excuse social difficulties and bad behavior. The intelligence or even genius of the person are rarely disputed; rather it is the question of diagnosis as “excuse” or license to “get away” with something. Niall Ferguson writes in 2004:

You may not yet have heard of Asperger’s syndrome. But you can be sure that someone will sooner or later offer it to you as an excuse for his own bad behaviour, for it is the height of hypochondriac fashion in New York…

A similar discussion from the popular humor page SomethingAwful.com, discusses this “excuse” idea in terms endemic to the Internet:

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263 Murray, 28.
A disease is sweeping the Internet. It preys on the fat, the moody, the anti-social, the lazy, and those very people that once formed the core of Internet users. It can strike at any moment, but is ironically most likely to infect those that have been warned about the disease. This illness is rarely diagnosed willingly by medical professionals, but is so commonly self-diagnosed as to approach an epidemic.

I am referring to Asperger’s Syndrome, the plague of the 21st century, but you can call it Internet Disease.\textsuperscript{264}

As we can see, if a diagnosis by the medical establishment is viewed with suspicion, the perspective on self-diagnosis tends to often be greeted with outright contempt. This attitude towards “self-diagnosed Aspies” is founded on questions of who has the power to “create” autism and whether, if neurological difference is an identity, anyone has the right to claim that identity.

However, the relationship between those on the spectrum and the Internet has been described as “libratory” by more than one and with good reason: the existence and pleasures of on-line community. Historically, autistics have often been spoken\textit{for} by others, whether they are doctors or other authority figures and to dismiss self-diagnosis out of hand is troubling. Judy Singer writes that “Thanks to the Internet, autistics are taking diagnosis … into their own hands.”\textsuperscript{265}

But familiar questions of community remain: how does one claim membership and how does one police those who do or do not belong? Does somebody “have” Asperger’s syndrome

\textsuperscript{265} Mairian Corker and Sally French, \textit{Disability Discourse} (Buckingham: Open University Press, 1999,) 65.
without an official diagnosis? How does someone prove their diagnosis? As mentioned earlier, the article in Wired which identifies the “geek syndrome” also includes the Autism Quotient test. It is a 50 question survey that is not intended as the final word in neurological status, but often is invoked in conversation, for example “I got a 32” or “I got a 44.”

One does not need to delve too deeply to discover the myriad ways in which the medical profession’s status as having the sole power of diagnosis has historically worked out poorly for many of those on the spectrum and their families. Self-diagnosis has long been a tool of autism advocates as well as older individuals, as official diagnosis was not possible until 1994. Many report that the arrival at diagnosis isn’t a disabling moment, but a moment of sense-making as they looked back on their life. Some in the community arrive at a condition of “self-diagnosed and peer confirmed” and that is good enough for them.

But the backlash posits self-diagnosis as more of an “excuse”; a way in which to explain away social functioning issues like arrogance or rudeness and perform an identity that emphasizes intelligence. Of course, people along the autism spectrum can have vastly different gifts and challenges and won’t necessarily fit this stereotypical persona. The backlash is therefore responding to the geek syndrome in the form of an idealized technological genius who is also stereotyped as rude and abrasive, “acting out” and getting away with it. The backlash narrative does the same thing as the geek syndrome does: it tells us more about what our society imagines autism to be, rather than about autism itself.

The picture that becomes clear from this discourse is that our imaginings of what autism is grows out of these culturally produced desires: it is perhaps more useful to think not of our technology favoring autistic states of minds, but rather, our technology helping us to imagine
what autism is or might be. If we learn anything from the history of autistic presentation from Leo Kanner’s initial descriptions to Bettelheim’s “refrigerator mothers” it is that the stories we tell ourselves about autism affect people’s lives. Positive representations can potentially help people on the spectrum, while negative representations can do great harm, even those that seem to regard autism simply in disease terms. Michael Fitzpatrick writes that:

It is not surprising that such a negative attitude towards autism sometimes seems to lead to a negative attitude towards the autistic child, who is depicted in metaphors of toxicity and disease.266

What we see when we shift away from the media emphasis on Asperger’s syndrome in terms of a genius trait or an object of fascination, is a very different kind of discourse emerging, one that tends to emphasize differences as dangerous. I argue that the manifestations of this backlash are new, but the basic idea of attributing such faults to the disabled are nothing new: Leo Kanner once had a direct response to the question of autistics and other cognately disabled people as being “dangerous”:

Let us try to recall one single instance in the history of mankind when a feebleminded individual or group of individuals was responsible for the retardation or persecution of humaneness in science. Those who caused Galileo to be jailed were not feebleminded, those who instituted the Inquisition were not mental defectives. The great man-made catastrophes resulting in wholesale slaughter and destruction were not started by idiots, imbeciles, morons or borderlines. The one man, Schicklgruber, whose IQ is probably not below normal, had in a few years brought infinitely more disaster and suffering to this

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world than have all the innumerable mental defectives of all countries and all generations combined.”

Kanner’s point is that violence cannot be seen as a province of those considered to be disabled within a culture. His reference to Adolf Hitler (Schicklgruber) can be seen as a moment in which we subject normality to the same kind of critical lens that is so often used to understand disability.

As we have seen, the “geek syndrome” idea of autism poses marvelous new possibilities that are removed from old narratives of despair and the plight associated with autism. But as our knowledge of this condition expands and evolves, we also can see the ways in which neurological diversity can always draw public repulsion as well as fascination at the same time, challenging us to not only embrace new narratives that celebrate ways of being but also to remember that these narratives are never free of their darker sides.

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CONCLUSION

In November of 2009, an article appeared in the *New York Times* asking the question: Is Asperger’s Syndrome “heading the way of the dodo bird?” Rumors have been spreading that in the updated DSM V, due sometime in 2012, the diagnostic category of Asperger’s syndrome may be replaced. If the speculation is to be believed, the new manual will remove the separate Asperger’s diagnosis in favor of the term “mild autism” along the autistic spectrum. The article raises the question: How do you essentially “take away” a diagnostic label in wide professional use that many people identify with? A variety of famous autism experts have weighed in on the controversy. *The Complete Guide to Asperger’s Syndrome* author Tony Attwood is quoted as saying:

“The general public has either a neutral or fairly positive view of the term Asperger’s syndrome,” But if people are told they should be evaluated for autism, he went on, “they will say: ‘No, no, no. I can talk. I have a friend. What a ridiculous suggestion!’ So we will miss the opportunity to assess people.”

Famous autistic author Temple Grandin agrees with leaving the diagnosis in place, saying that the “Asperger community is a big vocal community, a reason in itself to leave the diagnosis in place.” On the other hand, founder of the Autism Self-Advocacy network Ari Ne’eman,said “My identity is attached to being on the autism spectrum, not some superior Asperger’s identity,”

270 Wallis.
adding, “I think the consolidation to one category of autism spectrum diagnosis will lead to better services.”

Letters poured in to the paper from readers. One writer said that “For me, the greatest gift of the term Asperger’s syndrome is that it has given me an identity. If the label disappears, I fear that the distinction between Asperger’s and autism will eventually also disappear…”

Another added that the “reason Asperger’s syndrome should be retired as a category is not just that it lacks specificity, but that it also medicalizes large areas of the mind and stigmatizes the behavior of young mathematicians and scientists.”

Author of the AQ test, Simon Baron Cohen, wrote a letter to the editor of the Times on the subject:

We also need to be aware of the consequences of removing it. First, what happens to those people and their families who waited so long for a diagnostic label that does a good job of describing their profile? Will they have to go back to the clinics to get their diagnoses changed? The likelihood of causing them confusion and upset seems high.

Second, science hasn’t had a proper chance to test if there is a biological difference between Asperger syndrome and classic autism.

For me, this debate over the precariousness of Asperger’s syndrome’s status brings to mind once again Ian Hacking’s idea of “making up people.” Classifications such as Asperger’s syndrome or mild autism can be used for many purposes. They can be used to organize people or control them or help and assist them. But before classifications can serve any of those purposes, they

271 Wallis.
273 “A Vanishing Diagnosis (3 Letters)”
first “make up” a person, as Hacking calls it. This, of course, does not mean that the condition is “made up”; rather, it means that certain aspects of a person that simply are get constituted into institutional language, creating a new social being. Hacking calls this “looping.” Essentially, the people studied and defined are never quite seen as the same afterwards.

People can never be simply studied; they are always what Hacking calls “moving targets.” Once one is defined as having Asperger’s syndrome, in that sense they are reinvented as part of an Asperger’s population whose inhabitants have been transformed through the naming. Through this logic, we can understand that the same transformation might take place through the taking away of a name.

If the classification of Asperger’s should change or disappear in the DSM-V, it is therefore likely that who is considered a member of this population will change as well. But at the same time, Asperger’s syndrome is “out of the box.” At the very least, if such a change is made and Hans Asperger’s work is essentially re-lost, countless numbers of people have been “made up” and transformed through interacting with this diagnosis. If the DSM-V changes the classification, what then? Will people be rediagnosed? Will rediagnosis carry with it new challenges to insurance and medical costs? Will we see positive identity spread to the entire spectrum or will the geek syndrome disappear with AS? And what of the tremendously growing awareness of Asperger’s within the general public and in popular culture?

These are important questions, but ultimately, the change to the DSM is speculative and cannot be the answered except in the future. Given the growing population of autistic and Aspergian persons, this debate will no doubt continue. For my purposes, what I see as productive is that in this speculation we see the importance of Asperger’s syndrome. I see this
importance extending beyond simply a disease name or disability category, but rather as an identity with a strong place in our contemporary society, and with a rich history and culture all its own.

In this dissertation, I discussed the history of Asperger’s syndrome using the examples of Leo Kanner, Hans Asperger and Bruno Bettelheim. We saw the emergence of different narratives of autism and what shines through these stories is a progression from intense medicalization and stigma to a softening of these features. While nowhere near ideal, public understanding and acceptance of diverse people across the spectrum has evolved to become something approaching tolerance.

The recent concept of the “geek syndrome,” introduced by Wired magazine in 2001, has worked as a powerful agent in idealizing certain aspects of Asperger’s syndrome. It should be noted that the result of this paradigm shift is unclear as it pertains to developmental disability as a whole. Again, traditional understandings of disability are not entirely absent in the “geek syndrome,” and it is possible that the existence of a “superior” Asperger’s identity might serve to further stigmatize other areas of disability that aren’t as visibly culturally valued. Furthermore, as I discussed in the previous chapter, oppressive narratives co-exist alongside and with these more privilege-oriented narratives. However, the important point I take from this is that the trajectory that can be traced through this history demonstrates the changeability of popular understandings of disability. The “geek syndrome” is a site of interest that I believe will serve as a sign post in the future as the popular conception of the autistic spectrum continues to evolve. As we see more and more accounts of visibly Aspergian success stories, both fictional and non-fictional, I believe that cautious optimism toward the future is warranted.
Of course, while real world examples of autistic success grow, it is well documented that the social concepts and narratives of disability, which is the evolution we are discussing, have always been shaped primarily by people without disabilities. The “geek syndrome” provides a narrative that naturalizes the abilities of this population to contribute and be proud of these contributions. It must be understood that this narrative doesn’t give this ability; it merely helps people to understand and organize knowledge about the condition. Neurologically different people have been taking strength from narratives for a long time; the geek syndrome is simply a new permutation. One person with autism cites an old story as an example of autistic pride: "My favorite story about autism is 'The Emperor's New Clothes. The Boy didn't understand social norms, but he spoke the truth. I think society needs us."275

The more we critically interrogate normality, the more it resembles the Emperor in the story. As Robert McRuer says in Crip Theory: Cultural Signs of Queerness and Disability, the myth of normality, such as able-bodiedness or heterosexuality, “still largely masquerades as a non-identity, as the natural order of things.”276 Rather than be assured by the primacy of the “normal,” the geek syndrome throws it into question. As I have stated before in this dissertation, however, we must be cautious as this narrative does ultimately conform to normalist views of ability. As Murray reminds us, “Fascination with the subject must always be in the terms of the majority audience.”277

Still, the geek syndrome gives us a place to start. Psychologist Tony Attwood has described Asperger's syndrome as "having a brain that's wired differently—not defectively."278

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277 Murray, 13.
In many ways the most radical element of the geek syndrome is in how it encourages those on the spectrum to take pleasure in their own neurodiversity, emphasizes the value of neurodiversity.

Modern narratives of Asperger’s syndrome such as the “geek syndrome” transform what it means to be “defective.” Cultural approaches to autism and Asperger’s would be worthwhile even if it were only relevant to those personally affected. But even if the label of Asperger’s is in question, the list of people on the spectrum is growing exponentially and the implications brought up by the work done within studies of different disabilities is very much universal. I believe that as awareness of the autistic spectrum grows, cultural scholars will be spending more and more effort in grappling with the issues raised through this growth. Given the rise in diagnoses, learning to value the neurologically different may no longer be an ethical concern but a necessity given this rapidly growing population.

Furthermore, neurologically different people that have been constituted through disability are immediately impacted by diagnosis. At the same time, I would argue that this looping does not end simply at but extends to the ways in which we define and understand broad categories of gifts, intelligence and ability. If we begin to understand the Einsteins and Newtons or Warhols of our world in terms of an autistic quality first, before terms like “gifted,” “determined,” or “driven” enter our vocabulary, what does this mean for how we understand autism or even disability itself? The answer may lie in the fact that any condition such as autism does not just impact certain populations, but also leaks out onto the culture as a whole, defining and redefining what it is to be human. As writer Paul Collins writes:
"Autists are described by others--and by themselves--as aliens among humans. But there's an irony to this, for precisely the opposite is true. They are us, and to understand them is to begin to understand what it means to be human. Think of it: a disability is usually defined in terms of what is missing. A child tugs at his or her parents and whispers, 'Where's that man's arm?' But autism is an ability and a disability: it is as much about what is abundant as what is missing, an overexpression of the very traits that make our species unique. Other animals are social, but only humans are capable of abstract logic. The autistic outhuman the humans, and we can scarcely recognize the result."  

Could the geek syndrome idea be the first signs of people recognizing the result? There are ways in which we can think about the idea of “outhumaning” humanity as an idea that opens the door to valuing diversity within a community seen as disabled. But there are also ways, as have been pointed out in this dissertation, that the traits the larger culture chooses to value in such a community work to maintain oppressive hierarchies. Ultimately, the desired goal for such paradigmatic changes in understanding neurodiversity should be the increased level of valuing people on the spectrum, particularly those who are on what is referred to as the “lower end.” Tolerance and respect for neurologically different people cannot be seen as one side of an argument but should be a given in any argument.

As Nadesan points out, we understand the human mind in the twenty-first century in terms of a computer and the tension in understanding autism partially comes from the tendency to see the autistic mind as too machine-like. As a culture, we might be better served by the idea of what neurodiversity expert Thomas Armstrong refers to as a “brainforest,” where the metaphor for the brain is like a rainforest, where genes for a variety of difference have a place

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and are not seen as malfunctions as in the computer metaphor but instead are considered part of an ecosystem. This metaphor better exemplifies the complexities of human difference rather than a simple functioning/malfunctioning binary. Armstrong argues that even if this metaphor is not entirely accurate, it is at least every bit as inaccurate as the computer model.\textsuperscript{280}

I take this to mean that the metaphors we choose, such as the geek syndrome, should serve us well or we should change them. The benefit of thinking critically about social constructions is that they can be constructed in different ways to create better alternatives. As Armstrong says, what a difference it would make to stop talking about select people in terms that describe them as broken and damaged! It is worthwhile to consider what would happen if we began talking about children and adults in ways that are diverse and multi-faceted, that respond to individual care needs and nurture special talents.

The point of this dissertation is that metaphors and narratives matter. Through the history of autism we have seen the sad effects of metaphor and narrative. As we begin the 21\textsuperscript{st} century, Asperger’s syndrome, aka the “geek syndrome,” no matter what future holds, has already opened the door wider for narratives that challenge oppressive understandings of disability and the conventional understanding of what is called “normality.” By appealing to culturally valued skills and interests, the geek syndrome opens the door for all us to think critically of the means by which people are valued.

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