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# Assembling Autism

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ASSEMBLING AUTISM

by

KATE SUZANNE JENKINS

A dissertation submitted to the Graduate Faculty in Sociology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

2014

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This manuscript has been read and accepted for the  
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THE CITY UNIVERSITY OF NEW YORK

Abstract

ASSEMBLING AUTISM

by

KATE SUZANNE JENKINS

Adviser: PATRICIA CLOUGH

Autism is a growing social concern because of the epidemic-like growth in diagnoses among children. The lives and experiences of adults who have an autism diagnosis, however, are not as well documented. This dissertation project seeks to resolve that dearth of research. I conducted a year of participant observation at four locations of social, self-advocacy, and peer to peer support groups. I also conducted interviews with leaders and participants. I also participated (as a researcher) in an experiment in social skills acquisition led by participants from my ethnographic field work, fulfilling the planned participatory action research component of my original proposal. I found that many of the problems my participants experienced were both mundane and routine for individuals who are marginalized, but at the same time, made extraordinary by the presence of autism. I found that the affective and sensory components of the disorder were primary in the lives of my participants, though these issues are generally secondary to the social complications that typify the social construction of autism elsewhere. I also found that my participants struggled to control the very meaning of autism, especially as the diagnostic criteria were rewritten. Autism has implications for Western notions of citizenship and subjectivity, as well as identity politics and social movements, namely that capacity for rationality is not necessarily associated with capacity for social interaction or independent living. Autism presents as a spectrum and constellation of impairments and differences, and as such, contests the notion of a unified self.



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This dissertation is dedicated to Shirley Pressburg Jenkins, PhD, of blessed memory, whose exemplary academic record and persistent support for all of my pursuits continue to inspire me today.

The author would also like to acknowledge the various supports that have enabled her to complete this dissertation and doctoral degree, including her mother and stepfather, Drayton and Bill Gerety, who provided a place to live; her father and stepmother, Peter and Mary Jenkins, who generously supported and subsidized various aspects of graduate school; her extended family, half of whom are academics or campus brats and therefore expected and assumed the author's success; her spouse, Zach Strassburger, who not only supported her through this ordeal but is moving to rural Minnesota in pursuit of that elusive tenure track; and her circle of friends at the Graduate Center, especially the fabulous Kimberly Cunningham. She would also like to thank her committee, Victoria Pitts-Taylor, who introduced her to Foucault, Barbara Katz-Rothman, who also mentored her through the Disability Studies program, and Patricia Clough, her beloved advisor. Finally, she would also like to acknowledge the coffee shops and tea houses of New Haven, CT and Squirrel Hill, Pittsburgh, PA, for the millions of milligrams of caffeine, the broad bandwidth of wifi, and a place to work away from home.

## TABLE OF CONTENTS

Chapter 1...	Page 1
Chapter 2...	Page 31
Chapter 3...	Page 61
Chapter 4...	Page 78
Chapter 5...	Page 142
Works Cited...	Page 164

## Chapter 1

In almost every study, article, book or memoir of autism that I have read in the past decade and a half in personal and academic research on autism spectrum disorders, the opening section of that text is spent defining what autism is, why it is a problem, how it is a problem, on what level it is problematic. Sometimes they begin with a vignette, a technique I also considered for this introduction. A sympathetic character, often a child, usually male, and some problematic, abnormal, atypical behavior that sets him apart from his family, from making friends. He is rendered dependent, feminized, impotent, yet unpredictable and potentially dangerous, with no or limited sense of the future, for himself or on behalf of his self by significant others, usually parents. Always within the first section, chapter, what have you, autism is defined, and defined as a problem or disorder. Always a what is autism; always a who is autism.

What is autism? Autism is a problem of personhood, a problem of marginalization of a group or class of people based upon divergent expectations of what constitutes the human. I originally set out to document autistic subjectivity and autistic activism, but a significant disjuncture happened while writing, leading me to instead refocus on questions of personhood in relation to gender and violence instead of organizing and social movements. I seek to understand identity, social relations, genders and affect around autism. Who is autism? My participants were members of autistic run spaces that offered social support, cultural activities, and self-advocacy. They were foremost, however, adults, making their ways in the world and were of this world. These are my non-answers to those non-questions. By the end of this chapter, in which I will set up the project of my dissertation, locate it in a historical and cultural context, and summarize the arguments to come, I will come to a definition of autism. However, I will not do so before

examining the problematic ways in which autism has been defined, especially in relation to my group of study, adults who identify or are identified as on the autism spectrum. And instead of starting with a sympathetic character, I will start with myself.

### **Confession**

According to Michel Foucault (1978), the power is the resonance of the confessional. Confess the truth of the self, submit one's self to the medical gaze, and emerge knowing the self's location, a diagnosis, better able to manage the self as a product of psychiatric power. And so I start here with a confession: I was diagnosed with Asperger's Syndrome at age 18, after a long history of learning and affect related diagnoses in childhood and adolescence. The relevance of the truth of my diagnosis is, overall, I think, quite small and simultaneously immense. Relative to my ability to analyze, understand, and interpret my ethnographic scene, I actually think it is small. Any properly trained ethnographer should be able to enter a scene of dramatically different cognitive styles, and adapt to find the truth or truthiness of a given culture. Culture is engraved upon our neurology and cognition (Bourdieu, 1979/1984), after all, and socialization and cultural difference produce different pathways for perception, cognition, and sociality within the brain. At the same time, my access to my field sites was essentially predicated on the basis of having a diagnosis. Because of how researchers have historically (mis)treated those with autism, there is a healthy degree of skepticism for those in academe studying these groups (which I will hopefully demonstrate imminently in this chapter). There is an ironic relationship between researchers, both medical and non, and those in the communities I studied. As I will discuss later in chapter 3, autistics are dependent upon medical professionals for legitimizing diagnoses of and identities as autistic. At the same time, however, as much as

individuals rely upon these gatekeepers, and the community relies upon them as gatekeepers, the community itself shields itself from outsiders to prevent exploitation. I earned my trust as a researcher by documenting my diagnosis, by being a participant in two of the three groups of study, in two of four locations, prior to engaging in research, as well as other outlets of autistic culture (such as list serves, on two of which I was an active participant as a college student and thus known to organizers of the various groups and locations).

My intellectual engagement with autism does not arise merely from my own diagnosis, though my history with diagnosis and being in the world as autistic certainly inform my intellectual curiosities. It was instead a moment of interpellation, during my undergraduate course on social psychology. Early in the semester, we watched a film on the “wild boy of Aveyron” as part of discussing theories of socialization, the failure to socialize producing the phenomenon of feral children. Both the cinematic depiction of Victoire as well as the actual documentary footage of severely neglected children struck me as reminiscent of severely autistic behavior, including lack of eye contact, perseverative and self-stimulating behavior, and difficulties with symbolic language. The children over attenuated to sensory-perceptual inputs and were unable to attend to information at different levels, ignoring background information or foregrounding other information. Perhaps, I thought, autism is caused by an interruption to the process of socialization. This notion of interrupted socialization is not exactly uncommon in autistic developmental literature, but it isn't the dominant theory by far. I will discuss this further later in this chapter.

Later that semester, however, my thoughts on the problem of autism coalesced further when we discussed interaction rituals, reading “On Facework” by Erving Goffman (1967/1982). My life was revolutionized in two ways: first, that people behaved according to a set of culturally

prescribed rules, and that once the patterns were discerned, it was a matter of understanding and applying them in situ. This is the moment of my own becoming as an ethnographer, a constant sociologist of my everyday life. This was more revolutionary and helpful in terms of social functioning than years of behavioral therapies, though I do acknowledge the groundwork that these therapies lay in terms of being able to enter adulthood at all. However, it also made me realize that in order to successfully have an interaction, both actors must be following basically the same set of rules, be able to take the role of the other, and have the cognitive abilities to do so. To say simply that autistics lacked a theory of mind was just not true; non-autistics equally lacked an autistic theory of mind, a mutual unintelligibility. This remains a consistent finding in all of my research. The problem of autistic interaction is not just on the part of the autistic, it is interactional, between two or more actors, who do not or perhaps cannot share a meaning of interaction. The autistic actor isn't the disabled one, per se, as the disability and impairment lies between the autistic and society. A neurotypical might well be the disabled one in a predominantly autistic space, though most autistics (bringing this into the present line of research) internalized and perform many of the norms of the cultures in which they find themselves, as they are just as subject to hegemony as the rest of society. Whether they performed these norms adequately, or resisted performing certain norms due to lack of understanding of meaning or larger context, is almost an aside to the question of debility versus capacity, and refers back instead to the notion of the problem being in the interaction. While small talk, for example, is functionally useful for maintaining social ties, autistic resistance to small talk or preference for other forms of tie maintenance is more reflective of the shape of society, not some inherent problematic aspect of the autistic his or her self. Society is increasingly tailored to the neuro-normative, weirdness is medicalized, and the self is

increasingly known through biomedical discourse and risk, so of course any problem in interaction is individualized to the person whose self is discreditable as disordered.

One question posed to me during my proposal defense was the issue of self-reflection. How would I know I wasn't merely projecting aspects of my own self, through over-identification with my participants? I explained, as I will outline below in my methods, that I would be keeping somewhat of a diary of my experience, grounding my own emotional entanglements with my field in order to best understand my social location as researcher and participant. This auto-ethnographic account, of sorts, is useful for any participant-observer. For my own research, however, I noticed and documented an interesting phenomenon: the longer I spent in the field, the more I hung out with autistics, the more energy I found it took to engage in routine interaction in neuro-normative social fields. Attuning and then attending to other people's affective and embodied communication takes energy; autistic space allows for alternatives, for flooding out and verbalizing key shifts and all sorts of different ways of accomplishing transferences and other non-verbal informatics. The assumption, too, of shared communicative space is not present, and when engaging with non-autistics I had to constantly deduce what assumptions were supposedly shared a priori to engagement. Whereas I know that my participants welcomed the break from neurotypical space, welcomed the support and relief, I felt myself losing grip on the rest of my reality. It made it especially difficult for me to manage people who were very neurotypical, people whose behavior was antithetical to autistic behavior, who foreclosed upon alternatives to neuronormative behavior. Yes, autistics tend to be more self-referential and what some would call self-centered, but they are not deliberately manipulative of others the way many narcissistic individuals are. Prior to my field work, I sought out these autistic spaces when I felt myself needing a break from managing my neuronormative spaces.

However, deliberately engaging with these spaces for a sustained period of time was overwhelming to my learned coping mechanisms. I could be freer in autistic space, but overall, less functional. I was glad to put an end to my period in the field. I have not sought out autistic space since concluding my field work.

## **My Project**

The majority of the research for this dissertation involved over a year of participant observation with four different social/cultural/support groups run by and for adults on the autism spectrum, sponsored by three different national or regional groups. All groups were in major metropolitan areas, either within the city center itself or in a suburban location within an hour of the city center. I also conducted interviews and kept the diary mentioned above, as well as worked with various texts produced by the groups of study.

One group was on the West Coast, and I conducted my participant-observation while living in California during the summer of 2010. This group sponsored both a group for autistic adults, and a parallel group for non-autistic parents, partners, siblings, and other significant others. While there was some co-programming, it was generally understood that the autistic-focused group deserved space separate from the non-autistic space, and that those with autism dictated the general direction of the coalition. The group was small, ranging from six to eight other participants besides myself at the autistic-only events or group meetings. Three routine participants were female, and all but one participant were white; the lone person of color was Asian. The location space for the meetings was a conference room in a medical professional building, in a somewhat suburban area still within city boundaries, though there were also outings that occurred all over the metropolitan region.

The remainder of the groups were on the East Coast. Two groups were affiliated under the same national organization, but one was in the city center and the other was suburban. The city location was well attended, with attendance usually numbering around 30. There were usually five or so women in attendance; at times, however, the majority of women in attendance were non-autistics. They were partners, spouses, girlfriends, friends, or mothers, of autistic men, there either to support the autistic person, to scope out the scene to convince the autistic person to come to the group, or provide information to the group about whatever organizing they were doing. At the time, the group met in a community room in an apartment complex in a centrally located neighborhood, though they have since moved to other space. Racially, the city group was disproportionately white considering the city in which it was located. Racial ambiguity, however, leads me to inconclusive counting of breakdowns. Most participants I read to be white, but there were a fair number who were racially or ethnically ambiguous, and a number of Asian and Hispanic individuals (including a person who identified as both). There were a handful of African American participants here, as well, though none who were consistent meeting to meeting. The suburban location primarily met in a municipal community room in close proximity to mass transit. It was not as well attended as the city group, maxing at twenty five participants but averaging closer to fifteen. There were five routine female participants, the rest were male. There were only a few non-white individuals and to further identify them risks violating confidentiality. This group, however, was more tightly knit than the city group. Whereas there were friend groups within the city group, and some overlapping social circles, the suburban group was primarily a friend circle that existed a priori to the creation of the group. There had been a similar group years back that dissolved due to personality and leadership conflicts, but members of that group continued to meet socially and formed the primary

participants in the new one. Because of this, the new group also conducted social activities such as going for ice cream after a meeting. There was also a degree of involvement from a local parents group, which had secured the funding for the adult group to meet. Similar to the West Coast organization, this parents group was primarily interested in creating a space for autistic adults to become the leaders of their own space, albeit with some organizational and directional space from a regional support services organization facilitated through the parents group, which had invited the autistic-run group to do the actual organizing.

As for the final group, the focus was officially on self-advocacy and political organizing, but during my tenure in the field, the group primarily functioned as a less structured social group meeting, with off shoot groups focused primarily on support autistic adults cope with employment issues. It has since become much more active politically, under new leadership, as well as renewed focus on local chapter organizing from the national organization. The group met in a public space in a private development, a not uncommon configuration in the city in which the group met, adjacent to a coffee chain. To an outsider, the group looked like a somewhat odd group of friends getting coffee together on a Sunday morning, sometimes boisterous, sometimes quiet, with some members actively participating and others seeming to not be engaged with the group at all. Membership was more diverse and more fluid than the other groups, and the meetings had significantly less structure (occasionally formal introductions like the other three groups, but just as often, not). A few of the main participants overlapped with the other group that met in the city, but the divisions between the groups were distinct. While one might think that the divisions between a group focused on self-advocacy and a group focused on peer support might differ in the economic positions of participants (with those with employment having the resources to advocate and not be in need of support, etc) or other social factors, the division

seemed mostly to fall along attitude towards the problems of autism. The self-advocacy group was much more externally focused, while the peer-support group seemed to follow a more individualized model of where the problem lay. Within the city, the self-advocacy group attracted proportionately more people I read to be African-American, highlighting perhaps how autism and race interact as political identities and structural configurations. However, the self-advocacy group had fewer routine participants, and the size greatly varied, from five individuals up to twelve, with some meetings cancelled due to lack of RSVP via meetup.com, the prime tool the leaders used to organize the meetings.

During the course of my research, I also conducted interviews, some structured and formal with individuals I identified as ‘leaders’ within their respective organizations and some informal ethnographic interviews with individuals who just seemed like they might have something interesting to say. I also had access to digital archives of one of the organizations sponsoring groups of study, and materials from all three organizations. I ended up, however, not really using the formal interviews or archives, as I decided not to write a planned chapter on the actual structure of autism organizing. I made this decision in late December of 2012, after two individuals diagnosed with autism committed tragic crimes of national attention. Adam Lanza, the more famous individual, murdered 26 in a rampage attack at an elementary school in Connecticut<sup>1</sup>. Chris Krumm, who also spent time in Connecticut, murdered his father and stepmother with a bow and arrow, before committing suicide via stabbing, in Wyoming, the week before Lanza’s rampage. Combined with my experience of sexual harassment in the field and some of the stories in my field notes, I decided to refocus on understanding autism and masculinity, especially in relation to perceptions of danger. Multiple media accounts of both

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<sup>1</sup> For background information, see the Wikipedia article on the Newtown Massacre,

incidents connected their behavior and violence to their autism spectrum diagnoses, a fire further fueled by the *Casper Star-Tribune*'s publication of Krumm's (2012) suicide note, in which he squarely blamed the limitations in his life on his father's Asperger's diagnosis and the heritability of autism. The reader may recognize the disjuncture between chapters written before and chapters written after these two events.

My participants are admittedly self-selected. They are people who generally both self-identified as being autistic or on the autism spectrum, and generally had some degree of diagnosis or professional identification as such as well. They also generally experienced degrees of marginalization in their everyday lives, including isolation from family or friends, dependence upon family or friends, problems with employment, housing, and education, difficulties with comorbid conditions including anxiety, depression, and obsessive compulsive disorder (the three most commonly mentioned comorbid disorders among my participants). Their problems, as I will discuss later, were both exceptional – such as the participants who had moments of recognition that many of their social problems or executive functioning problems were likely autism problems – and extremely mundane – a fall out of the economic downturn of 2008 made it difficult for anyone even slightly marginalized to maintain steady employment, especially in the fields in which my participants were employed (low-level technical fields like help desk support, graphic design). The areas in which I did my research are among the most expensive areas to live in the country; living with ones' parents, especially after college and before marriage, was typical if not expected due to high housing costs. It was not remarkable that many participants lived with their parents (though most did not). Serial employment is not surprising, but also exceptionally autistic. They were, as Puar (2007) writes of her subjects, nonexceptional, simultaneously extreme Other while also being well within the norm. All but one of my subjects

could basically function independently in social situations; one utilized an aide, but participated independently of his aide in the group meetings and functions. Another handful of participants were often accompanied by non-professional helpers, caring siblings, intimate partners, or parents, or lived in such supportive environments. Autism may have interfered with the typical expectations of independently transporting oneself to a meeting of like-minded individuals of any stripe, but it is certainly within expectation that some situations generate anxiety in neurotypical individuals, and that those individuals may also desire to be accompanied to such situations by significant others. The vast majority of my participants, however, were generally independent, generally employed for most of my research time frame (albeit in low level jobs, and not always consistently or at the same job) or retired, and had lives and relationships outside of the groups. To reiterate what readers may deduce from my group-level accounting, the majority of my participants were white, the majority were male, and as I discuss later, the majority did not identify as LGBT or other sexual or gender minority.

### **Missing Bodies**

Implicated in the accounting of who was there is the question in the negative: who wasn't. Forty years ago, the chances of anyone being diagnosed with autism were low. Official statistics peg the prevalence rate at 1 in 10,000 children. By the year 2000, that rate had increased to 1 in 150 children. Two significant, and overlapping, reasons for this rate increase were the twin effects of greater awareness of the diagnosis and the addition of Asperger's Syndrome to the official diagnostician manuals in the early to mid-1990s, to the ICD in 1991 and the DSM in 1994. There is a time-lag in the effects of the diagnostic expansion, however. Using

media reports as a proxy for social awareness, the rapid expansion of media coverage did not occur until the year 2000, when the number of articles published by the *New York Times* actually increased exponentially (Jenkins 2009). Looking at Travers', et al, (2013) racial disparity data for autism diagnosis over time from 1998 until 2006, we find that at first Blacks were overrepresented slightly in proportion to other racial categories for risk of diagnosis (the chance of a white child being diagnosed was held constant to account for changes in diagnostic categories and increasing prevalence). However, by 2006, we find that Blacks are significantly underrepresented, along with Hispanics and Native Americans, relative to risk of diagnosis of whites. Asian/Pacific Islanders remain represented in similar proportions as whites, going from slightly overrepresented to slightly underrepresented, but not at significant levels.

While this diagnosis information is for children, I theorize that a relationship exists between diagnosis rates of children, media coverage and self-awareness or self-diagnosis. Therefore I suggest that at least part of the missing bodies problem in relation to various racial groups has to do with the racial bias of the diagnosis itself. Access to the diagnosis, as a child or adult, requires access to health care, as well as a certain educational and awareness level for the parents or person his or herself, as well as a belief in the culturally dominant models of biomedicine. As Liu, King and Bearman (2010) indicate, autism spectrum diagnoses travel along social networks, particularly among the middle class or above. The same processes that elevate a child's chances of diagnosis likely influence the chances of an adult discovering and identifying with the diagnosis, such as the phenomenon whereby a parent receives a diagnosis after the diagnosis of their child. Just as the cultural capital more readily available to white and Asian parents increases their odds of having a child diagnosed with autism, the same cultural capital

extends to white and Asian adults, though particularly white adults, in obtaining the same for themselves.

While the Travers study is exclusively post-diagnostic expansion, it does track the expansion of available treatment interventions under the Individuals with Disabilities Education Act, which changed significantly the specially situated nature of autism relative to other possible diagnoses. It was not until the renewal of IDEA in the late 1990s that general developmental delay was added as a category of treatment for children in elementary school, a temporary diagnosis that assumed a habilitable/rehabilitable child who needed aid in “catching up” but who was not specially designated as permanently or significantly disabled. While Eyal et al track this expansion along with the changing matrix of knowledge around autism (this point which I will be discussing further in the next section of this chapter), what came along with this expansion was the increasing inclusion of Asperger’s Syndrome and PDD-NOS (both now folded into the autism spectrum disorder diagnosis, to be discussed in Chapter 2 or 3) under the specially situated category of autism in eligibility for services. While IDEA does not provide for maximization of education, merely the provision of education, it dramatically increased access to special services. Lately it has also given parents access to special coverage of treatments that may otherwise be denied by health insurance companies as neither sufficiently medical (they are not) or with sufficient evidence of efficacy (there is scant). Specially situating milder diagnoses, especially considering the actual diagnostic substitution, not just the theoretical large scale diagnostic substitution documented by Eyal et al (2010) but also the practical substitution engaged in by parents and professionals in everyday life and pursuit of interventions documented by the likes of Ong-Dean and others, creates space for increased demands.

On top of this demand-side increase (Eyal's term), and societal scale diagnostic substitution, driven by what he calls a "blender" of information following deinstitutionalization and the rise of therapies that however, there is a category of people that I believe Eyal et al and others generally miss: those who would be diagnosed with autism otherwise. While Kanner (1943) admitted that those children currently institutionalized with feeble-mindedness might well be non-verbal autistic (and there is a poorly documented but existing history of non-verbal autistic children being sent to schools for the Deaf), and thus there is a population of people diagnosed as mentally retarded/feeble-minded/etc who are actually autistic (e.g. Amanda Baggs, internet-famous for a series of videos documenting her interactions with her environment unmitigated by semiotic knowledges due to her autistic perceptual differences, the most famous one being "In My Language" posted in 2007), there is also a population of people previously diagnosed with learning disabilities or simply undiagnosed completely who would now be diagnosed as autistic. Eyal notes that learning disability diagnoses may represent an earlier version of diagnostic substitution from mental retardation, but the rise of hyperkinesis/ADD/ADHD really portends the rise of surveillance of childhood. Eyal does some work documenting this, but the moral surveillance of childhood and the role of education is better documented by Cohen's (1983) work, especially around the changing norms of classroom behavior and expectations of childhood. Classrooms in the 1950s were based around obedience to authority, where the silent child was normal and discipline was rigid. By the 1970s, normative classroom behavior had shifted away from such obedience, were much more interactive, and more was demanded of children socially as well as academically. Students with attention problems, including autistic-related attention problems, who may have thrived with a more rigid environment or at least not have created as big a disturbance, were now expected to have self-

control or develop self-control. The hyper child was the problem, and became diagnosable. Eventually, the withdrawn child also became problematic, hence the autistic child. Medical surveillance of childhood in general was on the rise, as Eyal (2010) and Silverman (2012) both document, with the understanding that interventions and normalization of childhood might lead to a normalized adulthood. What was totally lost under a system of institutionalization of children, futurity, was gradually replaced by a contingent futurity, at least for those with severe impairments. For those with milder impairments, they got caught in the system that reformulated what constituted the moral problems of childhood, such that by the present time, even those with mild diagnoses may well be thought of as having limited futurity, despite the fact that I argue these folks were, in previous generations, missed as having an impairment altogether. Kanner, Asperger, Bettelheim: all noticed that the parents of their charges had remarkably similar personalities as the children under treatment, with Bettelheim going so far as to blame these mothers for their child's predicament (described in Feinstein, 2010). Adults who experienced the world as what we now define to be autistically have probably always existed. They were not subject to the label, either because they were mislabeled and exiled, or simply failed to register as social problems. The popular tendency among self-advocates to retroactively diagnose everyone from Bill Gates to Albert Einstein, Michelangelo, Isaac Newton, and others (including speculation about sociology's own Erving Goffman). There are gifts, they claim, to being autistic, including "naturally" acquired skills in mathematics and design. The "realness" of these claims is moot for my point, which is to say that many who would now be diagnosed by virtue of being deviant children in an era of medically surveilled childhood, an era of knowing oneself in relation to biomedical risk, an era of normalization of experience as fast as possible without thoughts to futurity and consequences of normalization to such futurity, existed and were

functional if not productive adults. As Eyal, et al, (2010) points out, and to which I heartily concur, the behavioral interventions currently offered to autistic children (and others subject to similar behavioral intervention, including children with low intelligence, with developmental delays, and with attachment and conduct disorders) are just systematic and structured ways that we treat typical children (p 125).

Indeed, even the previous point is moot to my larger point – missing from my analysis yet central to my narrative are adults who have come to identify themselves with the spectrum. Eyal, et al, includes this process as one aspect of the autistic looping, which I will address in the next section, but even this has been structured along other patterns in society, particularly along race and gender lines. The diagnosis is written along masculinist lines; there is no genetic or neurologic evidence that would support sex-ratios as presented, and both Kanner and Asperger had higher numbers of girls than the current skewed diagnostic rates would show. The statistics clearly also show that chance of diagnosis varies along race (Travers, et al, 2013) and class (Liu, King, and Bearman, 2010) lines. My participants showed all of these trends: the lack of people of color, the lack of women, the tendency for the women to be self-diagnosed, at least initially. What is missing from all of the accounts of autism is a critical focus on race, gender, and class. I sadly do not contribute to any of those accounts, though I contribute towards understanding the problematic aspects of autistic masculinity.

Darrell was my only regular participant who was both black and male. He attended every meeting of the group in which I first encountered him, as well as some social events and meetings of another group within the region. I cannot generalize his experiences to the experiences of all black men on the autism spectrum, but his experiences provide a counterpoint to the general white male culture of the groups.

“Do you know what it’s like being autistic in the black community?” He asked me as we walked to our shared transit station. We would ultimately share the same car on the same train, though headed to vastly different stops, but our conversation would cease upon arrival to the platform and the presence of another person; Darrell did not communicate in public. “People think you’re either retarded or crazy. My sister thinks I’m schizo and should be in a hospital. Lock me up, throw away the key, just don’t let me around her. I’m an embarrassment. My parents, everyone, growing up thought I was retarded. They don’t get me, they don’t want to get me. And those people (points towards the building where the group meeting was just held) don’t get it either. Seems to be easier being a white autistic. No one is scared of them.”

Darrell grew up in the inner-city of a small East Coast city that was plagued by drug problems during his youth and adolescence in the 1980s. His nuclear family was unstable for a variety of reasons, including poverty and drugs, but he mentioned how a lot of the familial stress was blamed upon his autistic behavior. The family lacked resources for intervention, and relying upon the limited resources available in their city, he was labeled mentally retarded and treated as such for much of his school years. It wasn’t until he was in high school when it was realized that not only could he read, he could read well beyond his grade level, that he was even given academic work to do. His MR status, never changed, allowed him to stay in high school until he was 21, and his teachers gave him more appropriate work to do until that time.

In public, Darrell was selectively and mostly mute. In private or smaller groups, he would occasionally interact, but kept the interactions brief. My informal interview was at his invitation, in response to a heated discussion in the group in which race factored heavily. Still, his preferred way of being, when out, was nose-deep in a paperback. He always had a well-worn fantasy novel held close to his face (on account of not being able to afford proper bi-focals, constrained by

Medicaid to a single pair of single-focus glasses). Occasionally, he would drop his book into his lap, slump his head down, and hunch over his shoulders; falling asleep was one of his main coping mechanisms with overwhelming social situations, even ones from which he seemed disengaged through his voracious reading.

Between his mutism, his reading, and his sleeping, his deviant physical appearance magnified the danger signals he was aware he was giving off. While only of average height, Darrell had a large build. He was often dressed inappropriately for the season, overdressed at all times. From fall through spring, he wore an oversized down coat with a hood drawn up over his head, often even neglecting to remove it at the group meetings. When it got simply too warm to wear his coat, he dressed in long sleeves and sweatpants. Through four seasons of field work, I only ever saw bare his hands and head. His skin was dark and ashy, and he had patches of eczema, his explanation for why he kept so covered. While logical and understandable, it did not signal skin problems. His clothes were shabby and stained. He primarily subsisted on Social Security disability income (which specific program I don't know) and he supplemented his income by selling tchotchkes on eBay. His ideal job would be a computer programmer of some sort; he had taken classes at a community college and done decently, but no one would give him a job. Still, he couldn't afford much, and his clothing and appearance overall reflected this, including his Medicaid glasses, thick plastic frames that did not fit his head very well.

He looked like a stereotypical homeless person. He looked like a stereotypical person recently released from a mental institution, both examples he used to describe his appearance. He looked like he didn't belong, and he knew this, yet also felt powerless to alter his appearance to be more socially acceptable and still be comfortable. And socially acceptable, he pointed out, to white people. To other blacks, he was invisible, as broken as many older black men [Darrell was

about 40 at the time] are after decades of dealing with the system, on the margins of the margins, and that is where he liked it. While this made him highly visible to whites, as a sign of danger, as a perturbation, especially in the suburbs where he occasionally found himself, he could safely retreat to his black community and disappear again.

One of the stark differences between Darrell's experiences and the white men's experiences in the group came when discussing dating and relationships. While most of the men expressed a desire to date neurotypical women, and some dated women on the spectrum, Darrell was the only one who clearly expressed a desire to date only women with disabilities. He was acutely interested in a dating service set up by a regional disability services organization, for which I provided him with the contact information. As he explained it, he was black and he was disabled, what neurotypical woman would want him? It was hard enough to find a quality black man, he said, so black women were out. And a white woman? If she was going to settle for a black guy, he would have to be extraordinary.

Darrell had a definite double consciousness, albeit autistically informed, that as a black man he was a danger signal, as an autistic man he was a danger signal, and as a person dually dangerous, he had to be particularly circumscribed in his behavior. While he was definitely atypical in his appearance and behavior, he tried to steer towards invisibility. To be anything but a tightly wound, if very odd, persona non grata would mean definite law enforcement involvement, possible psychiatric hospitalization, all things that have happened to him in the past despite his adamant claims that he has never consciously violated the law. I will discuss the relationship between autism and danger further in Chapter 4.

That night, after we parted ways on the platform, I witnessed Darrell on the train. He was hunched over, asleep, avoiding a group of young black male teens who were avidly bantering on

the train and who seemed on the verge of harassing him, pointing, making comments, etc, but not directly confronting him. The conductor moved through the car to check tickets, and came upon Darrell. Hey, buddy, tickets please. C'mon buddy, ticket. He couldn't touch Darrell, but clearly Darrell was in a social avoidant stupor, not registering the presence of the conductor. As the conductor's voice rose and grew more belligerent, inquiring if Darrell had been drinking, he suddenly awoke from his slumber, and pulled out his monthly pass which also indicated he was disabled. The conductor moved on, and Darrell retreated into his slumber.

### **What is autism<sup>2</sup>?**

Leo Kanner (1943), the American child psychiatrist who coined the diagnosis in the North American and English-speaking context, wrote that autism was a “disorder of affective contact.” Hans Asperger, the Austrian child psychiatrist whose eponymous syndrome is now defined as a form of autism, described a form of “autistic psychopathy” whose affective personality was curtailed (described in Feinstein, 2010). In contemporary sociology (and related disciplines), autism is primarily known through the lens of social construction. As a diagnosis and form of knowledge, it ranges, from being primarily a “negative social affect” (Silverman, p 2), a looping form of knowledge that resulted from deinstitutionalization of mental retardation occupying the liminal space between intellectual disability and mental illness (Eyal et al, 2010) to a matrix of practices and knowledges that reflect as much about the present expectations of normalcy as they do about the underlying biological cause of deviant behaviors (Nadesan, 2005).

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<sup>2</sup> The official diagnosis currently centers around two sets of criteria, each scaled on a “requires support” to “requires very substantial support.” The first set of three criteria is based around “persistent deficits in social communication and social interaction across multiple contexts” while the second set of four criteria is based around “restricted, repetitive patterns of behavior, interests, or activities.” The full diagnosis can be found at <http://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>

Social psychiatrist Digby Tantam (2009) sees autism as the result of the failure of an individual brain to connect to what he calls the “interbrain” while Olga Bogdashina (2010), a Ukrainian-British linguist specializing in communication disorders, takes this notion a step further, first privileging the sensory-perceptual differences among those with autism above the apparent resultant social deficits, and then argues that the autistic brain perceives at the level of the quantum, that instead of being disconnected to the interbrain autistics are overconnected, and experience what one may (using Tantam’s computational metaphors) be called a directed denial of services (social contact). Almost all focus on children, or the institutions and actors around childhood (parents, education, medicalization, etc), with scant reference to adult autistics, and generally even then, to autistic adults who occupy the role of public autistic<sup>3</sup> (the exception being Bogdashina in terms of focus, but she relies upon published accounts of autism in adults, thus continuing the reliance upon the public autistic). There is a persistent question of if autism is a single biological or neurological problem or multiple disorders with resultant overlapping social consequences. There is also the debate over the genetics of autism, if it is the byproduct of a single gene or multiple genes or epigenetics. Finally, there is a question of if it even matters if there is a singular or multiplicative etiology(ies). Certainly for my participants, real adults living real lives in the everyday world, these questions of what autism is are both relevant and irrelevant, for the social consequences were the same either way. My participants experienced a great degree of marginalization, a persistent inability to achieve full adulthood regardless of personal success or desire. Autism is the category around which this denial of full personhood, of citizenship, is organized.

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<sup>3</sup> My term for autistics who have become spokespeople of sorts for the autism community to the general culture, including most famously, Temple Grandin. Public autistics narrate autism that is sufficiently different and exotic to neurotypicals that they can disidentify with the individual doing the narrating, yet in language that is accessible to neurotypicals. See Jenkins (200?)

Affect is a clear thread running through many of the above mentioned understandings of autism. Despite the relative importance of affective exchange in Kanner's and Asperger's original diagnoses, defined for those times as general experience of emotion, including love or affection, the current definition of autism simply says:

**Deficits in social-emotional reciprocity**, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; **to reduced sharing of interests, emotions, or affect**; to failure to initiate or respond to social interactions. (emphasis mine)

Of the three core deficits in social communication, that is the first listed. Autism is, as Chloe Silverman suggests, a deficit of love or empathy:

...people with autism fail at empathy. **Adults with autism disagree, but they do so within the terms already set.** They say they experience empathy but arrive at it and express it in ways that are difficult for neurotypicals to recognize. This dissent is significant, and the scientific claims about autism and empathy have obvious limitations. It remains true, however, that autism can mean, in practical terms, that an individual is less tightly bound into the network of relationships that sustain most of us. (p. 8, emphasis mine)

Her book, framed around parental love for their autistic children, of course generally isolates the autistic difference in experience of empathy and love to the individual with autism. The autistic difference isolates the autistic person, an individual is less tightly bound into networks except for the saving grace of parental love. While certainly the parents she features in her book are extraordinary, going to great lengths both personally and professionally to help (normalize) their children, she only hints that this is actually a reciprocal relationship. One parent later in the book, when bemoaning how difficult and intentional his love for his son was, describes how autistic children fail to imitate and don't engage in typically masculine bonding behaviors, leading him to often feel like hopeless. His answer is to turn towards autism advocacy. (p 156) While Silverman attempts to be sympathetic to adults diagnosed with autism, her emphasis on parents and specifically parental love, and actions motivated by this love, leads her to ultimately discount

the love that autistic adults do experience and reciprocate, albeit autistically, as if the arrival to reciprocity dictates the validity of experience. She furthers the claim that most autistics will remain totally dependent upon others for the continuance of their lives (p 136), again justifying her focus on parents who are assumed, of course, to remain the primary care-givers. However, looking at her source for such an outlandish claim demonstrates that Silverman's attitude towards adults remains biased, as actually that study specifically focuses on autistic adults with intellectual disability, something that other researchers demonstrate to be no more than one-third of those diagnosed with autism (CDC, 2014). Furthermore, this line of thought continues the unfortunate notion that because a person is dependent upon others for some reason or another, they are less than full people, and it is justifiable to deny them citizenship. As I discuss in the conclusion to this dissertation but which runs as a theme throughout, the liberal notion of independence is inherently questioned by adults with autism, whose intelligence and skills could be productive given a different shape to society. While Silverman says that self-advocates might be "another set of experts that parents may call on for inspiration..." (p 136) the evidence suggests at best a contentious relationship between parent advocacy and self-advocacy, especially in debates over intervention, normalization, and outlay of autism research money and effort. My groups are local exceptions, but at the national scale, parent organizing is generally not welcoming of self-advocates. Recently, for example, John Elder Robison resigned from his position on the Autism Speaks (the largest parent group in the United States) science advisory board due to his perception of marginalization of adult voices in the direction of the organization (Robison, 2013). Robison was the sole autistic person on any advisory board of Autism Speaks. His resignation speaks to the factual lack of engagement by parents doing organizing on behalf

of their children with adult self-advocates, even those willing, at least initially, to partner with them.

But yet, affect and affective reciprocity is an essential component of the autism experience. The problem here is in how we are defining affect. As I will demonstrate further in chapter 3, affect is hardly the simple shared emotion states and capacity for empathy. It is more akin to Tantam's interbrain and Bogdashina's quantum mind (though these conceptions are also problematic, as I will discuss). To classify this as a deficit in social-emotional reciprocity is problematic in defining it as deficit instead of difference, though acknowledging that it is the social is note-worthy. Neuro-normative social-emotional reciprocity privileges particular forms of interconnection that may well be historically bounded, unique to our epistemic moment, configuration of knowledge and practice as Nadesan suggests. It is less about the deficient affect than it is our historical moment of affect. Furthermore, affect is not just emotional or empathetic connection, affection, but alignment of affecting, the capacities and capabilities to affect and be affected. To state that autistics are deficient in this is to again privilege a particular configuration of these capacities and capabilities and to ignore alternatives. Alternatives, even, is the wrong word, for distinguishing between autism and not-autism is gradual. While others disagree about the etiology of autism, as seen in the controversies over the remaking of autism as a spectrum disorder as well as the biogenetic origins of the disorder, my participants experience of the spectrum was as gradations and constellations, yet also kinship across these differences. Particular configurations of sensory over or under-stimulation were highly individual, yet both usually existed simultaneously in each person. Perseveration, sensory seeking, and sensory avoidance were also existing within each person, to greater or lesser degrees. Each person was thus a constellation of experiences, but they also all experienced being constellations, of having

inconsistent abilities and sensitivities. This seemingly random distribution of symptoms masks, to the neurotypical, the samenesses that my participants saw across their particular configurations. Drawing from this, I see neurology and cognition as performances, as Nadesan sees ‘normal’ behavior a performance by her son and I feel kinship with in my own experiences managing my ‘real’ life while in the field of lower social expectations. Going back to Silverman’s statement, then, that autistics arrive to empathy and express it in ways that neurotypicals fail to recognize, places the onus of that failure on the configuration of affect and capacity for neuroperformance. This is why I refer to autism as a form of neuroqueerness, elaborated in chapters 2 and 3.

It is unsurprising, then, that read through a lens of affect theory, the rest of the diagnostic criteria in the current Diagnostic and Statistical Manual (fifth edition) reads like a litany of other ways in which affect is performed, practiced, managed, and configured in relation to power. Affect is kinesthetic and non-verbal, so the second criteria under persistent social or communication deficits, of problematic eye contact and appropriate body language, is an extension of this configuration. Deficits in relationships, the third criteria, while individualized to the person such diagnosed, also represents the normative status of interaction and relationships. To be interested in peer relationships is normal, though the individual level of social desire is only problematized for the autistic, particularly for children.

The final set of criteria, focused on sensory problems, is better critiqued as a power relation through Bogdashina’s analysis, short of her ultimate fetishization of autistic perception. Throughout her work, Bogdashina connects the particular set of sensory-perceptual ‘problems’ that are associated with autism to differences in brain organization, but throughout emphasizes that these are normative differences, which seek mostly to reify the normative neurology.

Whereas Nadesan critiques the practices and surface level performances that create autism as a category, Bogdashina utilizes a deeper understanding of the neurological to in turn critique the neuro-normativity of neuroscience. That is a lot of neuro-ness, but the problem with most neurological research in autism is a lack of consistent results. The only consistent findings are with mirror neurons, which are thought to be the neurons of affective reciprocity, recreating emotional states within the observer's brain that they 'see' in others. Bogdashina uses this to understand that the brain of the autistic may be hyper empathizing, which in turn shuts down the affective capacity because it is overwhelmed. Alternatively, the autistic brain may need a higher level of kindling in order to engage. This is especially true during early neurological development, argues Bogdashina, which may explain why autistic behaviors resemble those who are neglected as children. Still, Bogdashina argues, the ways in which perception itself is altered away from normative by what we call autism reveals how perception is organized by human culture, language, and power. The ability to ignore, to guide affect exchanges to only the human or acceptable non-humans (i.e. dogs), is demonstrated by autism's indifference to human or non-human distinctions.

This line of thought is also present in Tantam's (2009) conception of the interbrain. Tantam sees human culture as akin to the internet, that our brains exchange information on both an emotional and informational level without our conscious brains being aware of such an exchange. The problem of autism is disconnect from this interbrain, or I as argue, affect, for whatever reason. Tantam's computational metaphor is apt, considering the reliance of autistic culture upon the internet (Rocque, 2007) as well as the role of autistics in the development of modern computational systems. If affect, the interbrain, is the wifi in the background connecting our computer-brains to the wider network-internet-human culture, then limited access would of

course limit participation and performances of normative connectivity. But is the problem the computer, the router, or the wifi signal itself? Tantam's question is if society can afford autism, and by afford, he means to make affordances, to grant allowances, to bear without substantive harm. His answer, yes, relies upon the same reasoning that Bogdashina ultimately grants humanity to autistic persons, that they reveal more about the normative than otherwise possible. Autistics are needed to learn about what it means to be human.

While Bogdashina and Tantam's analyses are useful for my own project, they swing too far in the other direction of the other researchers. Whereas Silverman discounts autistic adults, and Eyal might as well not have any actual people in his analysis at all, Bogdashina and Tantam ultimately fetishize autism as better than human, or necessary foils to the normative. Being placed on a pedestal of specialness does nothing for my participants. They don't want to serve as inspiration, as revelatory, as anything other than human. While some advocates employ the gifts of autism narrative as a way of activating a political autistic identity (see chapter whatever), Bogdashina in particular uses individual accounts of those with severe impairments, whose experiences are far from typical even for autistics, whose constellation of impairments skew towards creating a new normative narrative for autistics of significant differences in perceptual ability. While I do not seek to discount those whose autism is reminiscent of Tito Rajarshi Mukhopadhyay or Amanda Baggs, both of whom have significant intellectual gifts with seemingly corresponding perceptual differences that do not allow them to discriminate environmental inputs, leading to significant difficulties with normative communication and neuronormative executive functioning, I also don't want to create a blanket norm of what autism should look like, only what autism looked like in my field. My participants were nonexceptional, but by using those with significant visible impairments relative to normative performances of

behavior and cognition, Bogdashina and Tantam create what the disability should look like. This is just as those parent organizations that often case autism in the most debilitating light possible, a line of thought evident in Silverman's book and privileging of the parental perspective.

All of these accounts of autism have some productive value to the autism(s) I encountered in the field, to a greater or lesser degree, or productive in critique. For my participants, autism was a diagnosis, an identity, a label for the pattern of differences they experienced from typical, an explanation for a lifetime of hurt, isolation, and exceptionalism (in the multiple definitions of that word). Autism was an embodied aspect of their experiences, as much or greater than a social experience. Autism meant being clumsy, as a kid or continuing as an adult. It meant flailing limbs and disjointed movements, sensory deprivation and/or overload, compulsions and perseverations. The question of looping has a great degree of importance here. My participants experienced the world, that experience was labelled autistic, and then my participants understood their experience to be autistic. New experiences were then already labelled autistic, and surely behavior was altered by thinking of it as autistic. There is a recursiveness to autism that is well captured by concepts such as looping, on the micro as well as Eyal et al's well documented macro level. However, drawing from my participants' experiences, my experience in the field, and my analysis of autism in the larger social world, autism was its own becoming. It was a biosocial identity (as dismissive of biosociality as Silverman is), around which the project of the self could be organized.

## **Going Forward**

Neurodiversity is the claim about identity configurations in relation to diagnosable neurological and cognitive differences and impairments. While not unique to autism organizing,

groups like the Autism Self-Advocacy Network and the Global and Regional Autism Spectrum Partnership have embraced the term to describe the identity work and accommodation requests. It has direct ties to previous rhetoric of diversity employed as strategies of liberation in Western political structures. In Chapter 2, using critical race theory, queer theory, and the disability rights movement, I locate the rhetoric of neurodiversity in this historical and rhetorical context, noting how previous uses of the concept of diversity have not fundamentally altered power structures or increased tolerance of difference, despite some modicum of success, at least initially, in incorporating particular individuals into the existing power structure. I also explore the failure of neurodiversity language to incite a political identity among those participants in my field. It was not useful to conceptualize themselves as a difference among many differences due to the degree of marginalization they experienced.

Autism exists as a category of identity and social organization, but it also exists as a series of practices within the medical community. Those practices and the definitions thereof are in flux, especially during the time of my field work, during which the diagnostic criteria were being rewritten. The notion of expertise, then, is a contested field, and who constituted an expert was an important question to my participants. The desire for legitimacy and authenticity in relation to expertise was of high importance to those in my field. There was a fear of non-autistics colonizing autistic space, weakening the demands of those whose claims were “real,” and undermining the authority to speak for autism to the wider society. In Chapter 3, I explore these tensions, debates, imperatives, and the impact upon my field and autism organizing.

Breaking from the political orientation of the previous two chapters, I enter a disjuncture that emerged from my field work in a violent manner: the murderous rampages of Adam Lanza and Chris Krumm. Autistic men in particular are often unfairly thought of as more violent or

dangerous than non-autistics, though this is not supported by the statistics. However, many men in my field reported being thought of as creepy, and I was certainly a witness and target of sexual harassment and other ‘creepy’ behavior. Using these experiences, in Chapter 4 I explore more fully the affective understanding of autism. It was, as I discuss in this chapter, originally conceived at least in part as a disorder of affective exchange, but using a broader understanding of affect and insights from the field of affect theory and cultural studies, meshed with traditional sociological deconstruction of interactions both symbolic and non, I expand upon this and locate autistic affect in the body and cognitive practices. Affect, beyond capacity, is aptitude, performance, and socialized and disciplined practice. Turning back towards the creepy, I try to understand how masculinity, affect, and perceptions of danger coalesce into the figure of the creep. Autistics are subject to and participants in hegemonic masculinity, but they are inept at deploying it, and this ineptitude in combination with the affective produces a creep, which is I argue is the affective resonance for potential violence.

Returning to larger concepts of citizenship, in Chapter 5 I tie together the various models of citizenship from which my participants were marginalized, and speak to the assemblage of autism that includes affect as a central concept to understanding this marginalization. I explore the radical openings that autism presents in challenging the predominance of the liberal subject. Bringing together the various aspects of this project, I argue for understanding autism through the lens of assemblage actually makes for a more coherent understanding of autism than the unified subjects of other discourses and rhetorics.

## Chapter 2

Paul was young, in his early 20s, and an only sometimes participant in the group. While I had seen and spoken with him at other events, he only actually attended two meetings during the particular months I attended as a researcher. Each time I saw him, he wore a shirt with some version of Autistic Pride or Neurodiversity splayed across his shirt, and certainly this meeting was no different. In wavy Impact font imprinted in rainbow hues, his shirt proudly stated “AspiePride” on what surely started out as a white shirt. Like all of his other shirts, however, this one was well worn and slightly threadbare. It was only remarkable in the context of his wearing it. He had specifically come to this meeting because of tonight’s topic: politics of autism. An activist at his university (a large, well-known, somewhat elite private institution in the city in which the meeting occurred), he came to make sure the correct politics were represented. While he rarely attended the meetings for the other group I studied, he was far more active in their events and had organized a student group at his university, partially in response to actions taken by that university.

In what became an “autism politics 101” type meeting, the concepts of neurodiversity, assimilation versus accommodation, and autism pride were defined, debated, accepted and rejected. Paul was strident in advocating for neurodiversity as the correct politics of autism. As I will discuss later, neurodiversity was not universally well received at this particular meeting nor generally across my field sites with the exception of the more politically active site. It wasn’t so much that people argued against neurodiversity as much as they were reticent to adopt a political identity around their autism. Neurodiversity was, as Paul explained, a way of understanding autism as a neurological difference, just another way to be human. It wasn’t inherently a

disability, just another way of being that was disabling because other people weren't accommodating of autistic difference. As such, the correct politics of autism were thus a politics of diversity, where each difference is recognized, celebrated, accommodated, and each as such is given a place at the metaphorical table.

Diversity, as a political rallying point that indicates inclusion or mixture of racial, cultural, or other stratified groups to unofficially white masculine institutions or organizations, has become a key term in the disability rights movement, as activists have fought to include dis/abilities and capacities of bodies in the range of Other included in the language of the diverse. Autistic Pride, Mad Pride, and other activist movements for those with cognitive, intellectual, or psychiatric disabilities, critique the mainstream models of disability employed by physically disabled activists in that they often do not apply to the kinds of difficulties experienced by those with what are considered mental or cognitive problems. Adopting then adapting the human variation and social models of disability, these activists, particularly autistic activists, have begun to use the term "neurodiversity" to explain how they conceive of mental and cognitive disability. Neurology, they claim, is now a point or instance of difference, akin to race or culture. Diversity, as a social movement and political rhetoric, is then the answer to the problem of disability. It is attractive because it does not deny difference and does not attempt to normalize or assimilate, instead accommodating and affording, allowing a voice.

I find this language and movement to be problematic in a number of ways; diversity has been soundly criticized in the realm of race and post-colonial theory as a strategy of liberation and has been largely unsuccessful in effecting large-scale change. Further, it limits the possibilities on alternative conceptions of autism and other disabilities of the mind by remaining within, and relying upon, the Western concept of the rational agent and the use of medicine in

that agent's production. In this chapter I will first turn to critical race theory, looking at the general development of a multicultural/diversity model as a strategy before critiquing it from a Foucauldian/post-structuralist/post-colonial perspective. I will then apply that critique to the human variation model of disability more generally. Turning to specific writings from the neurodiversity movement, I will unpack how that language continues the problematic aspects of diversity talk. I will also discuss the impact of the neurodiversity identity movement among my participants, some of whom had acquired a political identity around autism, but others who rejected that notion entirely. Finally, I will explore alternatives to diversity language and strategies that may be of use for disability activists.

### **Critical Race Theory on Diversity**

“Yet this awareness of difference, an awareness that, at the level of government policy, serves, in the end, to mask and perpetuate the persistent problems of social inequality.” (pg 133)  
 Rey Chow, 2002, *The Protestant Ethnic and the Spirit of Capitalism*

Emerging out of the Civil Rights era and frustrated with the increasing failures of that ideology to produce substantive and distributive justice on behalf of Black Americans, critical race theorists began to critique the legal systems, then the socio-political systems, that continued to reproduce racial hierarchies despite formal changes. Derrick Bell, widely seen as a formative thinker in critical race theory, argued for a kind of Racial Realism (1995), a perspective on race and blackness in particular, that recognized the inherently racist systems which would continue to be racist despite formal equality under the law. He advocated for radically changing the liberation strategies of blacks away from a formal equality civil rights model; if the institution itself was inherently racist, formal equality could actually be used against blacks, and in fact, was often used against blacks. Bell, ever a controversial figure, went so far as to state

It is time we concede that a commitment to racial equality merely perpetuates our disempowerment.

Rather, we need a mechanism to make life bearable in a society where blacks are a permanent, subordinate class. (pg 307)

Bell's highly influential position on Racial Realism solidified an identity politic around being the marginalized Other, opposed prima facie to formal equality and the politics thereof, because of the inherently racist system, but not opposed to a politic of diversity or multiculturalism. In fact, Bell's political dance between opposing integration and promoting diversity is evidence of an early tension in critical race theory between different strategies of analysis and liberation.

Multiculturalism and diversity rhetoric, were, at first, promoted by critical race scholars as race-positive but theoretically anti-assimilationist strategies of social liberation. John Calmore (1995) describes the value of multiculturalism as a strategy of reinforcing a social grouping of oppressed peoples while systematically enacting civil rights claims making as a culturally anti-racist act. He writes:

Authenticity toward oneself and toward the world are reinforced as colored intellectuals reject assimilating absorption and rely instead on cultural autonomy, even while fighting to bring oppressed peoples into the national community as American citizens or members of society who are viably integrated within the nation's structures of opportunity, power, and privilege. (pp 326-7)

For Calmore, while there is a definite and palpable tension between integrated systems of hierarchies and the oppression wrought by said systems, there is a liberation strategy of relying upon an "authentic" sense of a racial/oppressed self in fighting to integrate into those systems. Similarly, bell hooks, when writing about a commitment to cultural diversity in the academy, speaks of its radical potential to rethink how education happens and what forms of knowledge are privileged. The truly radical form of cultural diversity, she argues, is often feared "that any de-centering of Western civilizations, of the white male canon, is really an act of cultural genocide." (pg 239) She writes of how the white colonial fantasy of multiculturalism was the

“comforting ‘melting pot’ ...the rainbow coalition where we would all be grouped together in our difference, but everyone wearing the same have-a-nice-day smile.” (pg 238)

And yet, as the Rey Chow quote at the top of this section demonstrates, that is exactly what other race theorists argue happens in any discourse of cultural diversity. Inevitably, Chow argues, any discourse of diversity becomes representational, and instead of displacing the white male centrality, these other ideas become colonized and brought into the center. The fear of replacing one form of cultural dominance with another is correctly unfounded; the degree to which colonization and assimilationist strategies under postmodern capitalism can center previously marginalized groups in order to become centralized and consolidated is set aside by bell hooks and others. Capitalism, using biopower’s generative potential to let live under a set of given conditions, uses benevolence, tolerance, and even celebration of cultural diversity as mechanisms or techniques by which it incorporates populations into its regimes. Chow, using Stoler, describes Foucault’s concept of state racism beyond just the identity politics of race; racism is the calling into being a population, a division of populations into who is let to live and who must die, and the governmentality of said populations through racist structures and knowledges. Ultimately, argues Chow using Wiegman, racial and ethnic diversity is co-opted by whites who gain advantage, in part by taking advantage of the turn in the definition of race from biological to cultural. Chow looks at the rise of “anthropological culturalism, which is oriented... toward the need to recognize the diversity and equality of all cultures.” (pg 14) By positing all cultures as equal in origin, “the discourses of tolerance, acceptance and understanding that are crucial to anthropological culturalism are, in this light, part and parcel of the multiplication and democratization of networks having to do with classified lifeworlds, populations, demographic

movements, ethnic differences, dispositions of particular social groups, and so on in late capitalist society...” (pg 14)

### **Human Variations and Habitus**

When critical race and post-colonial theorists adopted post-structuralism, they distinguished themselves from other race theorists by not utilizing culture as a primary organization of race. In fact, what distinguishes post-colonial race theory from others is the way in which minority group culture is not used; instead, according to Chow and others, minority group cultures arose out of both compliance and resistance to the calling forth of racialized subject-beings and the reduction of some races to objects. However, instead of taking references to minority group culture at face value, I challenge the representation of essential group-ness to be a “culture” in the essential form of traditional, but social, ways of knowing. Instead, I will use Bourdieu’s (1978) concept of habitus to describe that which organizes the minority group culture and status utilized by theorists like Bell and hooks.

According to Bourdieu, habitus is the set of embodied knowledge and practices that are socially inscribed and are homologous across different social fields. Examples of habitus include the gendered practices of stretching ones legs on a crowded subway bench and the ways in which different sports become identification markers for different social groups, like polo or tennis as opposed to soccer or baseball. These behaviors signify a particular social status, and in the case of stretching legs, the amount of power a given person has in that social situation. While habitus has been critiqued as vague and class essentializing, Bourdieu’s success at decoupling aspects of what was traditionally bounded as culture in relation to social status makes habitus a useful

concept when critiquing culturally based arguments, especially as there can be other forms of patterned habitus that don't necessarily meet the definition of culture.

When Bell, Colmare, and hooks refer to black culture, in particular, they are describing a black habitus. As habitus includes virtually all aspects of what is considered culture, but in the context of a pluralistic society with different cultural aspects bound by class systems, everything mentioned as part of black culture is thus also a part of black habitus. Further, as identified by Bell and hooks, there are power dynamics around race-based cultural struggles; the black person is automatically socially lower than whites, Bell argues, so equal protection is pointless. Cultural genocide would occur, hooks imagines white colleagues thinking, if non-white cultures were allowed to speak freely. These power-dependent versions of culture fit well into the theory of habitus. Bourdieu describes a hierarchy of classes laid up on a variety of social fields; what a class is able to call up into a given social field is dependent upon the power systems in place. While definitely more French-structuralist in orientation than either Bell or hooks, Bourdieu's concept would be useful, especially in the conflict between habitus, and the change over time of habitus.

However, just because culture and habitus are, on some level, synonymous, that does not mean that the presence or absence of culture impacts the presence or absence of habitus. While possessing a particular culture implies habitus, a group culture is not necessary for the development of a group habitus. One important difference between culture and habitus is identification. Bourdieu found that many identified as members of other classes, particularly in regards to economic class, but that there were still patterns of behavior and thought associated with, say, a lower-working class despite many in that class by income identifying with a middle class. Conscious identification with a different social class did not imply the lack of a lower-

working class habitus. Similarly, in the debates over a disability culture, I argue that, even without this unified culture and implications of identification, there is a disability habitus. Even if it doesn't rise to the level of culture, a person with a given disability responds to the same structural factors and must adapt in a particular way. These adaptations are a form of habitus. For others, however, it may be a lack of culturally appropriate habitus, a failure of habitus formation, that is at the basis of their disability; autism is, in many ways, a failure to develop proper habitus.

According to Scotch and Schriener, the minority group model as a liberation or integration strategy for disabled people is limited because equality before the law, and even measures to overcome physical barriers to equality still fail to address the ways in which attitudinal and non-legal structural barriers prevent true integration. Like Bell's argument that blacks were inherently subordinate in racist systems, Scotch and Schriener argue the disabled are inherently excluded when society has a narrow range of expectations for appropriate bodies and capabilities. Further, like Colmare and hooks, Scotch and Schriener propose an alternative conception of disability that speaks of a kind of disability multiculturalism. However, unlike the critical race theorists who posit culture as the defining aspects of out-group membership, Scotch and Schriener posit expectations of body types and capabilities, with no necessary unifying culture to accompany those failures to meet expectations. Scotch and Schriener refer to this expectations based model as the human variation model; some variations of humanness are elevated and privileged, while others are excluded and stigmatized, through both structural and attitudinal expectations of body type and capability. Their answer to this narrow range problem is a multi-body type, a widening of the range of human body and capability expectations, such that fewer non-normative bodies are excluded from the expected range of human being.

A recurring problem with various models of disability is the lack of applicability to intellectual, cognitive, and psychiatric disabilities. This is less true of the human variation model, as that model is easily adapted to behavioral expectations rather than bodily expectations. In particular, activists who have disabilities of the mind rather than body have, over the past few years, worked to create a model of mental disabilities around the concept of “neurodiversity.” While this term is not unique to the autism movement, it has become a central focus for autism activism. It is important here to reinforce the notion of habitus as socialized, learned without conscious learning, and deeply embodied as well as cognitive. As I emphasize in Chapter 4, embodiment and the affective aspects of communication are central to the ‘problem’ of autism, for the autistic who has difficulty taming an unruly body and maintaining frames, for the other actor in the interaction who lacks a frame for autistic behavior, and how those intersect with other aspects of sociality, such as gender and sexuality. Neurodiversity cannot account for these intersections, nor can it account for conventional framing or affective exchange. It reifies identity politics without addressing some of the fundamental issues experienced by my participants and forecloses on the radical potential of queering cognitive performances. It also reinforces the normative mode across disability rights, the benevolence of the normatively embodied.

### **Human Variation and Neurodiversity**

In a post dated November 7, 2009, rhetorician Melanie Yergeau, blogging as Aspie Rhetor posted a long entry, tagged as a rant. In it, she explains the title of her blog: as an autistic adult in a PhD program in rhetoric and composition, someone referred to her as an aspie rhetor, or a person diagnostically incapable of being a rhetorician, that is, one who analyzes rhetors and their rhetoric. She argues for reclaiming the words aspie and autie, despite their “cutesy” quality,

“in the name of disability studies/neurodiversity/autistic culture.” When speaking of the power relations of diagnosis, she states:

How we conceive of functioning labels, for instance, is a product of social and cultural power, where “functioning” really means “the ability to act and think like all us normal and therefore superior people.” In a large way, distinguishing oneself as aspie can institute this sort of cultural power — a way to call attention to one’s position on the functioning food chain.

Her rhetoric of power relation is strikingly similar to the rhetoric of race in Bell's work on Racial Realism. Autistics, she posits, no matter of functioning label, are pathologized and thus removed from power; reclaiming a diagnostic label as identity, especially of “autie,” is thus an act of cultural power reversal.

Aspie Rhetor's post is largely reminiscent of the language of the formal bearers of the Autistic Pride movement. On the “About Autism” page for the Autistic Self-Advocacy Network's website, autism is defined as “a neurological variation that occurs in about 1 in 150 people and is classified as a developmental disability.” The emphasis through-out the rest of the commonalities of autistics is on difference from expected norms, of going beyond the narrow range of normal and thus getting defined as different. This description of autism is in line with the human variation model of disability proposed by Scotch and Schriener (1997). Instead of outlining the diagnostic criteria from a medical model, the ASAN page highlights the differences away from expectations, not norms. In that way it doesn't reify the expected behaviors or ways of being as the ideal normal; it places the onus of the pathology on the structural expectations of being.

In many ways, too, the neurodiversity sensibility is reminiscent of Colmare and hooks, in that both value the input of a pluralistic, multicultural, or diverse society in liberating minority groups and ending racism. Neurodiversity similarly argues for the pluarlism of neurology.

While the critical race theorists rely upon “culture” to define what has meaning to being of a race, neurodiversity activists are engaging in active stigma transformation in order to bring legitimacy to being autistic. As they cannot rely upon “culture” to define what is meaningful, one strategy that is used is to highlight the potential positive aspects of autism. Examples of this include post-hoc diagnosis of famous figures (namely Einstein, though Bill Gates is often named as a potential autistic, and many in sociology may claim Erving Goffman), or focusing on other public autistics, namely savants and people like Temple Grandin. However, many in the neurodiversity movement critique this use of ideal positivity, in part because it denies that many autistics do need support services, even those who are considered “high-functioning.” Aspie Rhetor's note of the power differential between aspie (for Asperger's Syndrome) and autie (for autistic) is part of the resistance to the heirarchization of autism spectrum diagnoses. Another strategy is to organize an Autism Pride modeled off of Deaf Culture, and while this has had some inroads in helping autistics identify as such with pride, there has also been a lot of resistance, especially from parents. Thus the search for a third way, one that ends up relying on autistic habitus, albeit without that technical language. In a way, those who actively identify as autistic and can explicate an autistic way of being speak for those who refuse identification or cannot speak for themselves in a socially recognized manner, akin to a cultural-identity movement.

Yet neurodiversity as a minority group movement, or self-advocacy, is highly contested and contestable. When solicited to write a piece about the Autism Self-Advocacy Network for the Autism Society of America's magazine, *The Advocate*, Ari Ne'eman (2010) outlined some of the basic differences between the autism self-advocacy and what he called traditional autism advocacy, or advocacy by parents and interested others but not autistics themselves. Whereas traditional advocacy, he argues, focuses on prevention and amelioration within a medical

framework of research and policy-making, autism self-advocacy has radically different goals: to be seen as equals to neuro-typicals, with all enjoying the same rights, opportunities, and quality of life across all neurologies.

If we set as our goal the full realizations of rights, opportunities, and quality of life for all autistic people regardless

of age, ability or place in life, and if we then follow up with vigorous advocacy and research, we will no doubt face future pleasant surprises as well. It is only by undertaking this as our priority that we can succeed in creating a world that accepts and supports neurological diversity just as it has come to accept and support a wide array of other diversities across our society.

In stating the over-arching goals of the neurodiversity movement, Ne'eman places neurodiversity in the same category of other forms of embodied diversities, particularly race and gender, which he uses as foils in other areas of his essay. In this essay, too, Ne'eman constructs the autistic, no matter a person's particular "ability or place in life," as a person with rights, a citizen awaiting discovery. Neurodiversity, then, is code for expansion of full citizenship to autistics as autistics. Ultimately, the ASA decided against publication of Ne'eman's piece; it was, instead, featured in an issue of *Disability Studies Quarterly*, which focused on issues of neurodiversity.

Interestingly, throughout that issue of *DSQ*, a working definition of neurodiversity is only discussed once, when Savarese and Savarese (2010) quote a Wikipedia entry and give a brief history of the term. While the simple answer of "what is neurodiversity?" can be deduced with even a cursory reading of Ne'eman's piece, among others, a theoretical unpacking of neurodiversity language is not attempted, even in relation to other models of disability. Instead, I turn to an earlier and commonly cited work on neurodiversity. Baker (2006) defines neurodiversity in relation to "neurological disability," describing the two terms as opposing ways of understanding neurological difference. Neurological difference, she says, refers to a set of

medical conditions that cause a person's cognition or other neurological process to deviate from norms. Neurological disabilities, meanwhile, are the socially-produced handicaps and stigmas that follow from the presence of neurological difference. Neurodiversity, meanwhile, is the “individual or community identity which is more or less an elective choice of those experiencing neurological difference.” (pg. 15) For Baker, neurodiversity is not the mere presence of difference in neurology, but the identification with that difference, as neurological, as a fundamental component of both a person's and a community's identity. For Baker, neurodiversity represents another competing identity claim, another diversity to be managed through public adjudication, one which may be at odds with a social model of disability in terms of assimilating autistics into the social world. Within Baker's conception of the social model of neurological disabilities, the disabilities are ameliorated once the social barriers to participating are eliminated; this could be through public policy and formal inclusion, though Baker argues that therapeutic interventions for eliminating the autistic causes for impairments (i.e. speech or communication problems, etc) also fall within the social model of autism. Neurodiversity, on the other hand, assumes a stable category of disability identification which presupposes that the disability category is supra-social; even if all barriers were removed, neurodiverse individuals would continue to exist, even as non-disabled individuals per se.

While Baker lacks the language or sophistication to fully explicate the issue she has identified, referring to other disability studies literature, we can unpack this seeming conflict between the social model of disability in autism and the model of disability presented by the neurodiversity advocates. The social model of disability, as described by Oliver (1986) and others (such as the International Classification of Functioning, Disabilities, and Health revisions of 2001) separates into distinct areas the notion of disability, handicap, and impairment.

Essentially, impairment is the biological or physical deviation from expected biological or physiological norms. This impairment may or may not be associated with a disability, or ability to perform expected roles or norms. Presence of a disability may or may not lead to a handicap, which is, according to the social model, is the social consequences of failing to perform as expected. This model has never fit cognitive, psychiatric or other mind/brain based disabilities. In part, it doesn't fit because the precise impairments involved in these kinds of disabilities cannot be fixed or located. Psychiatric disabilities have been attributed to demonic possession, movable uteri, weak character, and now imbalances of neurotransmitters in the brain that can only indirectly be measured and even less directly manipulated through chemical therapies. The handicapping aspects of these disabilities varies as much as their supposed causes; the nature of their conditions as disabling are constantly debated and socially reinforced as “less-than” physical impairments/disabilities through policies that favor measurable impairment over psychic distress. Autism is no different, despite the preponderance of research into its etiology, as pointed out by Ne'eman. Therefore the social model that Baker employs, the concept of neurological disability, necessarily has limits that do not fully address the needs of those with cognitive and mental disabilities. Formal equality, policies of inclusion and accommodation, and recourse under law cannot address the problems associated with these kinds of impairments in the same way that these kinds of formal strategies of liberation aid those with physical disabilities; there are no ramps to accommodate an autistic person in a social situation. Still, an essential component of the social model of disability is that there is a remedy for disablement, without necessarily correcting for individual impairment. Remove the social barriers, the staircases or the reliance upon printed text or spoken language, and being a wheelchair-user, blind, or deaf would no longer be a disability, much less a handicap. The impairment would be

there, but the consequences of that impairment would be mitigated. Again, this has difficulty being applied to those with cognitive or mental disabilities; if the impairment cannot be located, or the social barriers fully explicated, then this remedy of removing barriers as suggested by the social model cannot be realized. Baker explains that removing impairments for autistics would necessarily be a component of autistic assimilation; while this is not a part of the general social model, it remains a vestige of the traditional medical model ever present in her concept of neurological disability as a social model of autism.

The alternative to the neurological disability concept that Baker analyzes is the neurodiversity model. While Baker refers to this as an identity-based understanding of neurological difference, another way of understanding neurodiversity is through the human variation model of disability as described by Scotch and Schriener (1997). Building upon the social model, but acknowledging the limits of a social model and the associated civil rights strategies of liberation, Scotch and Schriener posit disability in relation to social expectations of performance, with certain performances naturalized, normalized, and privileged, and others pathologized, stigmatized, and delegitimized. When society has a narrow range of expected performances, those that do not fit are necessarily excluded. The answer, then, borrowing from Zola's (1989) concept of universalism, is to expand expected or accepted bodies, capabilities, and behaviors. Instead of assimilating the disabled into the non-disabled world through formal equality, society should be expanded to include a wider variety of humanness. Ostensibly, this is what neurodiversity hopes to achieve: a wider range of neuro-divergent cognitions, neurologies, and associated behaviors accepted or expected as citizen-agents. The human variation model of disability, based upon the minority group model, requires the disabled participants to identify with their divergent bodies or minds and demand society expand to accept them as they are; it is

here where Baker mistakes neurodiversity as identification with neurological pathology or stable deviance. I will discuss issues of biosociality, or identification with diagnostic categories as a tool of biopower and capitalism, but that is a different level of identification, governmentality, and not the kind of identity politic that Baker finds troubling to diversity management. The human variation model does not directly challenge that which is considered normal; it instead seeks to expand what is considered normal. Baker finds this troubling; by expanding the category of normal, it continues identification as neurodiverse even if the disability falls away because of changing or expanding social norms. Unlike other kinds of diversity, autism can be ameliorated as a point of difference. Managing to both ameliorate the condition and support those who identify as neurodiverse is a challenge that she states is unique to autism as diversity<sup>4</sup>.

Similarly, bioethicists Fenton and Krahn (2007) both critique and praise neurodiversity for its identity politics. For them, neurodiversity is the seeking of formal equality under law and de-medicalization for individuals who are otherwise labeled as mentally or cognitively pathological, while recognizing that some may still need support as disabled adults. The authors first describe a model of understanding functioning as a spectrum of different kinds of abilities with the ultimate goal of good quality of life independent of self-care capabilities. This decouples traditional definitions of functioning from being a full citizen; it is also remarkably similar to the changes in diagnostic criteria for autism in the current DSM. They argue that there are two basic poles of autism spectrum diagnoses, high functioning and low functioning. High functioning autistics have a cluster of functioning that allows them the traditional measure of citizenship, if only depathologized and accepted as normal. For low functioning autistics in the traditional sense, functioning must be redefined towards quality of life, as they argue their

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4      Obviously she has not read any critical race theory or post-colonial theory.

impairments will always interfere in becoming full agents. For those in between, whose traditional measures of functioning vary depending on capacity being measured, the two measures of functioning must be intertwined, and interdependence must be seen as a form of independence. Essentially, they argue, neurodiversity is good for those who are traditionally high functioning, somewhat good for those with a mix of capacities, and useless for those traditionally low-functioning except in reorienting goals of quality of life. Formal equality can never really be given to this population, they argue, because of the extent of their pathologies. This is a common charge against neurodiversity as a movement: it only speaks to the needs of the high functioning. Similar to critiques of the human variation model and universalism, this critique argues that there will always be those who are too impaired, too disabled, to ever fit within society's expected ranges of performance. There must be some expectations of a user's capabilities when a designer creates a building or tool, and thus there will always be those who lack even those most widely conceived capabilities who are excluded from entering that building or using that tool.

Still, those within the neurodiversity movement respond with a call for unity within the autism community. From the earliest “unity pledges,” like the one circulated by [autistics.org](http://autistics.org) in the late 1990s/early 2000s, to the essay in the *DSQ* issue by Jim Sinclair (2010) calling for an autistic sense of togetherness, those who represent neurodiversity seek to present a commonness through all on the autism spectrum. Sinclair's essay points to the commonality of experiences, such as not understanding social situations, experiencing the pain of exclusion, or bullying, and the sensory disjointedness of many autistics, which manifest in varying forms. He also speaks to the inclusion of people of all different levels of functioning, in any sense of that word, and efforts at making all events and communities available to all who wanted to partake. The

critique of neurodiversity as benefitting those on the “higher” functioning end of the autism spectrum is really one of the politics of representation; can those who speak for themselves also speak for those who cannot speak at all? In the medical model, there is a default paternalism that relies upon wise figures to speak for those who cannot speak for themselves, as if doctors and/or parents know better than those with substantively similar but milder conditions. Indeed, Baker argues that the experiences of adults on the autism spectrum cannot be used as guides for the present children on the autism spectrum, because those children have been exposed to “better” treatments and greater socialization than those of a generation ago, a perspective that ignores the fact that many of the leaders of the self-advocacy and neurodiversity movements are under 30 and grew up in the world of educational service provision, therapy, and psychotropic medication for children. Neurodiversity, on the other hand, challenges this default paternalism that relies upon the medical model in terms of decision making, arguing that despite vast differences in experiences, those commonalities allow for better representation of those who cannot represent themselves. I will further explore the complicated relationship between autistic adults and medical expertise in Chapter 3.

Yet for all of the points of contention between the social model of cognitive/mental disability and the human variation model of neurodiversity, there is a fundamental commonality between these two models that remains problematic: the biological reductionism that collapses brain, body, and behavior. Baker relies upon this in developing her two contrasting models of difference; at some point, a biological-neurological defect is implicated in altering a person’s behavior, regardless of whether or not that defect is identifiable or consistent across different persons. Neither neurodiversity nor the social model of neurological disability challenge, in any way, the authority of medicine to create categories of difference, measure behavioral or

biological differences and reduce them to neurological processes, or manage the amelioration of the “pathological” aspects of those behaviors or biologies. While neurodiversity certainly argues against medical paternalism and for choice in service provision, with a goal of quality of life not “recovery” from autism, it does not question the existence of the categories to begin with, or the notion that behavioral difference stems from neurological difference which is a reified and material condition of the brain away from standard human neurology. Beyond that, neurodiversity does not question the power relations that produce medicine as authority, biology as authority, or neurology as personhood. Baker is correct in pointing out that neurodiversity requires identification with neurological difference, but cannot see how identification with neurological difference inherently perpetuates and reifies neurological difference, and thus also the power relations producing those conditions. Neurodiversity cannot resist medicalization, though it can ostensibly reorient its goals, because it is a product of medical power relations. Of course, medical power relations have long moved beyond the material walls of the clinic or hospital; medical knowledge is now a technique of governmentality, a condition of state population control more than an institution of positive health. Neurodiversity is a form of biosociality, the way of knowing oneself that Rabinow (1992) described as being through medical knowledge, medical risk, and medical care of the self. What neurodiversity asks us is to know ourselves through our neurology, as normal, autistics, mad, or so on. It asks for inclusion of deviant neurologies in the realm of expected performances, for granting citizenship to the neurodiverse, and for a focus on self-assessed quality of life as an outcome, not on cure or recovery. While it may appear to be counter to the goals of medicine because it is not promoting positive health, free of deficiency or pathology, it is actually within the medical-juridical power relations by reifying those categories of difference and seeking to bring them into the state’s

population. Neurodiversity does not offer alternatives to understanding autism, nor does it offer a critique of how the normal is produced. While it seeks to expand citizenship to those who currently lack it, neurodiversity does not critique the production of the citizen as rational agent, instead only seeking to expand that definition to include the autistic agent. Despite claims by neurodiversity proponents that it seeks to blur the normal and the abnormal, diversity rhetoric rarely disrupts the processes that create norms.

### **Neurodiversity and Lived Experience**

In my field experience, the concept of neurodiversity, much less the idea of a positive autism identity, was not as widely accepted as those advocating for neurodiversity's acceptance might make it seem. My field sites, as I discuss in chapter 1, lacked a true range of autism diagnoses; all of those in attendance, with one exception, had at least the functioning level to communicate with others without facilitation or aid. While a few were always accompanied by friends, family, or a support worker, most were able to navigate the transportation issue to get from their homes to the meetings, which included either navigating public transit or driving. At the same time, there is somewhat of a speculative missing bodies issue around those who are at the highest level of social functioning abilities. While one group tended to attract those with the highest levels, as it was oriented towards political activism, all who spoke seemed to think of autism as a problematic aspect of their life in some regard. It is likely this concept of the problem that drove people to seek out groups, though answering that particular speculation is beyond the scope of this research. Thus the concept of neurodiversity exactly addresses the population of my study: moderate to high functioning individuals who see autism as an aspect of the self around

which to organize at least some aspects of their lives. And yet, the concept of neurodiversity had limited success in the field.

As I will discuss in the next chapter, developing a sense of identity as autistic for many of my participants and being diagnosed as an adult was revelatory in and of itself. Many felt that there was a ‘problem’ in their lives that interrupted their social beings, prevented full and deep relationships to others, created confusion and anxiety particularly around social interactions on a micro or macro level. To have that cause named, identified, categorized, was liberating on an individual level. It removed blame from the person’s character and placed it on a disease category. It allowed them to identify with others and find common experiences. It gave them access to disability related services and accommodations. It gave coherence to a potentially incoherent self-narrative, allowing for greater self-awareness and introspection. Yet the step beyond that, into a politicized identity as autistic and perhaps even activism around being autistic, was rarely taken. Many were not even aware of the social movements around autism, which is why Paul’s outreach efforts during the meeting on politics of autism felt, to him, to be very important. If exposing adults on the spectrum, for the very first time, to the social movements, it seemed imperative to espouse neurodiversity.

Despite the relatively mainstream tropes used by neurodiversity advocates like Paul, I found two specific forms of resistance to neurodiversity in the field, as well as apathy towards politics that itself was a form of resistance. The first form, a kind of individualism, rejected the notion that autistics should be making demands upon society for special treatment. While the identity of autistic was useful and explanatory in their individual lives, the onus of the burden of autism still fell upon them as individuals to undertake self-improvement, else be crippled by the pathology of autism. The second form of resistance was less common, but closer to my proposal

of queering, detailed later in this chapter and the next. While those with this stance understood the need for distinguishing oneself from the neurotypical and using cognitive variance as a marker of difference, they also resisted categorization. However the dominant form of resistance to neurodiversity in situ was not active resistance or disagreement, but simple apathy. And it was against this apathy that Paul was so vociferously advocating.

Paul's spiel was well rehearsed, and he could rattle off the facts and figures of the neurodiversity movement easily. There are multiple kinds of brains, he argued, and each kind should be respected and accommodated. Frank, garrulous to the point of domineering, argued with Paul. While it may be true that there are multiple neurologies, some of them are working, and some of them aren't. And those of us who can work on it, Frank argued, should work on it, instead of playing a victim of our brains and demanding others change. Paul then argued against the notion of neurodiversity meaning victimhood, as he then rattled off a list of famous people thought to be on the spectrum and the gifts that autism may confer.

"I get that you're proud of being defective," Frank said to Paul, "but I'm not and I don't see why others should accommodate my defects." Similar to how male participants had incorporated hegemonic masculinity while being unable to temper their bodies and selves to the demands of hegemony (see Chapter 4chapter four), Frank had subsumed himself to the biosocial notion of mind as project of the subject, identifying with autism as a category, but not neurodiversity which demands that normal be extended to the autistic. He was firmly in the Other, against the Normal, seeking normalcy not through categorical extension but through medical/psychiatric/divine intervention. This sentiment was not that common, and just a handful of participants across three of four research sites actively voiced this perspective, but it

demonstrates one way in which the neurodiversity rhetoric fails those whom it claims to represent.

The second form of resistance, an appeal to the queer, or basics of queer, appeared in my field work in only two people. I did encounter this elsewhere, particularly at conferences of activists or academics when I presented my work, but within the context of my research, the attitude that neurodiversity simply wasn't radical enough was rare. Barbara identified herself as a queer lesbian, married to a transguy, her second husband, and she had three kids, one of whom was, as she said, like her, gender variant and probably autistic. The incongruence in her apparent identities were explained by her hand flip when I asked, a lesbian married to a cisguy? Identities are words used to make sense of feelings, she said. I'm not words, I'm Barbara. She felt similarly about her autism diagnosis. When the group discussed neurodiversity, in the general context of what is autism, causes, etc, she spoke up and said that it made the categories too rigid. In sum, her explanation was that while we may have a plethora of brains, yes, and while each cognitive type needs to be respected and accommodated, yes, to truly organize around that concept would mean ignoring how some brains are seen as better or worse, or that the words are realities instead of representations. While Barbara did not offer up a lecture on queer theory for the group, it was clear that her orientation towards neurodiversity was imbued with her queer understanding of identity writ large. The other person to offer up a similar perspective, Grant, said it more succinctly when he said that neurodiverse was like gay, and he was queer not gay. Indeed, all of those who have expressed this sentiment have been self-identified queers in terms of sexuality or gender. The notion that neurodiversity, a concept written by and for straight and/or cisgender white people, is undermined by those with queer experience is not surprising in the least. My lone routine black male participant, Kevin, bought into neurodiversity to some degree, but was

skeptical what it could do for him considering his already marginal position in society, as a bookish, large, black man.

Skepticism and political apathy dominated the resistance towards neurodiversity in my field work. Three of the four groups I studied were oriented towards mutual aid, peer-to-peer support, and social activities; the fourth was nominally oriented towards self-advocacy, but during my period of study actually engaged in very little advocacy; still, they were more unified in supporting a claim of neurodiversity. The majority of my participants were in the first three groups, however. What brought them together was not an interest in self-advocacy in particular, but of meeting others on the autism spectrum and participating in the peer-to-peer and/or mutual aid movements. As I discuss in chapter 3, those movements rest upon notions of legitimacy and authenticity in relation to the diagnosis; while neurodiversity activists also rely upon these concepts, perhaps even more so, the peer-to-peer/mutual aid groups don't seek changes beyond the immediate quality of life for participants.

Indeed, that immediate concern with quality of life seemed to drive the apathy towards neurodiversity. The neurodiversity movement's chief concerns, such as employment and housing accommodations, did little to address the immediate impact of marginal employment in my participants' lives. When Paul explained the difficulties with applying the Americans with Disabilities Act to cases of employment discrimination against autistics<sup>5</sup>, another participant, Linda, who was experiencing problems with her employers, asked how he could help her in the moment. Paul was left aghast; as a college student, his educational access rights were far different than Linda's accommodation issues. Her employer had classified her as "difficult" in a recent performance review because she was "unresponsive" to social cues. Clearly that was an

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<sup>5</sup> A topic I will explicate in chapter five

aspect of her disability, but worded in such a way that she could not claim accommodation or have redress were she to be fired. What could neurodiversity do for Linda? The answer was not much. But Paul persisted, talking about the larger scale changes that could happen if neurodiversity became a thing like other forms of diversity. Not many of the participants were convinced.

Of course, a queer resistance also does not offer immediate solutions. However, it may mitigate some of the stigma to say there is no such thing as neurotypical versus neurodiverse, only neuroperformative, neuroqueer.

### **Moving Towards Queerness**

The human variation model of disability, like the rhetoric of multiculturalism for race and ethnicity, follows from the concept of the minority group, which is typically conceived using Wirth's classic (1945) definition as "a group of people who, because of their physical or cultural characteristics, are singled out... for differential and unequal treatment, and who therefore regard themselves as objects of collective discrimination" (pg 347). Berbrier (2002) challenges this definition, arguing that minority group status has been attributed to African Americans, whose status in relation to whites has thus become unquestioned as hierarchical, with associated civil rights movements and respect for cultural difference instead of assimilation into dominant culture as social movement strategies. Minority groups in the United States since this attribution have been operating in relation to the unquestioned status of African Americans. He argues

...the existence of "minority groups" is neither inherent in the nature of things, nor even in the *idea* of minority groups. Rather, it is systemic and relational (i.e., *social*): the existence and meaning of all minority groups' "minority-ness" is dependent upon others in the social context. Groups are established in

minority space by indexical reference to others whose minority credentials are black-boxed and presumably unimpeachable. (pg 580)

Berbrier's example groups of gay activists, Deaf Culturalists, and white supremacists were not trying to advance their claims by associating themselves with the majority group, that is, assimilationist claims, but instead to align themselves with accepted minority groups, that is, African Americans. While not claiming to be like African Americans, Berbrier says, they are claiming they are socially situated or constituted in a manner similar to African Americans, as cultural groups with distinct but equal ways of being. As minority group strategies move into pluralistic and multicultural spaces, following this supposed success of African Americans, Berbrier demonstrates that this allows groups, particularly white supremacists but applicable to others as well, to "become normal without changing... conform without assimilating." (pp 580-1) Diversity rhetoric, then, allows for groups to reify their differences, or have their differences reified for them.

While the human variation model of disability complicates this conception of diversity rhetoric, and neurodiversity even more so, those models basically ask for expansion of normal to disabilities without rehabilitation or individual level removal of barriers, even as the decisions to use those services are restored solely to the individuals who might partake in them and are thus made to be on-demand and ever present. While these models of disability resist normalization, or assimilation, as a matter of force, they require normalization be normalized, so long as it is under the authority of the individual. Neurodiversity recognizes that the neuro-diverse may never be fully decoupled from medicine, just as disability in general may never be decoupled from rehabilitation or medicine. Instead, neurodiversity asks that use of medicine be seen as a normalized practice. This link of the authority through which neurodiversity is pathologized and the practices that make deviant the group seeking minority status reveals the irony of these kinds

of group representations; while seemingly advancing prospects for that group under law or through other normalizing power systems (Berbrier mentions the sympathetic use of media by white supremacists to depict them as any other minority group), it also creates fixed categories, which, Gamson (1995) points out, is the very basis of oppression to begin with. With neurodiversity, the oppressor becomes an instrument of the neuro-diverse, who is such because of the operation of power through oppressive systems. Despite claims, then, of confusing what is normal about neurology, neurodiversity is untenable precisely because it reifies the power of both medicine and biosocial governmentality as individual identity and collective representation of those who fall under those purviews. It cannot be both radical in challenging norms of behavior and accept as normal that which defines it as pathological.

If diversity and multiculturalism tropes of identity and social movement strategies ultimately are untenable, because they fix categories of oppression, because they become instruments of biopolitical state racism, because they inculcate a kind of necropolitics while celebrating that which diminishes life chances, etc, then we must theorize alternatives. Whereas neurodiversity seeks to expand normal to include the autistic, we must deconstruct the systems of power that produce pathological neurological difference, neurological disability, and neurodiversity. In short, we must interrogate the systems of knowledge of the brain, of behavior, and of difference that lead us to an identity politics of biosociality. We must queer cognition.

In its broadest sense, cognition refers to the mental processes of perception, memory, attention and execution, particularly those processes of which we have conscious awareness. But, as Danziger (1994) points out, even this term and its referent mental processes are culturally, contextually, and historically bound. This is not to say that Western empirical psychology is somehow superior to so-called folk psychologies of the non-West, but those

psychologies are radically different ways of knowing that are no more or less representations of the material substrate of the mind than our own representations. The truth of these psychologies is in the naming and knowing, the calling forth of a given epistemology. In this way, the historical development of psychological concepts is a form of scientific interpellation; through calling forth mental processes, the subject identifies as those processes, a Western subject of psychology, the biosocial neuro-divergent. We must recognize that the neuro-diverse is produced through interpellation of cognition, a first step in queering that which produces it as a subject.

Incorporating both Danzinger's basic critiques and a feminist model of science, Wilson's (1998) critiques of neurology and cognition point us towards understanding those models of knowledge of mental function as performance, akin to Butler's understanding of gender and sex. While not denying that cognition may exist as a product of neurology and environmental stimulation, Wilson interrogates the particular configuration of neuroscience that informs the production of cognition as empirical fact. She calls for a neuroscience that goes against the patriarchal systems of knowledge that are products of oppression and power systems, understanding that any empirical fact that emerges from such systems is inevitably reliant upon those systems. Specifically regarding autism, then, we must also interrogate the systems of knowledge that produce the configuration known as autism, a heterogeneous amalgamation of conditions which potentially lack an empirical center of truth.

### **Neurodiverse to Neuroqueer**

Against the categorical-based identity politics of neurodiversity, I offer an anti-identity politics (a form of identity politics, admittedly) of neuroqueerness. Like the queer politics of Gamson, neuroqueer resists the reifying, naturalizing categories upon which diversity rhetoric

relies in order to produce the diverse subject. It recognizes the performative aspects of cognition, both the actual embodied performance of cognition, of processing information, paying attention, and aligning actions, and the performance of knowledge regarding cognitions, the forms of knowledge that flow from and recursively enforce the systems of power in current cognitive neuroscience. Autism is but a point of queer in this field, equally as neuro-typicality, though autism is rendered visible through the processes of neuroscience, identification (both self and medical), and difference.

While neurodiversity offers a concrete path of action, that is, a set strategy of liberation modeled off of other cultural liberation movements, it cannot hold against the colonizing processes of diversity politics, which ultimately will not lead to liberation but further categorization.

It is hard to formulate an action or strategy within the politics of queer. Neurodiversity leads us, those invested in the dignity of those identified as autistic, down a dangerous path of assimilation and colonization, of reification of Otherness, of limited ways of being. It also leads the science studying autism and other neurologies, set and ephemeral, to forms of knowledge that foreclose upon other knowledges of the theoretically same empirical truth. However, neuroqueer does offer a pause, a moment to reconsider the implications of the neurodiversity movement, and is theoretically rich for understanding broader implications of autism in the (post)modern world. Haraway (1991) suggests a politics of affinity, but considering the nature of the autistic as the present day uncanny valley representation between neurotypical human and actual cyborg, I dare say that this possible politic assumes an affective capability and capacity that is ableist in formulation. Indeed, one of the difficulties of offering up alternatives to neurodiversity is that autism represents a potentially radical rethinking of being as subject in and

of itself. I will discuss that potential for radical ontology, especially in relation to the formulation of various autism social movements and state citizenship, in the following chapters.

### Chapter 3

The meeting began as usual. Introductions zig-zagged through the rows of chairs assembled in the room: name, diagnoses, or if not diagnosed, reason for coming to this meeting. Newcomers were then asked to identify themselves, and after the standard introductions were finished, also asked to speak a little more about themselves: name, again, plus age, living situation, social/relationship situation, and employment situation. They were also invited to ask questions of the group, to ask what the facilitator, Phil, routinely called a group of experts on autism.

At this meeting, there were five newcomers; Yossi was the third to introduce himself. A member of a Jewish ethnic groups, Yossi dressed in a conservative button down shirt and plain black pants, with two inches tzit-tzit hanging out from his otherwise tucked shirt. He was in his early 30s and employed in the computer industry, which elicited sympathetic nods from many in the crowd. He lived with his parents in their ethnic neighborhood, a situation not uncommon for the youngest and unmarried offspring from his background group, though also not uncommon among adults on the autism spectrum. He was currently single though starting to see a woman. He had trouble dating because he did not do well in his culture's traditional ways of arranging prospective marriages. He was not a good yeshiva student, he said, and held a secular job, which turned off many parents from setting him up with their daughters. He found this woman on his own, and though she was religiously Jewish, she was from outside of his particular background, which was causing strife with his parents. He was also worried about disclosing his condition. While not officially diagnosed, he explained, he had read the Carley and Attwood books<sup>6</sup>, and he

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<sup>6</sup> Understood to be Tony Attwood's (2008) "The Complete Guide to Asperger's Syndrome" and Michael John Carley's (2008) "Asperger's from the Inside Out."

“felt it.” Is there a point in getting the official diagnosis, he asked, or can I tell this woman about my autism without it?

Phil immediately redirected him, almost correcting him, by stating that Yossi didn't have Asperger's syndrome, he was “exploring getting diagnosed as Asperger's.” He couldn't tell the woman about the autism, Phil went on, because he didn't have the real diagnosis. Despite Yossi's obvious presentations, such as his inability to look group participants in the eye, his emphatic identification with both the clinical and experiential descriptions of Asperger's found in the Attwood and Carley books respectively, and his drive to meet others like himself found in his mere presence at the meeting, his true relationship to the autism spectrum could not be established, and therefore he should not claim a diagnosis. As much as it might explain his difficulties, in the present and in his childhood, a formal diagnosis was the “key” to understanding his true self.

Well, if it is so important then, how does one get an official diagnosis, Yossi queried. The group was ready with answers, each couched in personal experience. For those with amazing insurance or thousands of dollars lying about, private practice neuropsychiatrists with specialties in autism could do the diagnosis. Most people didn't have that, so there were two other options. One man shared his experience going to a local medical school. For under \$500, he obtained his diagnosis by letting students practice the diagnostic interviews on him. Sometimes it was led by a doctor and observed by students, sometimes students repeated tests, and sometimes it was just plain awful, but it was cheap, and he had his piece of paper making him officially autistic. Or you could do it for free, another man joined in. You could join a research study, and actually get paid to get a diagnosis. All you have to do is give some blood or

get a brain scan. It can take up a lot of time, though, warned another who had also used this method. But I got to keep the picture of my brain, chimed in another.

Fine, said Yossi, but he didn't have the time to go through that process. If he thought himself to be autistic, and therefore knew what his problems might be, even if he didn't tell the woman, what would be the point of going through the hassle of a formal diagnosis? He seemed unconvinced that a formal diagnosis would add anything to his previously formed self-conception of autistic; while this was his first meeting, he had slowly come to identify as having Asperger's over a few years, and was therefore not new to the diagnosis at all. The response, from both Phil and the crowd, was overwhelming in favor of formal diagnosis. How can you truly know who you are, the asked Yossi, if you haven't been diagnosed? You might be right, but only a specially trained doctor can really ever know if that is true, and that truth is the "key" (repeated frequently throughout this conversation) to understanding the self. A formal diagnosis is important to get services, it is important to get other people to understand who you really are, but most important, it is key to growing yourself as a person. While autism is a permanent condition, it can change, so on top of present diagnosis it is helpful to check back in with the diagnostic authorities to understand who you may be in the future. One man chimed in with how he was diagnosed at age three, but recently re-diagnosed, just to make sure his diagnosis hadn't changed and he was who he claimed to be: a person with autism. It was the key to ensuring his continued identity.

Encapsulated in this conversation between Yossi, Phil, and the other members of this support group is a fundamental tension between identity and diagnosis. For two of the three social and cultural peer-to-peer organizations I observed, the repeated emphasis on formal diagnosis as a key to knowing oneself is pervasive, with those who are self-diagnosed

encouraged to seek formal diagnoses, lest they prove to be inauthentic interlopers. Questions of the etiology of autism, treatments or palliative remedies for autistic traits, and the lived experience of autism inevitably get mixed into these conversations as well. It wasn't enough to identify with the diagnosis; diagnoses were granted on high by the medical authorities, and until a person was validated with a diagnosis, the explanatory powers of the criteria or memoirs of those on the spectrum were moot for the individual with such a desire to identify as autistic.

At the time of the above observation, in the Fall of 2010, many of the new revisions to the Autism Spectrum Disorders diagnosis in the upcoming Diagnostic and Statistical Manual V had been introduced and gone through a period of public commentary. Those changes included the media-attracting merger of the three autism-related diagnoses in the DSM IV: Asperger's Syndrome, Pervasive Developmental Disorder – Not Otherwise Specified, and autism. Shortly after this observation, in December of 2010 a new diagnosis would be added to the DSM V, Social Communication Disorder, with the only diagnostic criteria being pragmatic (expressive) language issues not attributable to autism<sup>7</sup>. By January 2011, a new set of diagnostic criteria for autism was presented for use in field trials. At the time, these new criteria garnered little of the media attention of the first major change; it would take almost a full year for the impact of these more substantive changes to the diagnostic category to be felt. By November of 2011, Dr. Fred Volkmar, a prominent autism researcher affiliated with the Yale Child Study Center, removed himself from the field trials and the Neurodevelopmental Working Group in general, citing issues with the way in which those trials were being conducted. Those issues were made clear on January 18, 2012, when he presented research conducted with two colleagues at Yale, which indicated a dramatic reduction in the number of individuals currently diagnosed with autism who

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<sup>7</sup> This diagnosis also replaces Semantic-Pragmatic Disorder that was previously listed as a Specific Language Impairment, but that change was not made until much later.

would qualify under the new diagnostic criteria (Carey, 2012). On the same day it was presented at a medical conference in Iceland, the accompanying article was accepted for publication in the *Journal of the American Academy of Child and Adolescent Psychiatry* (McParland, Reichow, and Volkmar, 2012). This news quickly hit the mainstream media; a *New York Times* article on the report, plus a ‘reaction’ piece featuring the concerns of parents and advocates, appeared first online on January 19 and in print on January 20. This was then quickly picked up by other news organizations; I first heard of this on the local news in Pittsburgh, PA the evening of the 20<sup>th</sup> and read the *New York Times* articles republished in the *Pittsburgh Post-Gazette* on January 21.

Had I been actively checking Facebook or my email while visiting family in Pittsburgh, however, I would have heard about this earlier. The first so-called action alert by the Global and Regional Autism Spectrum Partnership (GRASP)’s executive director Michael John Carley was put out on January 20, alerting members to the impending news and articles. Soon thereafter, the official position of GRASP and related groups like the Autism Self-Advocacy Network (ASAN) changed. Whereas these groups had originally supported the changes in the diagnostic criteria, long advocating the differences between autism and Asperger’s were incoherent and untenable and therefore should be merged, they now opposed the changes if it meant that individuals might be denied a diagnosis and therefore services or entitlements related to their diagnosis. GRASP launched a petition on January 25 and encouraged members and supporters to call the American Psychiatric Association with their opposition, as the period for public commentary had long ended; ASAN released a letter of opposition in concert with mainstream parents’ organization, the Autism Society of America (Ne’eman and Badesch, 2012). To be clear, these groups did not oppose the merger of the diagnoses; instead, they were opposed to the ways in which the changed criteria seemed to contract the category of autistic in a way that those currently

diagnosed would now face exclusion or cancellation of services. They were also wary of potential changes, since mitigated, that might make it more difficult for an adult to obtain a diagnosis.

Entering the growing fray once again, the *New York Times* published two op-eds on January 31/February 1 (first date online; second date in print), which seemed to indicate the real problem of the autism epidemic was over-diagnosis and over-enthusiastic use of the diagnosis to explain minor cognitive-behavioral differences. By tightening the criteria for the disorder and reclassifying some with Social Communication Disorder (per the suggestion of the op-ed by child psychiatrist Paul Steinberg), individuals could receive better treatments more tailored to their specific conditions while the perception of the epidemic could be stemmed. Further, the stigma of autism could be avoided for individuals who were merely “nerdy” or “clumsy” (per the suggestion of the op-ed by Benjamin Nugent).

For many of my participants, however, the avoiding stigma of autism was far less important than gaining the explanatory powers of the diagnosis in understanding their own lived experiences. Some felt an internal shame at the diagnosis and desired fundamental change if not cure for their condition, but most were grateful for, if not proud of, their autism diagnoses or identifications. Either way, the diagnostic criteria, deployed in medical offices, social situations, biosocial identifications, and media constructions, is currently up for grabs in a power struggle. I will tie together my participants’ use of and quest for legitimacy in the face of critique from outsiders with the power struggle over the re-writing of the diagnosis.

### **Authenticity, Legitimacy, and Biosociality**

The terms “authentic” and “legitimate” often have overlapping if not identical definitions, with both referring to truth claims about a particular status, and are sometimes used interchangeably. In this dissertation, however, the terms are distinct, arising from my field work as two separate (though still overlapping) categories of being autistic. One may have an authentic autistic identity and experience, but still lack legitimacy. Others may have a legitimate autism diagnosis, but not have a shared, authentic, autistic experience. For my participants, authenticity was granted by the autistic community, those who identified themselves as having an autism diagnosis, whether or not this diagnosis was granted by a formal diagnostic agent. Legitimacy, on the other hand, was the recognition by non-autistics of an autism diagnosis such that any advantage or privilege of the diagnosis was given to the individual, including disability claims. My participants reinforced or rejected the authenticity of others’ diagnoses, but were also concerned with perceptions of legitimacy by others. This distinction between authentic and legitimate is essential for understanding my participants’ perspective on the autism diagnosis “epidemic” and growing concern, at least among individual such as Steinberg, the author of the aforementioned *New York Times* op-ed piece, that it is overdiagnosed to the detriment of the truly disabled.

For my participants under the age of 25, the age of diagnosis was almost universally at some point in childhood. With the addition of Asperger’s Syndrome and incorporation into the autism spectrum of PDD-NOS in 1994, it makes sense that those who were in elementary school during the period of rapidly expanding diagnostic criteria would be caught up in that change and diagnosed. For participants between the ages of 25 and 30, however, there is a gradual shift. Someone who was 26 in 2011 (the last year of field work), and thus born in 1985, would have been 9 in 1994, and thus in the last year of eligibility under IDEA for accommodation. The

impetus for a school district to identify a student with a special need greatly diminishes as the student ages out of the provisions of IDEA, as the special funding associated with students under the age of 9 and diagnosed with autism no longer applies, thus the chances that a student would be singled out for an autism diagnosis diminish as well. While now the average age of diagnosis is 4 for autism and 4 years, 2 months for PDD-NOS, Asperger Syndrome is still not diagnosed on average until 6 years and 2 months, which unsurprisingly coincides with entering the school system, with schools likely being the first to suggest an autism screening<sup>8</sup>. Still, with an expanded diagnostic criteria and rapidly expanding social awareness, many of my participants, including myself, were diagnosed with autism in adolescence, often after a period of related mental distress. The majority of my participants, however, were diagnosed as adults, especially those over the age of 30. While a handful in that category had been diagnosed as children, the older diagnostic criteria were generally limited to those with more severe impediments, and those with lasting impediments were rarely found in the groups in study (though so-called functioning levels varied considerably within the groups, most were at least able to function semi-independently, thus excluding those with the most profound disabilities).

Besides authentic versus legitimate, the other major category of distinction for my participants was the formality of diagnosis: self-diagnosed, informally diagnosed, and formally diagnosed. In the example above, Yossi has come to identify himself as having an autism spectrum diagnosis; he is self-diagnosed. The facilitator of the group encourages him to become formally diagnosed, for reasons I will explore in this chapter. For my participants, a self-diagnosis is the start and indicates a personal identification, or biosociality, with the diagnosis; a formal diagnosis continues this process and reifies the biosociality. There is also the common

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<sup>8</sup> Derived from the Autism and Developmental Disabilities Monitoring Network data, which indicates origin of data and prior suspicion of possible diagnosis of autism, CDC, 2014.

informal diagnosis. That status is granted by a medical, psychological, or psychiatric professional, but not one who is considered an expert on autism; I will explore the contested status of the expert later in this chapter as well. It is a suggested diagnosis, one that invites a formal diagnosis and a referral to a recognized authority, but this informal diagnosis can also be a limbo stage for many seeking out social groups for those on the spectrum as well as the spark that begins the process of biosocial identification with autism. Formality of a diagnosis is on a gradient of legitimacy; a therapist may suggest an autism diagnosis, but rarely is that informal diagnosis legitimate enough to claim an autism diagnosis to other medical authorities. On the other hand, there are a handful of psychiatrists and psychologists considered experts on diagnosing autism in adults, but a multitude of doctors, psychiatrists and psychologists who actually do the majority of diagnosing. These practitioners may include general practice psychologists and psychiatrists, individuals who see a wide range of clients, who lack specialized training with regards to autism at any stage of the life course, but who are likely to encounter an autistic adult seeking general counseling prior to getting a diagnosis. A semi-formal diagnosis is a formal diagnosis that is legitimate enough in a given person's lifeworld, but may not have currency outside of that experience.

While having a formal diagnosis means having a legitimate diagnosis, neither are all legitimate diagnoses authentic, nor are all legitimate diagnoses indicative of biosociality. Authenticity, in this case, means that a person's experience, when shared, echoes the shared experiences of others on the autism spectrum. While it is often said (especially by Phil, one of the group facilitators) that if you know one autistic, you know one autistic and not the entirety of autism, there were in fact common experiences of *being* autistic in a way that is not quantifiable, nor described in the diagnosis itself (though the recent diagnostic changes take into account these

types of experiences more so than previous inceptions of the criteria). This sensorial, experiential, nay phenomenological sense of being autistic will be explicated further in this chapter and other areas of this project, particularly relating to affect and gender in chapter four. Legitimacy, on the other hand, which may grant the person in question the ability to speak for autism writ large, indicates that a person has a diagnosis from a recognized medical authority and uses it to garner the few privileges of that diagnosis. Typically this involves procuring services, but I will speak to other examples of this use of legitimacy later.

Almost all of those who self-diagnosed shared authentic autistic experiences. In three of the four meetings I regularly attended, participants were asked to share information about themselves. In Phil's group, when a new participant would relate their employment or desired field of employment, Phil would often repeat the same spiel regarding the ubiquity of engineering, accounting, computing, and graphic design among the types of employment preferred by autistics or their parents. A statistic he loved to quote was that nearly half of the subjects in Kanner's original study had accountants for fathers. This often elicited groans, nods, and other gestures of agreement; my own father is an accountant and his parents were both statisticians. Similar responses were found when participants in all three groups would relate more embodied experiences of sensory overstimulation, perseveration, and stimming. The effect of these markers of shared experience was to normalize (to make normal within the context of autistic experience) and authenticate the person's experience as truly autistic.

To illustrate the difference between authentic and legitimate diagnoses, I offer these two examples from my field work. Kirsten had a growing sense of identification with the autism diagnosis and her behavior was deemed authentic by the group she attended. Matt, on the other hand, had a (semi)formal diagnosis that was legitimate enough for him to gain privileges

associated with the diagnosis, but his experiences were invalidated by the group in which he shared them.

Kirsten had drifted around for most of her adult life, and hadn't been able to hold a steady job or commit to any project for long enough to see it through to completion. She had only recently been able to graduate from college, at age 40, and desired to hold down a lab technician job. It had been suggested to her by a counselor at her university that she might have Asperger's, so she did some research and concluded that indeed, this was a possibility. She was still unsure, however, when she joined the group, first for social events only but eventually for the support group meeting as well. It was unclear exactly how the tiff between Kirsten and Bill, a devoted Aspie with Neurodiversity Pride stickers on his ever present rollerblades, started, but it quickly escalated into ad hominem attacks that had nothing to do with the topic of the meeting at hand. It was too subtle and unremarkable to note in my field notes, at first, but the exchanged insults were clearly not spontaneous. After a couple of back and forths with Bill, Kirsten exploded.

"You people just don't understand me!" Kirsten shouted, grabbing her bag and storming out of the room.

"No we do!" cried Barbara, another participant running out of the room.

"Yes we do," said Bill introspectively. "See now I can see what was happening, now that it is over. I have a rigid mind and she has a rigid mind; we both have rigid minds because we're both Aspie. I hope Barb can get her back in the room."

From the hallway, we could hear Barbara pleading with Kirsten to return. Kirsten, obviously embarrassed, protested that we would judge her, look down on her for her outburst. Barbara assured her that no, in fact, we would not judge her, we would accept her, because we're like her. Maybe not identical, but we've all had inappropriate outbursts, we've all

misunderstood and all felt misunderstood. We've all been there, because, Barbara explained, we're all like you, we're all Aspies.

The room was awkwardly silent, except for Bill periodically muttering that they both had rigid minds, while we waited for Barbara to bring Kirsten back in. After a few minutes they returned, Kirsten clutching her purse tightly to her chest. Bill stood and reached across the table around which we sat.

"I'm sorry," he said. "We both have rigid minds and I should have realized sooner that because we both have rigid minds and that I was being too rigid."

When it became apparent that Kirsten was not going to shake Bill's hand, nor even reciprocate by accepting his apology, Bill began his occasional habit of pacing the room on his rollerblades while balancing his medicine ball on his head. Keith, the group facilitator, looked at Kirsten and said,

"Dear, if you were unsure that you were in the right group, be assured now that you belong here."

This sharing of experiences, especially the embodied experiences like physical outbursts and self-stimulating activities like rollerblading, not only makes autistically normal those experiences, but authenticates to the others that those are autistic experiences. Positing Kirsten in the framework of diagnostic status, her experiences are authentically autistic, but she does not have a legitimate or formal diagnosis, only an informal diagnosis and a growing sense of biosociality regarding autism.

Matt, on the other hand, had only a legitimate diagnosis. The self-appointed leader of a group of three young men from a post-incarceration transitional housing facility, Matt had discovered the group as a way of obtaining unsupervised off-campus time when one of his

minions, authentically, formally, and legitimately diagnosed with Asperger's, began attending on advice of his counselor. While I cannot affirmatively ascribe motive to Matt's behavior, it seems clear that his primary motivation was the unsupervised time. He inquired about obtaining an autism diagnosis and quickly received a provisional one from the psychiatrist at the facility. This enabled him to come to the groups, which he would attend, then take a "smoke break" with his friends about half-way through. They rarely returned from this break. While they were at the meeting, however, all three would actively participate. When relating their stories, the two friends had their experiences authenticated; Chris's ability and interest in playing complex drum rhythms day in and day out reminding others of their own rhythmic perseverations, while Troy's memorization skills and utter lack of social desires resonated with others. Matt, on the other hand, when relating his stories of manipulating girls into sleeping with him, executing complex drug deals, and other such wild tales, had his experiences downright unauthenticated. When speaking of "scoring" with girls, for example, he made sure to emphasize that he had little empathy for them; after all, autistics lack empathy, and as an autistic, he must not be able to empathize with them as he conned them into sleeping with him. He told how he lied about his desires for relationships in order to score. Peter, the facilitator for the group, actively questioned his diagnosis. Autistics may not empathize well or in a typical manner, explained Peter, but rarely do we have the capability to manipulate or lie to people to get our wishes. Despite having a somewhat legitimate diagnosis, Matt's experiences were not authentically autistic. His biosociality with autism was almost sociopathic in nature.

Yet Matt had a diagnosis, which he could use to gain advantage, services, and other entitlements associated with the diagnosis. Coming from an already stigmatized position, autism represented a clearly positively privilege position because it could be used to gain free time. For

most of my participants, the negative stigma associated with an autism diagnosis was, for various reasons, mitigated by the advantage, both socially, service-wise, and emotionally, that a legitimate, formal diagnosis had. Kirsten's lack of diagnosis meant that she didn't have an explanation for her behavioral outbursts and other atypical behavior, but she still had apparently, authentically, autistic behavior. For her, and Yossi, and countless others, the ability to use the diagnosis to explain their behaviors to others represents a stigma-mitigating move.

However, the difference between legitimate and authentic autism also plays out at the level of biosociality. Sean was new to the group, so Phil asked him to tell the group a little more about himself. He wasn't like the rest of the group, he said. He was diagnosed when he was little. His parents were psychologists. They tried every intervention under the sun. And yet here he was, still autistic. They tried everything to remove the autism from him, as described it, but it didn't work. He was desperate. He wanted to see how those who were "happy about their diagnosis" lived. Sean was legitimately autistic and his behavior rang authentic to the group, but he disassociated himself from the group. He knew in advance that his behavior was autistic, and rebuffed efforts on the part of Phil to normalize his actions. He didn't want to identify with the diagnosis, he wanted it gone, fixed. He wanted to know how those who did identify with the diagnosis lived, but he wasn't ready to do so himself. Sean was the literal poster child for intervention, his gains toted by his school as evidence of their efficacy. Yet here he was, an adult, still weird, still different, still disabled.

For Sean, the continued diagnosis reified the stigma he still experienced. Because the diagnosis had always already coexisted with the stigmatized behaviors, there was no separating the label from the actions that initiated the stigma. Yet Sean lacked a positive identification with autism, despite his authentic and legitimate autistic statuses.

Mary, on the other hand, still in process of becoming formally diagnosed, had only a slow growing awareness of her difference from others outside of the group. Whereas Sean's behavioral differences were made salient to him from a very early age, especially as his odd behaviors were so strictly normalized to societal standards through the use of Applied Behavioral Analysis, Mary was unaware of just how different her behavior was until she developed a sense of self-awareness as an adult. While she had always experienced social isolation, her awareness of her difference was a gradual awakening. One evening, when the group's discussion topic was social differences, Mary began weeping. Peter interrupted the discussion to check in with Mary. Why was she crying?

She recalled a vivid memory from when she was 15, about having a conversation with someone who kept asking why she never looked people in the eyes. Prior to that experience, she explained, she hadn't even been aware that people looked in each other's eyes when speaking to each other. After that conversation, she became painfully aware that she did not do this while other people did, and more, that she could not do this and other people expected it. But even more, she said, was that this conversation, that evening, was the first time she realized that her avoidance of eye contact was related to autism. The twenty-five year gap in awareness of difference, she said, was overwhelming. She mourned for the years where she could have understood why she was so different, that she could have a label and a frame for understanding her difference. She had twenty five years of awareness of stigma, yet no way of explaining it except to internalize her difference as a mark of character. Without recourse to the language of disability, social disabilities are seen as marks of character, poor upbringing, or immaturity, among other lay explanations for autistic behavior. In fact many of my participants reported hearing such accusations against them even after having the diagnosis available as an

explanatory device. If you know you are broken, why not fix yourself, despite the relatively unfixable nature of autism. Awareness of the self, of the problematic self, implies awareness enough to control or fix it, though for autistics this is akin to asking a person with cerebral palsy to control their errant limbs. When an inherent aspect of the disability centers on problematic self-awareness – of awareness of the self in relation to the other, of modulating the self in relation to social norms, of awareness of social norms in relation to the self – the ability to identify with and utilize autism qua autism lessens the stigma of being a problematic self in the world.

### **Queer and Beyond**

As discussed in the previous chapter, models of autism organizing based around neurodiversity require the continued reliance upon the kinds of medical authorities outlined above. The notion of expertise over the self, so long as that self has been legitimately identified as autistic, is deeply connected to this model of neurodiversity, despite the reticence or hesitance to adopt a further identity of neurodiverse. This is not that different from the dominant model of parent organizing around autism, that (neurotypical) parents are experts about their (autistic) children and act out of love towards them (Silverman); in both cases, the autistic cannot be the expert over the self without the legitimizing authority of their doctors or parents. Implicated in this is the denial of full citizenship for autistic adults, discussed at length in chapter five. However I indicated at the end of chapter two that perhaps a viable alternative to both the model of neurodiversity and the medical model of autism was the concept of neuroqueerness.

Queer theory challenges the roles of experts in defining the populations of control. By redefining autism around cognitive performance, understanding the power by which ‘typical’ or

‘normal’ neurology is produced, and refocusing around a politics of affinity, we can reconfigure autism away from the domain of expertise.

Bound into this are issues of other performances, identities, and ethics of answerability. Race is distinctly missing from this analysis as the primary actors were white, and much of this is a reenactment of whiteness. Gender and to a lesser extent, sexuality, will be discussed qua heteronormative and hegemonic masculinity in chapter four, though as I discuss in chapter five this is a problematic configuration and also fails to address non-heteronormative, feminine, and queer genders and sexualities. While parallels can be drawn to the genderqueer movement, autism as queer is only beginning to be formulated.

## Chapter 4

A friend of mine, recently single and on the dating scene, described to me a date she had, in part because discussing one's love life is a normative part of female friendships, but in part, she said, because the man in question openly identified himself as having Asperger's. He was nice, she emphasized, very sweet, earnest even. But he gave her, as she called it, the "heeby jeebies." She couldn't describe the feeling, or even figure out exactly where it came from, but underneath the veneer of sweetness and honesty, she felt something off, something 'dark.' He did not present as particularly macho, but had an almost chivalric approach to dating, such as insisting upon paying for the meal. He was also lacking as a conversationalist, despite clearly wanting to talk.

"I dunno," she concluded, "he was just kinda weird. Gave me the creeps."

In this chapter, I will explore interactional failure, masculinity failure, and the intersections and assemblages that produce the dangerous yet pathetic autistic male. Since my participants were almost exclusively white, much of this should also be read through a lens of white privilege, the social advantages experienced by people generally of European descent. White masculinity is, according to Connell, hegemonic masculinity, the dominant ideal of masculinity which serves as a reference for all other masculinities. As I previously discussed, my few black participants had a double consciousness of race, leading to circumscribed behavior to avoid problematic interactions; my black participants were already marginalized. This analysis suffers from a missing bodies problem, also previously discussed in chapter 1.

While there actually isn't a wide gap between the behaviors of autistic men and autistic women, the behavior is inevitably both socialized differently and interpreted by others in society differently, leading to dramatically different productions and performances. In both cases, neither autistic males nor females inhabit idealized gender spaces. Both fail at masculinity and femininity, consequences of failed gender socialization and failed social interactions. However, the consequences for failing at masculinity seem to be greater for my participants than failing at femininity, as there may be greater latitude in expected performances of femininity than masculinity, an ironic consequence of the privileges of masculinity. Further, while failures of femininity are neither passive nor aggressive, dangerous nor benign, failures of masculinity are read as dangerous even as they are read as pathetic. Hegemonic masculinity is an aggressive masculinity, but one checked and bounded by social norms and hierarchal maintenance. A masculinity that is inept is potentially aggressive without those checks and boundaries, benign or dangerous simultaneously.

According to Connell's (2005) typography of masculinities, there are four different ways of enacting masculinity: hegemonic, subordinated, complicit, and marginalized. While hegemonic is the form of masculinity that is given the most social power, few men enact it. Some men are subordinated (Connell's example is homosexuality) or marginalized (e.g. race); most men have to compromise with women in their daily lives, which Connell calls complicit masculinity. I argue that the way in which autistic men fail at masculinity is by not being complicit, but by attempting to enact a purely hegemonic masculinity and failing. They are not subordinated, per se, especially as so-called geek culture moves to the mainstream of masculine cultures. While twenty years ago, having interest as an adult in things like video games, computer programming, and speculative fiction might have resulted in a subordinated

masculinity, these things have increasingly moved into popular culture. Some say that they've been colonized by consumer capitalism, whereby aspects of geek culture are commodified and sold, thus not requiring the cultural commitments to gaming or speculative fiction that geek culture entails. These kinds of things have a high overlap with autistic realms, though having interests in geek culture does not now mean automatic subordination. This kind of commodification of geekiness has been met with resistance and frustration by many autistics in those cultures. Geek may be mainstream, but autistics are still experiencing social isolation.

The failure is also not quite marginalization. While many of my participants experienced long periods of un/under-employment, had financial problems, and/or were on social welfare programs, their social status was generally not reflective of their class backgrounds. There were many white men who had grown up middle class or above, in strong neighborhoods with good schools. Social reproduction was theirs to be had; the loss of class status was directly tied to their social problems, to their autism, the lack of proper services and supports, and an organic inability to take advantage of their privilege. Those with privileged backgrounds, though, fared better than their less privileged counterparts, so the kind of systemic marginalization that Connell describes does not capture the kind of gendered failures experienced by my participants. My female participants did not experience the wide swings in class discrepancy that some of my male participants did, so while psychiatric problems and disabilities in general are related to loss of class status, it seems particularly gendered in the people I studied.

If autistic culture is no longer a source of subordination, and autism doesn't cause diagnosis-wide marginalization, we must then question exactly what results in the masculine failure. I argue that Connell, despite his otherwise excellent analysis of embodied masculinity, fails to capture the importance of affective exchange, the non-conscious emotional energies of

communication, in negotiating social hierarchies. I will explore this further towards the end of this chapter, after exploring further issues of deviance and sexuality.

### **Autism and Danger**

The trope is familiar. A young man with autism, out in public, alone, behaving strangely, is arrested. The charges range in type and severity, but often include drunk and disorderly conduct, trespassing, resisting arrest and/or assault. A teenager is waiting for his brother outside of a restaurant in Georgia<sup>9</sup>. A twenty-something is shopping for groceries in Texas<sup>10</sup>. Another twenty-something is kicked out of a different grocery store before the police are called and told he is only allowed to return while leashed, launching a petition against grocery chain Whole Foods, the location for both the arrest and leash incidents<sup>11</sup>. Their behavior is read as strange, and indeed, likely violating one or more social norms. The Georgia teen was rocking back and forth. The man in the grocery store was loitering in an employee only area, calming himself down after finding the store to be overstimulating. When confronted about their strange behavior, they were unable to communicate clearly what they were doing, why they were doing it. Instead, they were further stressed by the interactions, and both asked for to contact their relatives. Denied, both were taken to jail, after first using a Taser against the teen in Georgia. In all cases, not just these exemplars but in the multitude of similar cases, violence only occurred when the person in question “resisted” arrest, made some attempt at fleeing, or otherwise was in the midst of a “meltdown,” a heightened state of stress and stimulation that often causes people on the autism spectrum to behave in unpredictable ways.

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<sup>9</sup> Ruberti, 2010

<sup>10</sup> CBSDFW, 2011

<sup>11</sup> Goldman, 2013

And to my participants, this trope was not just another story in the media. Todd, a white man in his 40s from the suburbs, was exchanging jokes with his coworkers when someone decided he had crossed a line; he was subsequently fired and escorted off the premises by a manager and security guards, who told him he was threatening a coworker. Fred, an older white man from a major city, gave a wayward peck on the cheek of a group leader after she was kind to him, which led to him being banned from a fan group. And for some, there was involvement with the criminal justice world, especially as angsty teen behavior combined with communication and socialization problems led to unfortunate encounters with various authorities. Troy and Chris, both white and from the suburbs of New York, were in transitional housing for young adults coming out of the juvenile justice system in their home state. Both had entered the system due to “anti-social” behavior as teens, which included minor crimes (loitering, shoplifting) and small time drug offenses.

And yet, for all of the above, they all were somewhat protected by their status as white men. None suffered the fate of Stephon Watts, an African-American autistic teenager shot to death in his home outside of Chicago for being violent when police came to restrain him. According to Watts’ father, who called the police, Stephon had been experiencing an autism-related sensory overload and he was physically unable to control Stephon’s behavior. The family had previously called the police to control this behavior, as per the suggestion of their disability services case worker, and this time they responded with deadly force<sup>12</sup>. Troy and Chris, my white suburban participants, had been through the juvenile justice system instead of being placed into adult facilities, a fate that is far more likely for a black teen with a record than a white teen.

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<sup>12</sup> Schlickerman and Ford, 2012

At the same time, autistics seem to have the same rate of propensity towards violence as the rest of the general population (Bjørkly, 2009, Woodbury-Smith et al 2006, Newman and Ghaziuddin, 2008), meaning that some are ‘correctly’ read as dangerous; they present a risk of intentional deviance and/or violence. The media speculation that Adam Lanza, the shooter responsible for the deaths of 24 school children in Newtown, CT, was diagnosed with autism, prompted others who had known him to recall him as “creepy” and “obviously troubled.”

There is also the autistic who is inadvertently dangerous, who knows not the boundaries of appropriate social behavior and without intention puts others at risk, who conflates desire with entitlement. The New York City area subway trespasser, Darius McCollum, falls into this category. Despite being black, McCollum’s criminally earnest interest in mass transit has yet to net him long-term incarceration, even after stealing a bus from a Trailways depot, for example, and taking it for a ride in New Jersey. This is perhaps because he is described as very cooperative and obedient to authority when confronted. McCollum loves mass transit and wants to be a transit worker, but he lacks the understanding that there are distinct social pathways to becoming a transit worker, those pathways apply even to him, and that there are real consequences for violating those pathways and other norms<sup>13</sup>. Some of my participants’ behavior in this category of ‘accidental’ dangerous may fall into sexual harassment, like Lee’s lecherous leers in my direction, to be discussed later in this chapter in detail. This behavior results from a conflict of wanting and feeling entitled to something while lacking the self-awareness or incorporated social norms that might stop such behavior before it is enacted. McCollum and my sexually inappropriate participants conflated desire and entitlement. This conflation isn’t limited to autistic men, however; it is a fundamental and problematic aspect of hegemonic masculinity.

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<sup>13</sup> <http://www.nydailynews.com/news/national/imposter-queens-man-busted-29-times-transit-thefts-article-1.1424372>

The very definition of autism rests on failures of social interaction. In all diagnostic criteria, the major thrust of abnormality is the lack of age-appropriate social interaction. What seems to be almost tangential to this diagnosis of failed sociality is the differential diagnostic rates between males and females. While the overall diagnosis rate is currently said to be about 1 in 88 children, the rate for boys is 1 in 54, while for girls it is 1 in 252, a ratio of about five boys to each girl. My research sites did not actually reflect this ratio, averaged over multiple meeting times and locations, though there was definitely a skew towards male-identified or presenting individuals and some occasions that were almost exclusively male.

In the next few sections of this chapter, I rely upon extensive analysis of media reports of ‘bad behavior’ among autistic adults. Despite evidence that the ‘true’ rate of autism is the same among adults as it is currently theorized to be among children (at least in the UK; Brugha, et al, 2011), the story of the autistic adult is most often known through media examples. While most under the age of 35 or so went to school with those classified as on the autism spectrum, my analysis from chapter one shows that few adults over that age would have known someone with autism as a child. Because of the lack of diagnosis of milder signs of autism, the missing bodies generation is unknown to most adults, on the spectrum or off. Surely the reader can identify a person that they know who is socially awkward, perhaps pathologically so, rigid in thought and with exclusive ideations. This person may or may not be on the autism spectrum, but the younger they are the more likely they are diagnosed as such. By not recognizing the autistics among us, the public relies upon media representations, which are naturally biased towards the spectacular. This has problematic implications for my participants, while also providing an analytic foil towards understanding my participants’ status in the larger society.

## **Autism, Violence, Crime**

The academic literature on autism, crime, and violence is generally conclusive that there is no explicit link between having an autism spectrum disorder and propensity towards violence or criminal behavior (Bjørkly, 2009). Studies that suggest a link are generally case studies, and the literature does show that the likely motivations for committing crime or violent acts is substantively different for people on the spectrum than those who are not (Bjørkly, 2009, Woodbury-Smith et al 2006). The literature also suggests that psychiatric comorbidity (Newman and Ghaziuddin, 2008) and/or a degree of pathological attempts at covering (Tantum, 1999) is what distinguishes the subset of those with an ASD who do commit crimes or acts of violence from those with an ASD who do not.

Setting aside, briefly, the idea that comorbid psychiatric problems are likely a causal factor in tendency towards crime or violence, I want to explore the differing motivations for anti-social behavior, as well as Tantum's notion that some may employ a mal-adapted strategy of covering through outrageous behavior. The literature suggests that autistics are often motivated to commit acts of deviance because they feel slighted, offended, or otherwise victimized, often in relation to a sensory or perseverative need, or because of a direct sensory-perseverative need. Tantum suggests that emotional perception might be stunted, leading to some autistics to provocative behavior in order to experience emotional/affective interaction with others, possibly also connected to sensory-perseverative needs. Leaving my research participants, I will analyze two local media reports of men with autism or Asperger's who are in serious conflict with their neighbors for behavior that is sub-criminal and usually not physically violent, but is definite anti-social behavior. I use these two examples because in both cases, the perspective of the autistic person in question is well represented, as is the perspective of the neighbors. I am not drawing on

similar stories relayed by my participants because the other side cannot be clearly understood on the basis of their retelling, though I will connect these media narratives to their stories later in this chapter. While media reports are not necessarily reliable for reporting either side accurately, the lack of autistic authored narrative and presumed lack of personal knowledge of autistic persons again means relying upon the media to construct such narratives. Both of the men in these accounts have comorbid psychiatric diagnoses, of obsessive compulsive disorder for one and post-traumatic stress disorder for the other, but these types of diagnoses are distressingly common among adults with autism, and were certainly present in the alphabet soup many of my participants gave in their introductions, when listing diagnoses by initials or acronyms. While comorbidity seems to increase the chance of committing crime, violence, or anti-social behavior, it is certainly not the only factor nor can we dismiss these stories due to comorbidity. There are deeper issues with these mens' behaviors, as enacted in a social environment.

When Shaker Heights, OH, passed their nuisance laws, the intended targets were absentee landlords with unruly tenants. According to the article on Cleveland.com<sup>14</sup> (website of the Cleveland Plain Dealer), owners of properties can be held liable if the residents of their properties constitute a public nuisance. It was under this statute that Neil and Judi Greenspan were held liable for the numerous calls to the police generated by the behavior of their son, Simon Greenspan, ultimately resulting in \$6500 worth of fines. Simon, who is diagnosed with autism and obsessive compulsive disorder, would often create disturbances outside when his favorite sports teams lost<sup>15</sup>, when he had disagreements with his parents, and when he felt that someone committed some slight against him. His parents argued that he was painfully aware of social rejection, that he was motivated by loneliness, and that he inevitably violated a social

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<sup>14</sup> Krouse, 2011

<sup>15</sup> He was a fan of Cleveland sports teams, so this was a common event

boundary which caused others, less compassionate, to reject him as a friend. When a neighbor refused to grant Simon permission to come into her house, goes an example in the article, in order to fulfill his obsession and perseveration with photographing interiors, he began late-night screaming rants against that neighbor, interrupting her sleep. His parents also argued that available interventions typically made the situation worse, so they coped as best they could and argued for more compassion from neighbors. Most of the slights that Simon perceived involved his desire to cross some social boundary and the neighbor refusing.

The younger Greenspan, in this narrative, perfectly fits the model suggested by the literature (Woodbury-Smith et al, 2006, Schwartz-Watts, 2005), whereby an autistic person acts in response to a sensory-perseverative stimulation with “overkill” (literally, in one case presented by Schwartz-Watts, whereby the defendant emptied a handgun magazine into his victim, then retrieved a second gun and emptied that one as well). Greenspan’s reactions to the loss of his favorite sports teams, for example, includes going outside, pacing around angrily, shouting and screaming. If interrupted in these rants, his father admits that he has become violent, though I argue that his menacing behavior is a kind of violence, at the very least an intrusion into the peace and quiet expected of his affluent suburban neighborhood. As both Greenspan and his parents perceive him entitled to exhibit these displays as coping mechanisms, any attempts at stopping or mitigating these rants become the source material for new offenses, new rants, and in at least one incident relayed by Greenspan’s father, physical violence. When not engaged in these behaviors, Greenspan’s behavior is not outrageous, though it does border on anti-social in his and his parents’ belief in his entitlement to fulfilling his compulsions (e.g. photographing his neighbor’s house).

Thousands of miles away, in Huntington Beach, CA, John Patrick Rogers is banned from filing civil law suits without judicial review, after using such minor lawsuits to harass his neighbors in two different neighborhoods in that city in the past fifteen years. In 2012, he plead no contest to electronic harassment, served a sixty day suspended sentence, and was banned from using Twitter for 3 years. He had previously accumulated 37 restraining orders put forth by various neighbors after he videotaped their children, wrote ‘blasphemous’ posts about them on the internet (including accusations of pedophilia and satanic ritual), and menaced them with his pit bull mix. His offenses were rarely criminal, much to the frustration of his neighbors. Rogers claims that actually, his neighbors are harassing him. He is forever the victim. He videotapes only those who come on to his property, he documents crimes they commit and dares bring forth to light, and they have purposefully made his life more difficult by stealing his dog, keying his car, and so forth. According to articles in the *Orange County Register*, Rogers has a history of this behavior through two different communities, and has frustrated local service providers by not abiding by attempts to normalize his extreme behavior. Rogers is diagnosed with Asperger’s, as well as post-traumatic stress disorder and Tourette’s.

In addition to showing the pattern exhibited by Greenspan, of overkill reactions, Rogers exemplifies the pattern described by Digby Tantum of the the malicious autistic. Tantum argues that these autistics aren’t motivated by malice, and are not acting as a psychopath might, but that their behavior ultimately gets socially classified as malicious because the neurotypical, has few available ways of understand the behavior. Instead, argues Tantum, these kinds of autistics do not have the same kind of inhibitions many autistics have in terms of social interaction. They still fail to understand the nature of social reciprocity, but also have a stunted ability to perceive the reactions of others. The only way they can process the reactions of others to their behavior is to

engage in extreme behaviors, often extreme negative behaviors. In this way, by acting outrageously, malicious autistics cover their own deficits by creating a ruckus and then becoming a victim of social isolation as a result of the consequences of that behavior. Rogers' perseverative documenting of fake offences on the part of his neighbors casts him as the hero in the situation, and the neighbors' reactions as victimizing him. He has a very limited ability to understand the consequences of his behavior, or see how negative it is, because of his hero status. This fits also with the narratives documented by other researchers (e.g., Woodbury-Smith et al), who found that criminal behavior was seen as response to victimization (e.g. using a knife to cut bus seats after the bus was late), though Rogers is clearly an extreme of the pathological covering that Tantum describes.

Given these narratives of motivation for crime, it isn't hard to see the kind of rampage violence attributed to autism spectrum diagnoses in the early winter of 2012. While Adam Lanza's violence remains unexplained, and his diagnoses remain unknown, two weeks before the shootings at Newtown, a young man with Asperger's committed a rampage involving bows and arrows at a college in Wyoming. Christopher Krumm apparently killed his father, his father's girlfriend, and himself, motivated by anger that his father, also diagnosed with Asperger's, had passed on defective genes. In his suicide note, published by the Casper Star-Tribune<sup>16</sup>, he described how, despite his academic accomplishments, he was stymied by issues related to Asperger's, including trouble organizing his thoughts, creating social networks, and performing his job adequately as a result. He chronicled his job losses, moving down the hierarchy of engineering jobs despite his Master's degree from a prestigious engineering school. He extolled the virtue of eugenics and said his father did not deserve to reproduce, as he was a failed person.

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<sup>16</sup> [http://trib.com/news/local/casper/chris-krumm-s-letter/article\\_b1ac0300-1423-5640-88d7-308594ef0a34.html](http://trib.com/news/local/casper/chris-krumm-s-letter/article_b1ac0300-1423-5640-88d7-308594ef0a34.html)

Ever the victim and also ever the hero, with a co-morbid depression diagnosis, Krumm drove from his apartment in Connecticut to Wyoming, and stabbed his father's girlfriend to death before heading to Casper College to shoot his father with a deer hunting bow.

However, in contrast to these sensationalized examples of autistic violence and restitution-seeking acts of criminality, most autistics fall more closely in line with Darius McCollum, the previously mentioned subway aficionado. His behavior is dangerous in that he is not trained to drive buses or operate subway systems, yet he has been discovered doing both. However, while this behavior is criminal and demonstrates my point about entitlement in tension with rule following, when interrupted, he is not violent. He has an intense perseveration regarding mass transit. He generally follows the rules, but feels entitled to act upon his perseverations without social norms.

My participants did not report as extreme behaviors as either Greenspan or Rogers, and certainly none committed serious crimes during my field work of which I am aware, though some did disclose potentially criminal behavior. However, the societal reactions to these various behaviors varied on the basis of gender. When Cindy was much younger, her apparent extreme stalking behavior of a man she wished to be her boyfriend eventually landed her in a psychiatric institution; I will outline this case in detail in the next section. Much more minor incidents on the part of my male participants, however, led to perceptions of danger, and generally exile from a particular social setting (e.g. fired from a job, removed from a fan group, sent to a youth detention facility). Autistics generally do not become violent in response to their perseveration or sensory drives being interrupted or redirected, yet autistic men are perceived as dangerous when their behavior begins to appear deviant and not innocent. I suggest that it is the confluence of hegemonic masculinity and affective deviance that creates the creepy, dangerous, autistic male.

As a note, whenever dealing with masculinity and gender, especially hegemonic masculinity, the implication is heteronormativity and heterosexuality with that formulation of masculinity. Of my approximately 100 male-identified routine<sup>17</sup> participants, only two identified openly as not straight: James was gay and married to a man, and Bill was bisexual, though his most significant relationship was with his ex-wife and he was still active in his step-son's life (his step-son also being on the autism spectrum and a sometimes companion to Bill at the meetings). While there may have been others in the closet, or just not choosing to disclose their sexual orientation in the group meetings (two of which were explicitly on sexuality and dating, where folks were asked to identify their preferences), the clear majority of male participants were straight. That cannot be said about my female participants. While it varied significantly from one meeting to another, with one group of study having only one non-straight female participant out of a half dozen routine female participants, at another meeting, all but one of the eight routine female participants identified as not straight. In a third group, half of six the routine female participants identified as other than straight, though this includes a woman who was avowed asexual.

Also, let me remind the reader of the racial demographics of the group meetings.<sup>18</sup> The majority of my participants appeared to be white. There was only one consistent black male participant in any of the groups, and while there were a handful other black participants that met my looser definition of routine (see the footnote on the previous page), there was only one black woman who met this loose definition. One group was entirely white, except for one Asian man,

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<sup>17</sup> By routine: came to a meeting more than twice in the year; seemed to have previously established relationships with members of the group; expressed familiarity with the group procedures, meeting routines, etc, even if not familiar to me as a participant. Females were more likely to come on a monthly basis, while the male population was more unstable, leading to a per-meeting proportion different than the routine proportion of genders.

<sup>18</sup> I will detail the race and gender breakdowns in the intro chapter

of the two dozen or so routine participants. The groups that met within the bounds of New York City were the most diverse, with racial and ethnic backgrounds that were not necessarily discernible from visual or nomenclature clues alone. I am not going to assume racial or ethnic identities for my participants with ambiguous backgrounds and/or names. However, the ones that I read to be white were in the majority in both groups. While it is possible to be light skinned, blonde haired, with blue eyes and the name Kevin, and yet not be white, I categorize that participant as white because that is how he would be read by the general public lacking full background information. Perhaps identity is less important in this context than how one's racial and ethnic background is read by others, as privilege is often a result of others' actions rather than identity claims.

### **Autism and Normative Interaction**

In order to understand the assemblages of interactional failure and masculinity in autism, we must unpack the ways in which autistics fail at normative interactions. To some degree, this is what has been repeatedly found in the literature: autistics don't understand interaction rituals, fail to take a theory of mind (I will argue against this point, but it is a common theory), have trouble reading social cues, etc. I argue that these interactional failures are in part due to not understanding the interactional ritual. For all of the talk around autistics being good systematizers (which I will discuss later in this chapter), many of my participants reported difficulty in seeing the patterns that underlie much of human interaction, of picking out the important information in a given pattern, and few could see the connections between everyday interaction and the underlying patterns of the whole of human society. While most non-autistics are not natural social scientists, they are relatively easily socialized into the importance of

cultural practices, as well as those practices themselves. However I also argue that a large part of the interactional failure is embodied and affective. Neither the cognitive aspects of interaction nor the embodied and affective aspects of interaction can be separated from the gendered systems through which interaction is produced, but I will first look at these aspects without gender, then add back in a gendered analysis by looking at the social skills self-help group that organized itself around a popular men's dating manual.

Zenia was twenty, a single mom with dark dyed hair, dark eye shadow and dark brown-black lip liner. She often wore tee shirts of metal bands and ripped dark jeans, but generally had a congenial disposition. Despite often laughing and smiling, at least in the group (which she called her respite group from the rest of humanity), Zenia was always ready with a rant, no matter the topic. On the issue of autism and social services, she ranted, angrily, about how her diagnosis was missed until her teens, how she got no services in her public school, how her behavior prompted her parents to pull her out and send her to Catholic schools, which she rebelled against because she was an atheist. On the issue of autism and gender, she ranted about how neurotypical women were shallow, focused on sex and evaluating their lives by their worth to men, how they could not hold intelligent conversation and were backstabbing, how she could not maintain friendships with any women as a result. Her only friends, she explained, were guys, even though one she didn't quite think of as her boyfriend took advantage of her, hence her daughter. Guys were still safer because interacting with them required no emotional energy the way it did with women. But no matter the topic of the group, Zenia often ranted about small talk.

What is up with sports? she asked the group. The topic of the evening was autistic perseveration, not people's specific interests per se, but managing them in a world that had little

tolerance for train spotters, walking Wikipedias, calendar calculators, and other specific, perseverative interests or skills that are markers of autism. Someone else, a male, had mentioned his perseverative interest in sports statistics, though watching was sometimes insufferable. In response to her question, yet another male participant mentioned that guys liked to watch sports and cheer things on to exhibit male bonding. He didn't understand sports, he explained, but thought it might be something like the guys he played online role playing games with. Zenia professed to not understanding cheering on a team, feeling emotional connection to the performance of overpaid professional athletes. The consequences of games didn't have real world consequences outside of the world of that sport, so why did people persist in following it and more importantly, wanting to talk about it? She related an awkward conversation at her workplace, whereby a coworker had inquired if she had seen an important post-season game for a local professional baseball team. "I don't get why people want to watch little figures running around their screens hitting each other, and then worse, talk about it the next day!" her fingers acting out the part of the figures, ramming into each other at random, before being thrown up with exasperation at the thought of Monday-morning quarterbacking. She had a series of why questions: why would I see it? Why would I care about the outcome? Why would I follow this team? But most interesting to me, at least, was her final why question: why do people make small talk?

I had, in other situations, explained various sociological theories of small talk to the group, and this time was no different. I referred back to the other participant's role playing games and his theory of male bonding to talk about social solidarity. I talked about interaction rituals, frame making, interactionist views of social hierarchies through talk. In the context of

speaking about perseverations, my sometimes lengthy discussion of sociology was normal, as I had mentioned it as one of my own perseverative interests.

But most of this was lost on Zenia. The idea that society itself would crumble if people stopped making small talk did little to persuade her of its larger value, and that things like sports teams ultimately signified things like regional affiliations, conspicuous consumption, and celebration of particular forms of gender relations. The idea that conversations were rituals that signified things far beyond their face values was, for the most part, lost on this group of people who so often failed at those conversations, whose disability by definition meant that they spent far more cognitive energy decoding those rituals than most. There were some, however, who got what I said, and who agreed. Joe, a doughy thirty something whose main source of income was doing IT work for pornography websites, brought up Goffman, and that reading Goffman showed him why people do things like make small talk. He still didn't like it, often refused to, would rather talk about porn or computers or comics, but he got that other people thought it was important. In a different venue, Joe and I had spoken extensively about Goffman, in part because Joe and I had similar experiences reading Goffman as college students.

I remember very clearly the first time I read "On Facework," the introductory essay in Erving Goffman's *Interaction Ritual* (1967). It was a badly photocopied version on reserve for decades in my college's library. I had neglected to buy the book after seeing we were only reading excerpts from a single chapter, but reading that chapter, or rather, skimming that chapter in the crunch time before the class meeting, I was awestruck. For the first time, the patterns governing everyday interaction were revealed to me. While other students found the reading pedantic, boring, almost condescending in how conversations were diagrammed, I found it revelatory. Social interaction finally "clicked" in a way that it never had before. Goffman gave

me concrete concepts through which I could organize social interactions and process them in situ. I became an ethnographer of my own life, in order to understand those around me and how to communicate with this otherwise foreign species known as humans.

### **Deconstructing Interaction: Unwritten Rules, The Game, and Goffman**

Well before the advent of my field work, Temple Grandin coauthored a book on social interaction called *Unwritten Rules of Social Relationships* (2005). The book, seemingly aimed towards autistics themselves, purported to reveal to the masses of socially inept folks on the spectrum, ten basic rules of social conduct that were unwritten (in popular literature, perhaps) that seemed to be roadblocks in successful interaction for autistics. Grandin is a popular figure in the mainstream media, yet is controversial within the culture of autism in which I found myself enmeshed. While her early books, particularly *Emergence*, are cited as awakening moments of self-discovery for many of my participants, her later books, whose audience is clearly the popular masses, are disregarded, acknowledged as existing but generally not read or thought about. Her political views regarding interventions and medicalization further alienate her from many in the autism social movement world. Still, her book is purported to be aimed towards the very people I was studying. Yet when picking a social skills manual to study and emulate, the sub-group of participants chose not Grandin's book, but instead the dating manual *The Game*. In part this choice reflects popularity; *The Game* was a bestseller, while *Unwritten Rules* was not. However, there are serious stylistic differences. Both offer advice in the form of narratives: Neil Strauss's experiences learning how to be a pickup artist versus Grandin and coauthor Sean Barron's experiences and thought patterns learning social rules. However, Strauss detailed the applied rules of the game, how exactly to speak to a woman to get her into bed, how to move and

adorn his body to be attractive, and exactly how to develop a personality that is appealing to others and demonstrate it in a way that is not alienating. Grandin and Barron's accounts, on the other hand, are pedantic without being practical. There is little talk of the embodied or affective aspects of interaction, except to speak to the concept of 'emotional relatedness' as a skill that many autistics lack. As Grandin and Barron point out, perspective taking is perhaps the most essential skill in social interaction, but they fail to clearly outline how one might take the other person's perspective (unlike Strauss, who while misogynistic in his aspersions in understanding the female perspective, at least attempts to guide the hapless virgin into understanding that perspective). In classic autistic fashion, they emphasize following certain social rules ("Being Polite is Appropriate in Any Situation" is the title of one chapter, for example) but neglect to relate it to larger social patterns that underlie those rules. The autistic way of thinking, which they document from their personal perspectives of specificity and attention to detail, cannot necessarily connect such cultural frames to larger social systems.

Well before either *The Game* or *Unwritten Rules*, however, Erving Goffman documented the everyday social patterns of ritual interaction and framing. Unlike both *The Game* and *Unwritten Rules*, Goffman connects the specificity of ritual to the larger social patterns that form cultural glue. While many scholars of Goffman focus on the cognitive aspects of his interaction ritual and framing, I wish to bring forward his writing on the body in these analyses. I will use affect studies and Grandin and Barron's autistic perspective on emotional relatedness to understand how the embodied aspects of autism and interaction coalesce into the problems my participants faced in general interactions. While Grandin and Barron argue that there are two aspects of interaction, social functioning and emotional relatedness, and that the goal should be improving social functioning instead of normalizing emotional relatedness, I argue that the two

are not so easily separated, that affect is inherent in social functioning and that the affective disconnect is a prime driver of stigma against those with autism. Further, this combines with gender in ways that make autistic men either benign or dangerous, neither of which is absolute nor true.

Where, exactly, do autistics fail at social interaction? They fail in at least three ways, each of which is highly interconnected and not as easily separated as I will initially make it seem. The first is cognitive: autistics have a limited repertoire of social scripts and frames through which they understand and perform in social interaction. The second is embodied: their bodies are the sites of frame breaking, performance failures, and otherwise unruliness when order is expected if not demanded. The final is affective: in combination with the cognitive and embodied failures, the affective economies generated by autistics are “off” or “weird,” or in the case of particularly men on the spectrum, “creepy” or “dangerous.”

While Grandin describes her method of categorizing and understanding various social situations and relations as pictorial, in general her manner of engaging in social situations is not all that unlike other autistics, even those who are not picture-thinkers. She describes how, for each kind of relationship or situation, she has a picture of how that dynamic is expected to go. From those pictures, she knows how to interact, or at least has some understanding of the situation. For a more verbal or emotional thinker, though, she claims this method does not apply. I disagree, based upon my field work, where my participants all related similar overall cognitive mechanisms for understanding social situations, even if the particulars of using picture memories varied. Jose, who for years sold high-end menswear, memorized particular scripts, facial expressions, body positions, and even faux-emotions in order to interact with his customers. His manner of memorization was not pictorial, but kinesthetic. As he began to demonstrate his script

one evening before the meeting, it was clear the transformation in his being, from nervous and jerky, to smooth and polished. One deviation away from this embodied script, however, and he was thrown. He talked about how he learned how to deal with routine disturbances and how to make small talk while doing his performance, but ultimately he said he would never go back into sales because it took so much energy to manage his performances and learn the scripts. His repertoire was limited, inflexible, and exhausting, much the same as Grandin's.

Similarly, autistics have difficulty with keys and keying. Goffman describes keys as degrees away from the real that are symbolically represented by the action in the situation. Well within his dramaturgical metaphors, Goffman uses theatrical performances as keys of reality, and television as another key, especially as different frames are added. The television show *Batman*, popular at the time Goffman wrote *Frame Analysis* (1974), served as both a key of satire, as well as a key of real events, depending on the frames used to contextualize the show. Keys can also shift within a frame, such as when children's roughhousing turns into actual fisticuffs, down keying from symbolic struggles to physical, actual, struggles. Keys are the gap between the virtual and the real. Still, autistics struggle with keys, especially key shifts. Understanding the symbolic nature of interaction itself was outside of many of my participant's ability, such as Zenia's struggle with sports fandom above. Shifts in what those symbolized were especially problematic, and as I will discuss later, key shifts often played a role in conflicts my participants experienced.

More basically, autistics struggle with the fundamentals of the interaction ritual. Taking the role of the other, negotiating the definition of the situation, and the basic rituals of face work are difficult. Indeed, this failure has been somewhat codified in the autism realm by claiming that autistics lack a "theory of mind" that others' thoughts might differ from their own. It is equally

true, however, that non-autistics lack an autistic theory of mind, and indeed, fail to take the role of the autistic in a given social interaction. Later, I will argue that this isn't just limited to the cognitive aspects of interaction; affective interaction is also non-reciprocal, a failure on both the autistic and non-autistic side. As Grandin points out, emotional relatedness is a widely varied skill and desire among those on the autism spectrum, ranging from non-existent in the normative sense to overwhelmingly intense. Perhaps the intensity of relating and taking the other's perspective effectively shuts down communicative action, suggests Grandin, echoed by Barron in his sections of the book. Neither absence nor abundance is accounted for in normative affective economies. Between the cognitive and the affective is, of course, the body.

The body is constantly present in Goffman's writing on interaction. From the metaphor of the face in impression management to the ways in which bodies embody frames, it is impossible to read through Goffman's work without encountering the body. And yet, the take away of most Goffman scholars emphasizes the cognitive rituals, the knowing the rules, the ways in which socialization is vocalized, presented, managed, maintained. In part, this is because of how Goffman himself writes of the embodied actions he describes. Keen on the physical aspects of interactions, Goffman notes the use of physical touch and proximity to determine deference and demeanor. Vocal inflection and bodily position, for example, are all signs and symbols of the meaning of the interaction. From these signs, one could determine the meaning of interactions. In discussing keys and keying, the nakedness of the female art model embodies the keying process. It is assumed that most actions are deliberate, guided doings, and that unintentional movements in social interaction are breaking frame. Goffman writes, ". . . [I]t is apparent that the human body is one of those things that can disrupt the organization of activity and break the frame. . . ." but goes on to describe how those performing a deception ". . . need not become improperly

involved emotionally but merely act so as to discredit the cognitive assumptions of the scene that is being sustained.” Frames are not just meaning, they are also involvement (Goffman’s term for emotional relatedness, perhaps affect), but in the end it is the cognitive perception of the situation that is disrupted or maintained. As Goffman writes:

Given that the frame applied to an activity is expected to enable us to come to terms with all events in that activity (informing and regulating many of them), it is understandable that the unmanageable might occur, an occurrence which cannot be effectively ignored and to which the frame cannot be applied, with resulting bewilderment and chagrin on the part of the participants. In brief, a break can occur in the applicability of the frame, a break in its governance. (P. 347)

Frames are cognitive lenses; bodies can break those frames, as “one sees that the human body... can fail to sustain the frame in which it finds itself.” (p. 349) The body, at once an instrument of face and the self, is also potentially outside of the self. The body itself can break frame, regardless of the self embodied within.

In discussing facial expressions, Goffman describes the delicate nature of frame breaking. Facial expressions can be fleeting and subject to myriad external, non-social forces. Goffman uses the example of a gust of wind as a non-social environmental condition that might alter one’s facial expression, calling such expressions and their interpretation “labile.” (p. 349) Similarly, I argue that this can be extended to most bodily positionings and movements; so long as they are within possibility for a given frame, slight changes in movements or positions will not alter the overall framing. Goffman goes on, however, to describe two instances where one’s bodily expressions might excuse an actor from a frame. One is a temporary retreat or excusable retreat, such as a speaker taking a drink of water (p. 349), but the other, the one with which we (and

Goffman) are most concerned, is what Goffman terms the ‘flooding out.’ Floods occur when a person is overcome with an affective response that is embodied: overwhelming laughter, uncontrollable rage, etc. This occurs when the frame is broken, when an actor is unable to sustain the frame, or when the actor has been using an incorrect frame and that is no longer sustainable. These delineations are minor for the autistic, who I argue has a fundamental difficulty with socially negotiated frames to begin with, a limited repertoire of perfected frames, difficulty applying one frame to another, and a frustrating difficulty with the exact labiality Goffman suggests is requisite for framing. They also refer back to the centrality of cognition in Goffman’s framework, which also fails to account for the autistic, whose body is much less subject to the kind of socialization and control of the non-autistic.

However, two points about flooding are apt for my participants. Goffman writes “it is interesting that flooding often occurs when an individual must accept restraints on bodily behavior over an appreciable portion of his body...” (p. 353) While Goffman is specifically referring to holding still for a tailor or portrait artist and the like, those with dyspraxic bodies might find these kinds of controls in routine interaction. Many autistics have physical actions that are self-stimulatory or perseverative. To not engage in these behaviors, to willfully restrain them, is difficult, and may lead to a flood out in the negative sense. Indeed, in Goffman’s examples, he notes the use of humor and laughter to ritually maintain face, the flood outs being a somewhat routine if not acceptable break of frame, and routine movements to return to frame, such as covering one’s face in embarrassment. Fidgeting is a good example of a physical behavior in which many of my participants engaged. Careful observation of the room in any given meeting showed people engaging in various activities, ranging from the barely noticeable playing with clothing to the obvious, such as one participant who routinely juggled, rollerbladed,

or played with a small medicine ball during meetings and group activities. In daily life, that last participant generally restrained himself, but for times of stress or duress, he carried a stress ball to squeeze as an alternative. In the autistic space of the group, he engaged in those behaviors otherwise unacceptable in any frame. Like Goffman's examples who find their acting performance challenged in certain situations, this participant felt he was acting every time he was out of his house in a non-autistic space. This was an experience common among my participants.

The second point about flooding out that is useful for understanding my participants is one Goffman makes, writing ". . . [I]t should be apparent that when an individual discovers that he has misframed events and is lodged into cognition and action on false assumptions, he is quite likely to flood out, breaking from the unsupportable frame he had been sustaining." Because of the general difficulty many of my participants had negotiating and understand frame, this kind of flood was sadly common. This applied particularly to complex situations, though banal, routine social situations were also often difficult for them. Indeed, many of my case vignettes in this chapter are examples of exactly this: the autistic definition of the situation, the autistic frame, misaligns with the general accepted definition of the situation, with the normal frames, and the autistic breaks their frame, the other frame, and floods.

Goffman emphasizes in all instances of flooding the ritualistic nature of covering the flood and attempts to restore the original frame, if applicable. However, he does not indicate that the flood itself is indicative of anything; flood, in and of itself, is not symbolic, but rather a failure of the symbolic. While floods have come to signify breaks in frames, and fall from breaks in frames, and are thus socially produced, they are rather akin to a natural sign of the body's discomfort with the social environment. Goffman notes that flooding appears to be a cross-cultural phenomenon, though the rituals associated with rectifying the situation vary. So while

Goffman's emphasis on the socio-cognitive aspects of flooding may not directly apply to my participants, the concept of flooding, especially the two forms described above, is very relevant.

What Goffman writes around, then, is the central role in the socialization and sociability of the body in ritual action. The presence of bodies requires a labiality in interpreting social frames simply because the degree of socialization is much more limited than so talk or other aspects of the interaction ritual that are, in fact, purely symbolic. The body can break frames, react to frames in unexpected ways, and in the case of my autistic participants, remain in the unsocialized domain. Dyspraxia, a developmental disorder related to dyslexia and other learning disabilities, is a common comorbid condition on the autism spectrum. Awkward gait and clumsiness are two of many reported physical signs of autism. Motor development is often off, sometimes 'backwards' (from fine to gross, instead of gross to fine), likely a result of the biological or neurological roots of autism.

The autistic body is an unruly body. While physical or embodied aspects of autism are not part of the diagnostic criteria, there is strong evidence of the disorder extending out from the mind and social to the physical and embodied. Dyspraxia, the diagnosis of clumsiness, is often comorbid with autism spectrum disorders, but also found in subclinical levels among those diagnosed with just autism (cite here). This study found that children with autism could recognize gestures, but had difficulty executing an imitation – this disconnect between brain and body that is called dyspraxia. The dyspraxic body is one that is not fully under control of the willful mind. The mind's gestures are not fully realized, the soul's presence in space is unbounded, and the affective corporeality escapes embodiment.

Sean, a moderator-in-training for one of the groups I studied, embodies a typical autistic guy's walk. In a still photo, Sean would pass for handsome, almost Fabio-like, in part because of

his long blonde hair, in part because his devotion to martial arts has resulted in a chiseled muscular body. But despite his mastery of two different kinds of martial arts, and thus his apparent skill at controlling and executing moves with his body, his walk is... autistic. His arms are held straight and stiff down the sides of his torso, his head is cocked slightly to the left, his eyes mostly trained on the ground in front of him. His shoulders are squared and his gait is stiff, as if he is doing as little bending in his joints as possible to pull off the walking motion. There is nothing smooth in his movement. His posture while standing and holding a conversation is similarly awkward to observe. He leans slightly on one leg, while his hands and arms do a circuit around his torso, first shoved deep into his front pockets, then shoved deeply into his back pockets, then crossed straight across his chest, then one hand running through his hair while the other hangs alone in the air. It is as if his arms are not controlled by him directly, and they don't know where to hang out while the rest of Sean engages in interaction.

Sean's arm crossing is also very autistic. In my observational research, those not on the autism spectrum cross their arms such that their hands are on the insides of their elbows or between their upper arms and torso, towards the armpit. Autistics tend to cross them across their chests in such a manner that they are gripping the outside of the opposite elbows. Because the manner and presence of arm crossing varies cross culturally, this behavior is most likely learned. The imprecise copying of arm crossing signifies a socialization failure on the part of the autistic body, the fracturing of mimicry that is essential to the depths of embodied socialization. This is likely related to the gendered way in which resting one's hands in one's pockets is learned and observed: the masculine way is to hook one's thumbs into one's front pockets, while the feminine way reverses this, putting fingers into back pockets or resting on the waist. Masculine folks rest their hands on their waist with their fingers forward; feminine folks with their fingers

backwards<sup>19</sup>. This behavior is, indeed, symbolic, as the masculine pose indicates aggression, hands at the ready to fight, while the feminine is more vulnerable, exposing weak joints.

Autistics, meanwhile, make a circuit with their hands, unsure of where they might land, where might be most comfortable or appropriate, where the sensory desires are met.

Lisa Blackman (2013) describes the notion of the self through the body as a recent development, with two countering concepts in sociology: the body as performative, and the body as habituated. The first she describes as surface and appearance while the second is depth and personality. These are not either or states, but simultaneous and in “dialogic relationships” (p. 49). Further, she argues, there is an excess, “a kind of incorporeal aura which is co-present but not in a direct or obvious way.” (p. 50). She suggests that through hindsight and analysis, we can identify codes or markers that belie this aura, but that this excess or remainder is the affective body. Thus the excess habitus, the excess face, which is co-present but neither habituated nor managed, is embodied affect. Affect, defined simply as the capacity to affect and be affected (a definition which Blackman seeks to complicate, but which will work at this moment) is a key aspect of the social disruption that has come to be defined as autism. Certainly the excess bodily motions that are clearly outside of impression management, outside of the frame, are but one aspect of this affective disregulation.

## **The Game**

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<sup>19</sup> Rekers, Amaro-Plotkin, and Low. 1977. P 277. Rekers, along with Barlow, is famous for developing scales of appropriate gender-based behavior, mannerisms, and posturing. Hands on hips and hands in pockets are both aspects to be measured on the Barlow Gender-Specific Motor Behavior form, an instrument used up until recently (and perhaps still) in determining gender-identity disorder among children (with great controversy, of course). Arms crossing is, as well, but both genders cross arms with hands above the elbow; there is no research around hands held to the elbows.

Prior to reading Goffman, I sensed that I was missing significant aspects of social interaction, but lacked a framework through which I could interpret others' behavior. While Goffman gave me that framework, I often felt like a character on *Star Trek*, observing another species and attempting to understand their society. This sentiment, of feeling alien, is quite common to the autistic experience. A popular social network website for adults on the spectrum is called *Wrong Planet*; Oliver Sacks used Temple Grandin's description of being like "an anthropologist on Mars..." as the title of his best-selling book. Yet most of my participants did not report having a revelatory experience; most remained baffled and confused by routine interaction, remained feeling alien, without a framework for understanding social interaction. This is why Andrew's presentation to one of my groups regarding a new way to teach social interaction skills to autistics caught my attention. His revelatory reading on social interaction was a far cry from my own rather academic experience. His entrée into the world of the rules of social interaction came from Neil Strauss's book on pick up artists, called *The Game*.

In *The Game*, Strauss, a self-described virginal geek, unattractive, bookish, and socially awkward, enters the supposedly secret society of international pick up artists, men who can flirt with and eventually have sex with almost any woman they want. These men have made an art of the one-night stand by reducing social interactions with women to a set of rules and a scientific study of successful scores. The process of becoming a pick up artist is, to some degree, an exercise in applied sociology. These men break down social interactions into patterns, record their own behavior to study later on to improve chances of success, experiment with different breaches of social norms to see which ones work, and change their presentations in order to figure out which presentations are successful. They create a new face, which often includes a new pseudonym (or sometimes multiple pseudonyms), and experiment with that face. They put

into practice the kinds of facework which Goffman so carefully documented over the course of his career. While some of these men are “naturals” and came to the art of picking up women through their own charisma and self-awareness, most are like Strauss and start off their careers as socially awkward virgins who need the rules in order to become successfully masculine. These men learn to perform Connells’ hegemonic masculinity. This performance goes beyond linguistic, and involves specific ways of moving and being in the world. The men alter their appearances, practice body movements and skills such as magic in order to improve their embodied performances of “smoothness,” and even alter their voices and intonation in order to engage women. These are core areas of interaction, and by extension, hegemonic masculinity, in which autistic men often fail, a point I will later explicate.

Andrew wasn’t drawn to *The Game* in order to score with women, though he admitted that might be a tangential benefit to a close study of the book. Instead, he found in its pages a guide to successful social interaction of any stripe. He had asked Phil for a longer than usual bulletin board time in order to pitch his idea. As he described then, and elaborated later in his email correspondence, he had a very different idea about the problems autistics had with social skills and a very different idea about how adults with autism should go about learning social skills. Instead of intuitively learning the rules, he claimed, autistics needed explicit instructions. We’re good with rules and numbers, he argued, and therefore needed those things when it came to everyday interactions.

Lay validation of my research hypothesis (autistics do best with explicit cognitive frameworks, not just on what rules exist, but how to derive them) doesn’t come often, so I signed up for the project Andrew proposed, as a co-investigator, not participant. His project involved two rounds. The first round would be a select group of people who together would read *The*

*Game*, parse out the specific rules, and enact them in their lives. Feedback would be given and a larger group would move on to round two, where more autistics would learn from the first group, and the cycle of peer-to-peer alternative social skills acquisition would grow. The project eventually faltered before reaching round two, but it was not without success. Many participants reported self-growth and increased social confidence. The group was small, though, with fewer than eight participants, all male. All read the book, and via Andrew's website, discussed the rules outlined therein. Andrew also produced a series of videos discussing the book and demonstrating techniques (though always solo). Face to face physical interaction is where the group faltered, thus never giving feedback the way the group leaders in *The Game* did, an aspect of the project I attributed to aspects of the autistic personality.

Imitating pick up artists in order to have normal interactions is an interesting idea. First we must analyze what they do, through an analysis of the book itself. Then I will trace the complex relationship between autism and masculinity, including narratives of neurology, before returning back to my participants to understand why they are creepy. Pick up artists, while representing a form of hegemonic masculinity, are seen as creepy. There is something about being too hegemonic, too aggressive, but failing at the goals such a display, that seems to result in the label of creep.

### **Deconstructing *The Game***

Pick up artists utilize one of several popular methods, all of which are riffs on popular social-psychological theories. Some of them are explicit; Strauss notes that the biggest rival PUA to the one from which he learned the game is a man named Ross Jeffries, a disciple of applied neuro-linguistic programming. This method, NLP or Speed Seduction, relies on the theory that

subtle linguistic and behavioral clues can alter a person's psychological status, such as in hypnosis. In a brief account of a conversation Strauss had with a follower of Jeffries, the PUA, called Grimble in the book, describes how NLP works:

[Grimble:] "How much technology do you use in your sarges?"

[Strauss:] "Technology?"

"You know, how much is technique and how much is just talking?"

"I guess fifty-fifty," I said.

"I'm up to 90 percent."

"What?"

"Yeah, I use a canned opener, then I elicit her values and find out her trance words. And then I go into one of the secret patterns. Do you know the October Man sequence?" (pg 39)

NLP is explicitly a technology of manipulation, utilizing code words and sequences to pattern interaction. While NLP as a therapeutic practice has been generally discredited due to lack of scientific evidence, it remains popular among the pop psychologists and self-help gurus; Strauss points to Anthony Robbins as a popular motivational speaker who employs NLP in his programs. Still, NLP appears to use some basic framing techniques and interaction rituals to manipulate the unsuspecting female actor into being seduced by the male actor. As Goffman describes, the person who is in control of the framing of a situation is the one whose mental frames ultimately direct the action within the frame; he uses the example of the liar, who can perform an expected role within a frame while hiding the truth behind the frame from the other participants. The liar's affective and symbolic control dictates the course of interaction. PUAs are akin to these liars. Their definition of the situation is different than the female participants. While yes, nearly all of those at a given heterosexual bar might be there to interact and potentially have sexual encounters with members of the opposite sex, the pick-up artist is more efficient and directed

then most others in the bar. His behavior is deviant in motivation and strategy, a deviance often labeled as creepy if it is noticed.

Framed this way, there are not substantive sociological distinctions between NLP/Speed Seduction and the methods employed by Strauss's mentors in *The Game*. Told in a clear, narrative form, with plenty of examples and model dialogues, *The Game* outlines not just the cognitive strategies of picking up women, but also the accompanying body language and affective strategies. The masters of these methods, those who lead the workshops that Strauss attends, are, as he describes one such leader, "social deconstructionist[s]":

...what he lacked in coolness and grace, he made up for in analysis...he could watch a human interaction and break it down to the physical, verbal, social, and psychological components that powered it." (pg. 234)

Later, when interviewing Tom Cruise, Strauss has the opportunity to observe Scientologist training sessions for followers who are preparing to recruit from the general public through e-readings and the like. He notes that "what they were rehearsing... was a form of pickup. Without a rigid structure, rehearsed routines, and troubleshooting tactics, there would be no recruitment... I began to think that perhaps routines weren't training wheels after all; they were the bike..." (pg 248) Pick up artists are lay social scientists, carefully observing and deconstructing social behavior in order to create frames that manipulate the other participants into their desired behavior: sleeping with them. This includes carefully manipulating the affective economy of the interaction, through selectively devaluing ("negging") or complimenting the target, as well as the physical aspects of that, like turning one's body in a particular direction, specific kinds of movements and touches, and bodily adornments.

And like true social scientists, they also have theories as to motivations. While these tend to be reductionist and shallow, they reveal the nature of pick up artists as gendered and essentialist. As skilled as they are regarding observing behavior, they have an innate bias towards

confirming their suspicions, especially regarding women. For example, Mystery, Strauss's main mentor, "... recently developed another theory of social interaction. It basically stated that women are constantly judging a man's value in order to determine if it can help them with their life objectives of survival and replication... just as most men are attracted in a Pavlovian manner to anything that is thin, had blonde hair, and possesses large breasts, women tend to respond to status and social proof." (pg 252) This theory of human behavior, while popular in the media, is not supported by cross-cultural data, and in fact is representative of a form of patriarchy that is situated and specific. While multiple theories of motivation are presented in the book, ultimately all objectify and essentialize gender roles for both men and women. Women are variously depicted as lonely, immature, in need of guidance or dominance, or on the edge of being sluts. ASD, in *The Game*, is not autism spectrum disorder, but anti-slut defense, moves that women make to avoid being labeled as sluts by themselves or others (pg 439 is the clearest definition). The trick is to take advantage of either the denigrated status of women or potential for denigrated status and use it to make them feel as if they aren't denigrated; this positive status can then be used to begin a sexual relationship.

As Strauss eventually points out, seducing women and seeing them as targets eventually inculcates a kind of misogyny (pg 350). However, this is unsurprising as what *The Game* discusses is hegemonic masculinity. Unlike compromised masculinity, the masculinity of *The Game* is in control. Men may be beaten back by attractive women who do not give them the time of day, but by acquiring a hegemonic masculinity, these men can retake what is rightfully theirs by virtue of being men: the sexuality of women. AFCs, average frustrated chumps, have a complicit masculinity: they wish to attract and have relationships with women, but do not know how to do so while still respecting women. They see women as equals, if not more powerful in

the gendered interactions of sexuality, and are therefore stymied in their quest to have sex or establish a relationship. Meanwhile, AMOGs, alpha males of a group, who exhibit hegemonic masculinity ‘naturally,’ win over the women and disrupt the games that the pick-up artists, who lack a certain intrinsic quality of masculinity, play in order to front the requisite masculinity needed to succeed. AFCs find women intimidating whereas both the AMOGs and the PUAs do not and instead see access to women’s bodies and sexualities as a given right of masculinity. The strategies and technologies employed by the PUAs involve a great deal of asserting hegemonic masculinity, such as “negging” or verbally diminishing a woman, which paradoxically creates interest in the PUA on the part of the woman. A man boldly asserting hegemonic masculinity without a sense of irony seems to be an intrinsic part of these strategies. Negging is only shades away from the examples of denigrating women that Connell (2005) lists as examples of how masculine folks, as part of a privileged group, assert and maintain that privilege. Cutting down is also a strategy that the PUAs use in competition with each other or AMOGs in order to win a score.

Asserting hegemonic masculinity, for the PUAs, is a tool or technology of attraction, yet when a man fails, he is creepy. As Strauss notes, on pg 234, when an AMOG reveals a PUA to be playing tricks with women, he is revealed as a creep. Some men, in Strauss’s system come by hegemony naturally, while others must front it and are at risk of being creeps. A dynamic missing from Connell’s otherwise erudite analysis of masculinity, this aspect of the creep is important to note for my male participants. Men who are complicit or marginalized are not inherently creepy, but men who ineptly assert hegemonic masculinity combined with normative sexuality are. This is an important point to make, as my participants generally were white and heterosexual, and thus were often asserting an inept heteronormative hegemonic masculinity.

Indeed, my participants were, in some respects, hyper-hegemonic. Hyper-masculine is not a new descriptor for those on the autism spectrum, however. The theories of Extreme Male Brain put forth by British psychiatrist Simon Baron-Cohen (e.g. Baron-Cohen, 2009) are exactly this, but posit the origins of this hyper-masculinity in the neurology of autism itself, not in the complex cultural practices and ideologies that produce patriarchal systems.

### **Autism and the Gendered Brain**

To those familiar with the critiques of the neuroscience of gender difference, or the gender differences of neurology, the premise of Simon Baron-Cohen's 2003 book *The Essential Difference : The Truth About the Male and Female Brain* is what Cordelia Fine calls 'neurosexist'. In short, Baron-Cohen argues that not only are male and female brains essentially different, but that autistic brains are extremely male brains. Male brains purportedly are better at certain tasks, such as logical thinking and spatial reasoning ('systematizing'), while female brains are better at communicative and emotive tasks ('empathizing'). As Baron-Cohen summarizes on the first page of the book, "The female brain is predominantly hard-wired for empathy. The male brain is predominantly hard-wired for understanding and building systems." Despite evidence that these are socially engendered tasks, and that with socialization and practice, brains sexed both male and female can do equally well at the given tasks, Baron-Cohen insists that the autistic brain exhibits the male brain to the extreme, lacking utterly the skills of the female brain and excelling at the skills of the male brain. He uses this theory to explain sex disparities in autism diagnosis as well as various diagnostic features of autism itself. Baron-Cohen attempts to connect his extreme male brain theory of autism (EMB) to current moves in

neurology, psychology, and evolutionary psychology. In a 2009 article, Baron-Cohen states that regions of the brain that are smaller than males than females, and visa versa, areas that are larger in males than females, correlate to areas that are similarly disproportionately small or large in the autistic population. The statistical game engaged in here, that the autistic samples are disproportionately male while the study reference groups are not, is ignored in face of evidence of support. Joseph Dumit's book, *Picturing Personhood* (2004), deftly critiques the kinds of statistical games utilized in brain scan research that give rise to the kinds of conclusions Baron-Cohen utilizes in his work. Further, evidence of neuroplasticity influencing brain region activity and size is also ignored or dismissed, despite evidence that environmental conditions, including mere socialization and practice, can literally change the size or activity of different regions in the brain. Baron-Cohen further suggests that autism might be related to fetal testosterone exposure, which can cause hypermasculinization of primary sex characteristics, and has been theorized to cause masculinization of the brain. For a thorough debunking of this branch of neurology, I refer readers to Rebecca Jordan-Young's 2011 book on the subject, *Brainstorms*. While she only briefly mentions Baron-Cohen and his EMB model, she deconstructs the kinds of research Baron-Cohen employs in his narrative.

We can logically deconstruct his model here, briefly, by questioning the logic of fetal testosterone exposure. If fetal testosterone exposure masculinizes the brain, and per Baron-Cohen's EMB theory of autism this increases the likelihood of autism, then females with congenital adrenal hyperplasia, a condition which produces an excess of androgens and is one of the main causes of ambiguous genitalia in chromosomally XX babies, would experience a higher rate of autism diagnosis. There is little evidence of this in the academic literature; all studies on this topic were actually conducted by Baron-Cohen himself. In one study, Baron-Cohen

compared parent-reported prevalence of secondary masculinization effects in girls with autism spectrum disorders to girls without. He found that those with ASDs had higher rates of things like acne and “tomboyishness” as well as queer sexualities than girls without. He also found that their mothers also had higher rates of these characteristics than the other mothers. In another study, he looked at autism rates among those diagnosed with CAH. Genetic females with CAH had slightly elevated scores on a standard autism quotient compared to genetic females without CAH, but it should be noted that none met the clinical threshold for diagnosis. To bolster this claim, we look at Jordan-Young’s research and find that other supposed evidence of masculinization of the brain have also not been found in CAH XX babies (some of which are assigned male at birth, depending on the extent of the masculinization of their genitals). In a 2012 article that updates the research in her book, she continued to find that many of the factors associated with masculinization effects in genetic females with CAH had better explanations in social and environmental factors, such as expectations of masculine behavior, intensive medical surveillance and surgery, and the experience of living in a substantively atypical body. Some of the masculinization effects documented by Baron-Cohen can similarly have other genetic and social explanations.

There are also alternative neurological explanations for autistic difference. For example, there is evidence that increased brain size in autistic people is due in part because of an overabundance of connections between synapses, a sort of hyper-functionality, which lends support to the “intense world” theory of autism proposed by the Markrams (2010). This theory suggests that instead of social deficits, autistic people actually experience the social world too intensely for them to process it efficiently, leading to the social ineptitude that is a hallmark of autism. This also supports both Bogdishina’s (2010) and Tantam’s (2009) models for

understanding cognitive-perceptual differences of autism. Finally, this also meshes well with qualitative accounts of autism, including my own, such as descriptions of social experiences as being too intense and of perseverations as a way of modulating sensory experience.

Despite the fact that Baron-Cohen's science is tenuous, the content of his theory points to a configuration of autism, gender roles, and behavior that is worthy of brief analysis. Using his 2009 article, which ties autistic behavior and the EMB model with an emerging theory of personality around different nodes of systematizing and empathizing, we can see how what he is actually describing is hegemonic masculinity, and that further, the hypermasculinized, hyper-systemitizing, autistic is the hyper-hegemonic yet inept masculinity I argue characterizes many of my male participants.

As Connell writes, "a familiar theme in patriarchal ideology is that men are rational while women are emotional... hegemonic masculinity establishes its hegemony partly by its claim to embody the power of reason, and thus represent the interests of the whole society..." (pg 164). Rationality is a component of systematizing, thus the entire dichotomy of systematizing versus empathizing seems to be a knowledge produced by patriarchy rather than scientific evidence. Further, autistic systematizing can be seen as hyper-rational, rationality to the point of irrational adherence to rules, procedures, and routines. Thus in this component, autistic rationality is hyper-hegemonic.

I want to make clear that I am not against the idea of autistics being strong systematizers. Indeed, the way in which Baron-Cohen himself presents systematizing is rather sympathetic to the autistic experience and one which places the autistic as being in control of his or her own knowledge and sensory needs. However, this framework cannot be uncoupled from the gendered lens through which scientific knowledge is created. Autistics are systematizers, masculinity is

constructed around systematizing, regardless of individual aptitudes, and therefore, argues Baron-Cohen, autistics possess an extreme male brain. In a way, that is true, but truth in this game only because a priori to the definition of autism, masculinity was already given the domain of systematizing and rationality. Understood in this way, the logical fallacy of Baron-Cohen's theory of extreme male brain is clear. The neuroscience of gender is just not that simple or linear and the neuroscience of autism is just not that settled. What we have are overlapping social constructions, interpretations, and performances, potentially with bases in neurological processes. Even then the linearity is not established, in part due to brain plasticity.

### **Defining the Creep**

In order to understand what behaviors are perceived as creepy I first want to understand what behaviors are understood as dangerous, particularly gendered and sexualized behaviors. In sexual assault/rape prevention education, women are typically explicitly taught the signs of danger in men. Rozee and Koss (2001) assembled the main signs women are taught in these curricula in their study to evaluate the effectiveness of sexual assault prevention programs. These were grouped under four categories, sexual entitlement, power and control, hostility and anger, and acceptance of interpersonal violence, and include specific behaviors ranging from sexually inappropriate talk to escalating non-violent situations into violence<sup>20</sup>.

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<sup>20</sup> From Rozee and Koss (2001) p. 299:

1. Sexual entitlement: touching women with no regard for their wishes, sexualizing relationships that are not sexual, inappropriately intimate conversation, sexual jokes at inappropriate times or places, or commenting on women's bodies, preference for impersonal as opposed to emotionally bonded relationship context for sexuality, and endorsement of the sexual double standard.
2. Power and control: high in dominance and low in nurturance, interrupting women, being a poor loser, overcompetitiveness, using intimidating body language, rigid traditional notions of gender roles, and game playing.
3. Hostility and anger: quick temper, blaming others when things go wrong, and transforming other emotions into anger.
4. Acceptance of interpersonal violence: using threats in displays of anger, using violence in borderline situations, and approving of and justifying violence.

Unsurprisingly, these signs align with what Connell describes as aspects of hegemonic masculinity, and furthermore, are even strategies employed by the pick-up artists in *The Game*. Except for overt violence, which Connell includes as a product and strategy of hegemonic masculinity but which Strauss claims PUAs avoid, the signs listed are degrees away from the behaviors described in *The Game* as effective methods to seduce women. These behaviors include touching women against their wishes, acting over competitive, interrupting women, and quick to escalate emotions, either hostile or sexual. These are also behaviors I will show that my male participants exhibited with women. The difference between my participants and the successful PUAs and others is degree of skill, aptitude in social situations, which my participants utterly lacked, as well as being read as having sexuality. Ineptitude, such as being revealed to be playing a game or not responding to definitive negative responses or signals, is a sign of danger, a reason to label the person in question as a creep. For some of my participants, who were seen as asexual and thus benign, it was the acquisition of sexuality that caused the creep label. Inept masculinity is not necessarily dangerous if it is lacking sexuality, but the presence of sexuality creates the danger.

Paul is the epitome of creep in my fieldwork. His voice was high pitched, his manner almost delicate in how he tried to control the otherwise disjointed movements of his hands and torso. He had a tic of clearing his throat, often, and a habit of leaning in towards whomever he was speaking with. When discussing employment one evening, participants were asked to describe their ideal jobs. The facilitator encouraged the group to think beyond what he called Wal-Mart jobs. What jobs fit our skill sets? Our dreams? That were potentially obtainable even if there was a small barrier (training, a degree, etc) between us and that dream? Paul's ideal job was being a greeter at the charity shop in which he was already employed, because, as he put it,

he would “get to talk to the ladies.” In his current position, running stock, he rarely interacted with customers, and this was apparently deliberate. He had once been a greeter, and was demoted after he took “too much time talking to the ladies”. Ladies. The word was drawn out, lilted, and accompanied by a hand motion and wrist flip, as if he was gently holding someone’s hand in his palm. Female customers had complained about his inordinate attention to them and him following them around the store. In essence, he was demoted for being creepy. His sexuality burst at the seams (once, literally, during a discussion of sexuality and relationships) and his excitement at the mere thought of interaction with women was creepy, even to those in the room who were otherwise oblivious to inappropriate behavior. Though tall, Paul was not physically imposing, so while creepy he was not seen as dangerous enough to fire from the shop completely, just to minimize his contact with customers. Most of my participants, however, were not quite as obvious as Paul. Fred was benign until definitive moments of becoming a creep. Lee’s attempts at conversation were creepy with sexual desperation that led to sexual harassment. Kevin’s creepiness became dangerous with misogynistic rage. And Cindy shows how, despite having much more egregious deviant behavior when it came to sexuality, women on the spectrum are not seen as creepy or dangerous, per se, and do not suffer from the same potential consequences.

### **Fred**

Fred was a regular for years at this particular meeting. And at every meeting, he requested bulletin board time, the special time at the end of meetings for general interest announcements. Fred’s announcements were rarely of general interest; instead, he used his bulletin board time to update the group on the status of his relationships with women, his success at meeting them and tabs on how they were progressing. This inappropriate use of bulletin board

time, per the group rules, was allowed as it was actually a long-time compromise between Fred and the group leader. Prior to the compromise, Fred would often attempt to update the group during introductions, or if the topic of conversation was even vaguely related to something related to Fred's romantic successes and failures, he would derail the group conversation to talk about his issues. During my year of field work, Fred chronicled his use of MeetUp.com to find like-minded people, especially women, and the demise of a relationship with one woman, Diana<sup>21</sup>, and the kindling of a relationship with another woman, Emily. Both women he met through different MeetUp groups whose defined interests overlap with stereotypical autistic interests, namely board games and sci-fi movies.

When Fred spoke generally about MeetUp groups, he talked about how welcoming they were of autistics, that a lot of people in the groups were also socially awkward and liked the groups to meet people. They had pre-defined topics of conversation or group activity, which eliminated a lot of the awkwardness autistics might feel in meeting people, though Fred's exact words were not as articulate. Fred, generally, was not articulate, in verbal or embodied communication. In his mid to late 50s, overweight, and balding, Fred only recently started living on his own. Previously he had lived with his now deceased parents and had some degree of supportive services. He had some degree of intellectual disability as well as an autism diagnosis, but the social results of these dual diagnoses were unclear. His social inhibitions and ineptitude could be a result of the ID or the autism, but in combination it made him come off as a kind of gentle giant. His manner of speaking was almost childish, painfully earnest and honest, but lacking in self-awareness and reflexivity.

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<sup>21</sup> These names are also pseudonyms

The narrative arc of Fred's relationships with Diana and Emily took the entire field work year. At the beginning of my field work, Fred was still reeling from the loss of Diana, which apparently had occurred about three months before (while I had attended this particular group prior to commencing my research, I had only attended intermittently and missed the build-up of the Diana story). In listening to Fred's story, it was clear that his feelings for Diana were unrequited and that he quite obviously read intimacy in their relationship that was not mutual. He had met her at a MeetUp for fans of sci-fi movies. This meant that the group would get together to see a current movie at a local theater or, if there was a dearth of movies in theater, they would get together at the organizer's house to watch an older sci-fi film. Diana, one of the organizers, had apparently been very kind to Fred, who in turn interpreted this as a potential romantic interest. As he explained it, few women were kind to him, so there must be a meaning to her kindness. This motif of kindness conflated with interest repeats itself, not just with Fred's later infatuation with Emily, but in many stories related by men and women on the autism spectrum when discussing romantic relationships.

Fred and Diana had made a fair amount of small talk after the meet ups, though it seemed from his description that these chats were in a group context to discuss the movie they had just seen. He said that she was interested in what he had to say, so he became interested in her. He had started to act on this, at first by specifically saying good bye to her when leaving the meet ups, and later, giving her hugs when leaving. Leaving the theater one evening, he said he leaned over and gave her a peck on the cheek, to which she apparently smiled but did not give him a peck back. The next meeting, he explained, was at her house, where they watched a classic sci-fi film. Afterwards, he lingered, and was among the last to leave. Again when saying good bye, he hugged her, and leaned in for a kiss, this time aiming more towards her lips. As he explained it,

in the multiple times he repeated this story for the group, she violently pushed him away and told him he was inappropriate, pushed him out of her house and banned him from the meet up. He couldn't understand this behavior, and it took at four months of repeating this story for the group for him to fully process that maybe she wasn't interested in him after all.

His descriptions were plaintive and pleading. He longed to understand what went wrong, what mistake he had made. It took months of processing the final incident in the group to understand that he probably had been wrong about her romantic interest in him, even though this had been suggested to him on multiple occasions. So as his narrative about Emily began, the group felt some obligation to give him a reality check, asking him to verify why he thought she was interested in him.

This time the group met up to play board games, and rotated among various organizers' houses. Emily, like Diana, engaged in small talk with Fred during and after the meet-ups. Emily also seemed to look after Fred in the meetings, as the activity was more diffuse. While sometimes there were only a handful of participants, and they all played the same game, often there were a larger number of participants or multiple gaming options. Emily often invited Fred to play wherever she was playing, ensuring he had a place at the table. Fred interpreted this as her having interest in him. She tells me to sit with her, he said, she has conversations with me. In Fred's perspective, there was only one explanation for this, and it was in alignment with hegemonic masculine interpretations of female behavior: kindness as an invitation for sexuality, talk as a proxy for interest in a relationship, the gaze always already sexualized. Others in the group reacted differently. One participant suggested, after one such Emily update, that maybe she thought Fred was 'retarded' and felt bad for him and took him under her wing. He rejected this possible explanation, exclaiming that she could not think that about him as she engaged him

in conversations and therefore knew he was not “really retarded,” though she knew about his autism diagnosis.

Indeed, Fred seemed resentful at the suggestion that he was somehow fundamentally different from any other guy. Of course he had sexual feelings, and of course women might find him sexually interesting. In movies, he said, when women want me they are nice to them, otherwise they are cold. Just like in his life, Fred explained, most women are cold to him. Therefore Emily must be interested because she wasn't. She was warm and kind and let him put his arm around her shoulders, and she put her arm on his back. But he only ever stood next to her to do this. And he only ever gave her a very brief, light hug to say good bye. He was taking it very slowly this time around; he didn't want to miss the signs he had clearly missed with Diana. His next goal was to hold Emily's hand, and after that, to have a conversation to make it official that they were dating (though they never hung out except for the MeetUp group).

By the end of my fieldwork year, Fred had still not advanced to hand-holding or the dating conversation (the arm around the shoulder developed two months before the end of the research period), but felt confident enough in his relationship with Emily to give dating and relationship advice to others. His advice was broad and basic, to take things slow, don't presume, find someone with similar interests, but the irony of Fred offering advice was not lost on at least some members of the group. Kevin, who I will talk about more extensively later in this chapter, was particularly hostile to Fred's advice, through his own framework of misogyny. Others passively-aggressively questioned Fred's credibility with dating advice; during the second-to-last meeting I attended as a researcher, one young man asked him how his relationship was going after Fred offered advice. Defensive, Fred explained that he was still developing his relationship with Emily, that yes it was mutual and he knew because of her kindness and allowing him to

touch her, and he was building confidence to talk to her about officially dating, and he was following his own advice to move slowly and be patient. His voice was plaintive and child-like; there was no alternate framing for what he was experiencing, nor could he possibly see it from Emily's perspective, even if she was interested in him. He could not even reframe his own behavior, to understand how it might be interpreted as anything but sexual interest or how he might be read as more disabled than he was.

Fred's difficulty with framing fits the descriptions earlier in this chapter regarding autistic difficulty with framing and affect. Sexual signaling is very much an affective exchange as it is a verbal or symbolic exchange, but certain frames exclude or presume this kind of affective signaling. Fred's framing always already presumed sexual interest with any sort of act of kindness and excluded the possibility of rejection. It was clear that with Diana she either failed to read his signals properly or her own framing excluded the possibility of sexuality in that context. My own read of Fred's general behavior and affect, however, leads me to conclude that he inappropriately frames interactions with women around sexuality, and that his behavior is the kind of behavior that gets stigmatized as asexual: naïve, childish, earnest. His affective resonance, too, was unlike Paul's mentioned above, who burst with erotic affect. While Fred was certainly capable of sexuality, his overall presentation of self generally excluded the possibility of sexuality prior to him enacting it. While affect generally indicates capacity, Fred's affect did not, the hallmark of affective exchange dysfunction that I argue is more important to the autism diagnosis and experience than anything overt or cognitive. To act sexual towards his romantic interests was within his framing, but broke frame for others, especially the women in question. Fred was seen as benign and asexual, a large teddy bear, safely retarded. When he frankly

inappropriately sexualized his relationships, he became understood as dangerous and was removed from these situations.

### **Lee**

Lee was in his late 50s, with a shock of red hair muted by gray, thick aviator glasses, and an obese body that seemed to curl in on itself – shoulders hunched forward, hands crossed, leaning forward in his seat, knees crossed. Closed off and fidgety was his usual body language, except when a young woman, including or perhaps especially, me, was near. Then he would turn his body, lean on the next chair towards the woman, separate his hands, and speak in a low, almost furtive, tone. He would attempt to initiate conversation at inopportune times: during group discussions, introductions, bulletin board time. Until I explicitly told him to stop, he would occasionally touch my shoulder or hold my hand longer than was comfortable after shaking hands hello. While to the group he explained the downfall of his relationship as a function of growing older and growing apart (he was in the process of divorcing from his wife), to me he explained that it was in part due to sexual dysfunction on his part, but really it was his wife you see, who was old and unattractive. He included explicit, inappropriate, detail.

I often drove to this particular meeting, and Lee lived vaguely on my way. He had difficulty with his car, with affording gas and maintenance, and he was petrified of public transit, though there was good public transit between his house and the meeting location. He periodically requested to the group that if anyone drove to the meetings, he would appreciate a ride, glancing at me all the while. I had told him no the first time he asked me directly, but instead of accepting this, he changed his tactic, asking the group facilitator to be a proxy and asking the group in general.

At the very first group meeting I attended for this particular group, I of course participated in the routine introductions. At that time, I disclosed that I was living with my fiancée. My presentation of self was similar to as it is currently; masculine of center, gender non-normative, with short cropped hair, primarily men's clothing, and wearing a silver (now white gold) band around my left ring finger. After that disclosure, while the group was still doing introductions, Lee turned to me.

“So you're not married?” He asked.

“Not yet,” I replied, “one month to go.”

“I don't think you should settle.”

I responded with a polite but confused smile. I had no idea what this man was saying, could not even remember his name, was trying to focus on the rest of the introductions and take notes. He turned away when I didn't respond verbally.

After that meeting, he began with the questions. Tell me, he begged, about your fiancée, and issued a litany of questions, all of which used masculine pronouns.

“Well,” I began, “the correct pronoun is hir because [my fiancé] is trans.”

“So is [your fiancé] a boy or a girl?” interrupted Lee.

“Uhh, not really your business, but female bodied; I consider myself a lesbian.”

“But you'd do a guy because [your fiancé] is really male?”

“That is really not your business.”

I walked away from that conversation, but it didn't stop. At the next meeting Lee again interrogated my fiancée's sex and gender, my sexual orientation, my openness to sexual relationships with men. At first, I decided that he simply didn't understand trans\* or queer identities, and tried to explain it on a simple level. Few members of this particular group were

well versed in queer theory much less vanilla gay issues, so I became accustomed to answering the direct questions. My fiancé was assigned female at birth, but doesn't identify with either gender or with a sexed body. We're monogamous so it doesn't matter. We're married (because that did happen between the first and second meetings of this group). By the third meeting, when he yet again asked me to explain it again, I told him that the internet existed for a reason and he could google things that he was confused about. He avoided me the next meeting, but by the fifth meeting he was back with more questions, more revelations about his life, apologetic that he was intrusive before while asking me exactly how my spouse and I had sex within the same conversation. While at first he had looked vaguely at my face during conversations, he began to focus if not fixate on my chest. He also began touching me inappropriately, insisting upon shaking hands when we greeted each other then enveloping his hands around mine and letting the handshake linger until I pulled away. He would move seats to sit near me, even long after a meeting had began, working his way up to putting his hand on my shoulder when initiating conversation. Those conversations were rarely at appropriate times; cross-talk was discouraged, but yet he tried to engage me during other people's speaking turns.

Lee knew I was married. He had been told that I was not attracted to cisgender men. My gender presentation was neither normative nor feminine, and while perhaps he found that attractive, most straight men interpret it to be a signal that I am not interested. Even after directly telling Lee that I was not interested in hanging out with him outside of the group, that I could not give him rides, that I did not want to speak on the phone with him, and that he was being inappropriate, I finally had to basically lie to get him to stop touching me. I told him that I did not like it when he touched me the way he did because my autism made it feel painful to be touched by other people, so please stop. Telling him I didn't like it when he touched me because

it made me feel uncomfortable and as if he was flirting with me had not worked. He could not relate to it. He said he understood the autism thing, we all had our individual sensory issues, and so he stopped resting his hand on my shoulder. But that did not stop him from trying to sit next to me, or leaning over me, or whispering how much he missed having sex. I figured out where to sit to minimize the chance of him sitting near me, which was not optimal seating for observations or note-taking, but he was far too intrusive to just continue to let be. He did not, could not, see his behavior as inappropriate, from the simple breaking of the no cross-talk rule to the complicated attempts at flirtation driven by what I sense to be deep loneliness and despair over the break-up of his marriage. He did not intend to cause me discomfort, but he could not understand, even after being told, that he was causing me discomfort until I insinuated it was an autistic thing, not a sexuality thing.

While Lee's behavior was towards the extreme end, it was degrees away from the behavior exhibited by other men in the groups. Women were more common than the ratios usually make them out to be on the autism spectrum, but they still constituted only about a third of my participants. One participant, Ryan, joked that new women were "fresh meat." Regarding his friend John's girlfriend, a woman on the spectrum named Joanna, Ryan stated that she was like "an Aspie bicycle going around the [group name] track," a clumsy interpretation of the anti-woman slur to refer to a woman who has a lot of sex as a bicycle, because she "gets around" and "gets ridden hard." However, Ryan and most other men understood when a woman said no, that they were not to pursue a relationship. Ryan himself, when finding out I was getting married to a person he considered to be a woman (I gave up on correcting for this), he said "double no, ok, got it, you're out of the running." Elizabeth, another woman in the group who identified as bi, was also a "no" because as Ryan said, "I only date girls who only want to date me," revealing

some stigma against bisexuality but at the same time showing that he clearly respected certain boundaries, including those around sexual orientation. Other men were less clear cut, but still at least kept their distance. To Lee, Paul, Fred, sexual orientation didn't matter, the sexuality or desires of the woman in question didn't matter. Though none of them were violent, their behavior matched up to the specific behaviors mentioned as being danger signals, and their affective resonance was creepy.

### **Cindy**

The topic of the group was technically dating and sexual relationships, and usually the facilitator had the various groups he led divide by gender in order to discuss it. However, there were only three women in attendance, and since two identified as queer, it was voted to be a co-ed discussion. Cindy was the lone straight woman. In her 60s and dressed to match her idealized hippie youth, Cindy had the aura of a crazy cat lady or eccentric aunt, with excess makeup, wild clothes, and a gaunt face. There were aspects of her behavior that also seemed rather immature and naïve, and this was especially apparent in the discussion of sexuality and relationships. She had a few boyfriends over the years, but most ended up dumping her. One such man, back in the 1970s or 80s (she was unsure of exactly when this was), was her passion, her soul mate. After a single date, he stopped returning her phone calls, but she pursued him none the less.

The facilitator, Jim, was making a list of appropriate and inappropriate dating activities. How does one appropriately show interest in someone, he queried the group, and what are some inappropriate behaviors? For the list of inappropriate behaviors, someone suggested stalking. Cindy objected. What is so wrong with stalking? She asked. If you are interested in someone but they are ignoring you, how else can you get their attention?

Jim stuck to his guns and repeated that stalking was never an acceptable behavior, that it made the other person feel scared and intimidated. Cindy, too, repeated herself, and asked how else a person could demonstrate continued interest in a person. Why call it pursue if you don't actually pursue?

Jim asked Cindy to expand on her story. Maybe it wasn't stalking, he suggested, but a borderline behavior that was misinterpreted. That was a common problem, he explained to the group, for a lot of autistics who get accused of stalking when they overstepped any boundaries, even if wasn't full on intentional stalking.

No, Cindy explained. She had actually been arrested and charged with stalking. She was found incompetent to stand trial, however, and had been committed to a mental hospital for a few months instead of jail. She had shown up to his house at random times and all hours. She called him an upwards of 50 times a day. She sent him incessant love notes. She really was stalking him, deliberately even, because she rationalized it was the only way to keep on his radar. She worried that the moment she left him alone, he would forget about her, or not think of her as often as she thought of him. He was her perseveration, and since we had just talked the last month about our special interests, what was so wrong with having another person as your special interest? He wasn't harmed by her stalking, she didn't bring him any danger or physical discomfort. He screened his phone calls before she started obsessively calling him, so what was the difference? Eventually, she was arrested after trespassing on his property and charged with stalking. She was peeping through his windows when caught.

Cindy was unable to see how her behavior affected her target. Much like the autistic style of deviance I described earlier in this chapter, she had a perseveration and felt entitled to fulfill it. She was unable to fathom the consequences of her behavior on others, the kind of inadvertent

danger of Darius McCollum, though her behavior was targeted towards a specific individual instead of the object-oriented behavior more common among autistics. Like Fred, she was unable to formulate how appropriate sexual relationships developed. The consequences of Cindy's actions seem out of step with her behavior, however. She was not mentally ill and she vaguely knew that stalking was wrong, just justifiably so. But instead of being held accountable for her actions, or punished, she was given psychiatric treatment and then released without prejudice. She had a restraining order in place against her, at least after she was released, and she still generally avoids the town in which she was arrested, but she technically does not have a criminal past. Male participants of mine had similar treatment over far less consequential behavior, and surely men who did what Cindy did were not present in my groups of study, likely because they may have become involved with the criminal justice system or were in some other form of care. Cindy may, in fact, have presented a real danger to her perseverative love interest, and after revealing this story, was told directly by Jim that her behavior was creepy and inappropriate.

And yet, Cindy, not being masculine presenting or identified, is not read as dangerous. She was ill, in need of help, and acting inappropriately, but not dangerous. She had, as most of my participants had as well, internalized many aspects of hegemonic masculinity as the normative rules of cross-gendered sexual relationships, but her ineptitude was centered on her gender (generally regarded as feminine) and therefore was understood as pathological, but not scary.

My participants' ineptitude at deploying hegemonic masculinity centers around framing and affect. While there is a rich sociology of affect and emotions that extends from the symbolic interactionist tradition, I seek to extend this further to understand that non-symbolic interaction is similarly socialized, and that while emotions are the meanings given to particular states of being,

that much of affect is a preconscious kindling, a resonance, deeply social and essential to meaning making but outside of the realm of traditional symbolic interaction. This is hinted, for example, in the realm of social cognition, in theories such as affect control theory (Rogers et al 2013), whereby emotional meaning making is embedded in cultural and social systems and constitutes a significant aspect of the definition of the situation, but neglects the body as the location of affective exchange. While the psychological version of difficulties in framing, namely, the concept of the theory of mind as being lacking in the autistic, or in the neuroscience literature around mirror neuron differences between autistic and non-autistic brains, are well researched, affect and the body is generally disregarded, with one notable exception I will discuss later. First, however, I turn to the spontaneous, field-driven, participatory action research project to which I was an invited observer, namely, correcting the ineptitude through a close study of Neil Strauss' *The Game*.

### **Learning *The Game***

As I previously discussed, Andrew, a participant in one of the groups I studied, proposed the formation of a small group to do a close text read of *The Game*, creating a group much like the group in the book itself. The PUAs in the book form collectives, which gave feedback on techniques, went out in groups to hit on women, and helped to perfect the science and art of picking up women. Andrew, of course, thought better sexual outcomes were secondary. Really, he said, it was an opportunity to learn basic social skills. By understanding what social information was important (including embodiment), members of the group could reflect back to each other what they were doing, right or wrong, and how they might improve their performance.

Our first task in the group was to acquire the book and read the first few sections, with Andrew's suggestion of ignoring the 'plot' and just studying the behavioral aspects, especially

the feedback from other PUAs and the way in which Strauss became more confident and ‘smooth.’ He made sure to emphasize how each PUA used some gimmick, like magic, to demonstrate social worthiness, and that our autistic perseverations could, with more skill, be used in a similar fashion. He also emphasized that while many neurotypicals interacted for the sake of interaction, many autistics interacted to derive some other need, like necessary information, or to fulfill the drive of a perseveration. In order to get to those kinds of interactions, we needed to learn the neurotypical game, and then manipulate them for our needs, just like PUAs.

About a week later, Andrew sent a link to a private YouTube video in which he demonstrated an approach. Narrating his movements along the way, Andrew looks into the eyes of the imaginary person he is approaching. Shake hands with your right hand, he says, but make contact with their upper arm with your left. Not too hard. Remember the eyes. Engage the eyes before the hands. You can immediately look away if you draw their attention to something. Stand to the side to avoid eyes after the initial approach. Confidence is key. Practice is key. Have an opening line. Hi I’m Andrew isn’t good enough. Compliment. But not too personal. Swagger.

Repeatedly, Andrew comes in to the imaginary person for a greeting. He starts off haltingly, but improves his smoothness as the video goes on. It is clear, however, that the entire thing is staged – he has already practiced this many times before the camera was rolling. He never looks directly at the camera, focusing on the imaginary space of the person he is greeting. Even then, he narrates how he is able to immediately distract the person away from lack of eye contact, once a certain level of contact has been established. His body is oriented towards the imaginary, not the audience, even as he describes to us what he is doing. Dominate the conversation, but focus it on the other person. Have a trick. Flatter. Impress. Smooth your body.

Smooth. He ends the video instructing others to make and post their own videos of themselves working on their greeting, such that other members might critique their style, a la the group of PUAs we are to emulate. No one does.

Emails were exchanged, however, and the tone was generally revelatory, almost celebratory. Just as my own revelation had occurred while reading Goffman, these men were amazed to discover that interaction had some sort of underlying rules. That beyond learning the psychology of neurotypicals, of personality types and how to interact with them for one's own ends, there was a way of holding oneself in public. *The Game* never reaches Goffman's level of abstraction regarding social rules and interactions; Goffman's style of analysis is useful cross-culturally, while it is doubtful that *The Game* would hold up even within American culture as being accurate, but it is still a level of social abstraction that simply had never occurred to the participants. "It always seemed so random," said one, "but apparently it isn't."

There is a deep irony in this situation. *The Game* is fundamentally the story of emotionally stunted (by the author's own admission) men, who are so disconnected that they must objectify women in order to front a connection, perhaps resulting in a physical connection and then perhaps an emotional one. The PUAs were always on guard for forming deep relationships; it was looked down upon, mocked, avoided, until for many of them, the draw of a stable emotional connection results in them leaving the lifestyle, or in the case of one of Strauss' mentors, suffering a mental breakdown. The story here, in my fieldwork, is of socially stunted, affectively stunted, men, who in order to form any social bonds, must learn to objectify all people in order to decode the rules of interaction. What is revealed, in both narratives, is the sociological 'truth': that we act towards others as if they are objects, towards ourselves as an object of manipulation, and there are rules of engagements and limits on objectification. Yet this

particular form of objectification is based upon a hegemonic masculinity, one that has a strict gender hierarchy and that while enabling participants to develop social capabilities and perhaps ultimately an emotional and affective connection to others, generally inculcates misogyny. As Strauss writes, being a PUA eventually results in many developing a hatred of women (pg 350). The narrow allowance for autonomy of the objects of a PUA's attention, and the actual autonomy of real living women, generally did not mesh in such a way that allowed the PUAs to see women as people. I wondered for these participants if greater social capacities would result in a similar anti-social attitude.

### **Sporting Bodies**

So far, this chapter raises as many if not more questions as it addresses. Some of these questions are a result of the scope of study. I cannot, could not, study every aspect of my participants' lives, and gender is an especially complex phenomenon that intersects and assembles in myriad ways. Gendered differences between my participants might be explained by some yet undescribed neurological or other biological basis, but due to the inherent instability in the category of autistic itself, I propose that the answer is less bio than it is social, a production of the two that cannot be decoupled from the social. Girls and boys are socialized differently. Even just reading the Grandin and Barron book, when each in turn describes their childhoods, the differences in treatment of each by gender are obvious. While Grandin explains this difference variously as a difference in time span or a difference in autism style or a difference even in privilege and location, gender is overlooked. However, there is larger evidence that girls are more policed when it comes to normative behavior, whereas "boys will be boys" excuses many from learning the subtlety of social interaction. Girls are expected to be inward and quiet, to wait to be approached instead of doing the approaching, so the drawing inward that Grandin

describes in the book and elsewhere is a consequence of the gender-based socialization towards norms. The consequences for women who are quiet and awkward are far less than the consequences for men, whom are often labeled as creepy if not dangerous in their ineptitude. However, attributing the differences to socialization is speculative. My focus is not on cause, on effect, on being not on origin. My participants lived in a highly gendered realm where some were marked and others not.

For the male participants, who were overwhelmingly white and straight, this degree of internalized ideal of hegemonic masculinity with an inability to code switch and variously be complicit and hegemonic, interacted with an embodiment that belied any cognitive efforts at interaction and generated an affective economy which contributed to their maligned pathos. This embodiment generally prevented acquisition of a hegemonic masculinity, a point hinted at but not fully explicated earlier in this chapter. To be clear, my [white, male, straight] participants did not seek to be “alpha males” as those who embodied hegemonic masculinity were described in *The Game*, but had none the less integrated the ideology of hegemony in their daily relations, especially in terms of entitlement and privilege. Some even decried the hegemony, because of the embodied aspects of hegemony at which they often failed spectacularly. Sports, for example, were a source of deep division between hegemony and autistic culture.

Mark was a rare breed: unlike most of the young men who came to the groups, he was very into sports. His perseverations involved things like parkour, a sport in which participants treat everyday objects as obstacle courses to be navigated with acrobatic displays. A fall from a parkour stunt, he said, explained the thumb to shoulder cast on his right arm. Bored and unable to engage his favored ‘extreme’ sports, and even having difficulty with the video game versions due to his immobile right thumb, he sought out this group to finally tackle an aspect of his

identity that had haunted him since diagnosis in middle school: Asperger's. He had friends, he said, but not close ones, and he related to them mostly through their shared sport. They hadn't been to visit since his accident.

Despite the facilitator's experiences in sports, his obsessive love of baseball and clumsy attempts at playing as a kid, no one else related to Mark's love of sports. His love of parkour and other extreme sports prompted a short discussion of sports, and few other men in the group had participated in sports or found enjoyment in them. One said he liked to track sports statistics, but couldn't actually stand to watch them much less play them. The topic of sports was a common one across my field sites, and in general, the attitude towards sports by many autistic men was a lack of interest and a lack of understanding. Two reasons often cited in describing why they were not interested in sports were lack of physical coordination, which very early on turned them off of participation in sports, and lack of interest in the social side of sports.

The lack of ability (or perhaps resistance?) for the autistic body to be disciplined and socialized to sufficient normative convention plays an important role in the rejection of sport. Chris was in his late 30s, had held down the same part-time job for 17 years, and lived in the mother-in-law suite above his parents' garage. Years before, he had been obese, he explained, but had undertaken a routine of self-improvement when he decided the true barrier between him and a dating life was his weight. With everything else out of control, he gained control over his appetite and began working out. He still could not master his perseverations or his obsessive-compulsive related compulsions to pick at his skin (he often wore bandages to cover or prevent wounds on his fingers), but he could attempt to get fit. At the gym, he had one session with a personal trainer, whom he described as well-meaning but a meathead. He could not fathom devoting ones entire life to bodily discipline, and while on a quest to fix what he saw as his

broken body, he found sustained membership in the gym unbearable. He couldn't master the movements to lift weights properly or run at a consistent speed on the treadmill. He felt judged for his bodily fails at the gym, so he quit and began just walking laps at the local school. He had lost over 75 pounds, he claimed, but the experience at the gym reified his hatred of sports. His body could not be directed towards the purposeful movement of sports and by extension, could not understand the devotion of enthusiasts. And yet, each person was responsible for the condition of their bodies. Despite not mastering his own on multiple levels, a person's weight and appearance were their responsibility for upkeep. Hegemony was fully internalized: he had a keen sense of governmentality over the body but could not discipline his own unruly body. This ties in exactly with Connell's concept of body-reflexive practices, the physical practices of maintaining a masculine body, or a body as a masculine body, which form and inform embodied experiences of masculinity. As Connell (2005) describes them, the systems that produce and are produced by such practices are "far from coherent. Indeed, [the systems] contain substantial contradictions..." (pg 64) Part of the compromise between hegemonic and complicit masculinity is the contradictions of body-reflexive practices and the production of the masculine body. The ineptitude to navigate these contradictions, the inability to discipline the body, and yet, accepting if not enforcing aspects of the practices, all contribute to the messy assemblage of the autistic masculine person.

**Fin**

The autistic body, the dyspraxic body, resists the enclosure of the self in the body, the notion that the body can be disciplined into symbolic form of the self. The non-symbolic interaction of kinesthetics produces an affective exchange. And the confluence of masculinity, hegemony, and ineptitude, produces a sense of danger. The aggression of masculinity cannot be properly located within the symbolic social, it is dismissed and when introduced, becomes creepy. Or it is present in abundance, an inappropriate and thus potentially dangerous abundance. The challenge of the pickup artist is to convey masculine desire and domination without being too overt, too dominant, too aggressive, to play with those tropes and manipulate the object of desire into acquiescing to those desires. To be any of those things (overt, dominant, aggressive), or inept at manipulating them, reveals the PUA to be a creep. The men in my population were like many neurotypical men, and not overly masculine, not even desiring to be skilled pickup artists, but unlike most men (one can assume) they were inept and often inappropriately abundant with the aspects of masculinity coded as creepy.

I leave the reader with two cases from my fieldwork. Both of these men I read to be creepy, good examples of the creep figure. Kevin seethed with misogynistic, masculinist rage. Alex did not. Both had complex, dependent relationships with their mothers. Kevin and Alex were both accompanied to meetings by their mothers, and while Kevin had moved out of his mother's house, it was to a house that she had purchased for him, near her own house. Alex still lived at home. Alex only attended one meeting, didn't say much, didn't interact much before or after the meeting, and was reticent to say anything at all, even when asked directly. Kevin, on the other hand, was quite a regular, even without his mother, and when she was not there, was an active participant, ranting and raving. The particular moment of Kevin's creepiness was when he told a woman who had just disclosed being the victim of sexual assault that rape didn't really

exist. He claimed empathy, that she surely regretted it, but it probably wasn't rape, she was just saying that to make herself feel better about probably being a slut. Kevin's affect leaked from his overweight, unkempt, body. He radiated rage all around him, alienated those with whom he engaged, claimed all of the trappings of hegemonic masculinity with none of the practices. Alex, on the other hand, closed himself off, hunched over in a winter coat, encapsulating his body, foreclosing on alienation by foreclosing on any interchange. He was affectively flat, and as a result, he was avoided. Kevin was abundant; Alex was absent. Kevin is, in all practice, innocuous, not dangerous; he has yet to commit any sort of criminal offense, despite his personal offenses. Alex went on to commit a particularly heinous crime, the details of which reveal too much about his actual identity, which I am bound to protect. There is nothing inherent to their autisms that create an absolute risk of danger. There is, however, a social perception of danger that results from the combination of disordered affective exchanges, contradictory masculinities, and the unruly autistic body.

## Chapter 5

As documented throughout this dissertation, my autistic participants experienced problems directly related to the construction of autistic personhood. On the one hand, their lives are deeply problematized/are made problematic by the non-autistic hegemony, casting autistics as financial, social, and emotional burdens to society. Unable to author even that which distinguishes the autistic from the non, autistics create notions of expertise that still ultimately rely upon the hegemonic culture of medicine to form the basis of legitimacy. Advocating for new language around autism, current autistic activism is unable to break out of the rhetoric of diversity and equality, despite the lack of resonance with many of my participants dealing with far more mundane problems of daily living and not relating to the notion of equality out of difference, only the problematic aspects of difference. Included in these problematic aspects include issues of basic communication that goes unrecognized by those in authority, namely the affective exchanges of autism that are different from typical. As a consequence, attempts at deploying hegemonic masculinity are read as always potentially dangerous for my male participants.

The final problematic aspect of subjectivity for my participants is citizenship. Defined in the literature in two distinct ways, as the status of a subject in relation to the state and as the status of a subject in relation to participation in civil society, autistics ultimately suffer from a lack of citizenship in both arenas, denied entry into the full benefits of state citizenship while increasingly called upon to define themselves in relation to their autism as a medical category of management. By collapsing these two distinct categories and revisiting the issues discussed in previous chapters, we can see how the figure of the autistic subject is threatening to traditional

notions of citizenship as well as newer conceptions of biomedical citizenship, which reifies the transfer of authority from the state to other forms of capitalized power structures. There is a productive power of alternative understandings of reason and biosociality that is potentially within autism, without risking the fetishism of autistic difference, an assemblage of autism that challenges the ways in which we know citizenship.

### **State Citizenship**

The premise of citizenship, according to British social theorist TH Marshall, is that unto each citizen are rights guaranteed by the state, and in exchange, responsibilities of the citizen towards the state, namely productive labor and reproduction itself. Rights are always exchanged with demands for responsibilities, and vice versa. Marshall (1973), describing the rise of the socialized health care system in the United Kingdom immediately after the Second World War, explained that with the development of the National Health Service, Britons were now expected to maintain their health. While other rights and responsibility pairs were less explicit, Marshall maintains that it is this reciprocal relationship between state and citizen that undergirds the modern welfare state. Besides health, the citizen engages in productive labor, participates in civil society, and reproduces himself. While the United States is hardly the welfare state of the United Kingdom, this principle of reciprocity between state and citizen can still be seen here. Increasing regulation and requirements for health insurance have moved the United States towards universal health care, albeit in a capitalist, not British style social democracy, fashion. We have a moderate system of unemployment benefits, a voluntary military with moderate veteran benefits, and a somewhat robust civil sphere (though, as is happening in the United Kingdom, the civil sphere is on the decline in terms of participation).

Against, then, the figure of the citizen as productive worker and active civilian, are the beneficiaries of the welfare state, those who are essential to the citizen but who are excluded from full citizenship. Priestly (2000) argues that the development of British welfare policy is structured around four stages of the life course, all in relation to the normative ideal life course of heterosexual white man: childhood, motherhood, disability, and old age. Of these three, the presumption is that children are unable to be contributing members of the workforce, while mothers are excused from the workforce in order to provide for their children and presumably their spouses who are members of the workforce, or perhaps displaced out of the workforce due to acquired disability or death. Older adults are, following Marshall's scheme, reaping the rewards of a productive life course as a worker. This leaves the (already) disabled, which Priestly argues is a marginal category, always in the position of taking, without the time limitation or contributions of childhood and motherhood, and without the previous contributions of the elderly. The original legitimate disability claims were those who became disabled, who aged into disability (though, he points out, the elderly are rarely thought of as disabled, but merely old). He points to continued discrimination against those with disabilities and the individualization of disability policy as evidence of the marginalization of those who enter adulthood with disabilities. I will return to the question of legitimacy of claims later in this chapter, with reference to my earlier discussion of legitimate identity claims.

The parallels to US policy are not direct. For one, our anti-discrimination act for the disabled is much stronger than the British policy. While initially weakened by certain Supreme Court decisions, the Americans with Disabilities Act Amendments Act corrected for many of those decisions by broadly defining impact on a major life activity, making it inclusive of those who are able to correct or pass their disabling condition until a point of contention (e.g. wearing

eye glasses, or a person with mental illness who does not disclose until having an episode of instability), and generally orienting the courts towards being in favor of those filing claims. The British policy is much more limited in impact and efficacy. Further, our education laws, while not initially interpreted as strongly as they are now applied, guarantee a degree of free and appropriate publically funded education that is simply much stronger than those found in British law. American policy is geared towards integration and mainstreaming of those with disabilities and accommodations granted with the greatest degree of freedom, at least in the letter of the law. In practical experience, this is not always true; the truth of the law is structured a great deal on class, race, and socioeconomic status, of both the individual and family, as well as the composition of the school district in which the accommodations are requested.

Still, in other respects, the British social welfare system is much stronger than the American system. Disability income is much higher, maternity/parental leave is paid and for a longer period than allowed under American law, and health insurance, until recently a large barrier to care in the United States under a homologous medicalized regime of care, is single payer and universal. Indeed, the recent changes to the way in which health insurance is provided in the United States is too new to assess what impact it will have among folks like my participants, whose experiences of serial, unstable, and part time employment prevented participation in programs like those under the Affordable Care Act, especially for those who did not live in Medicaid expansion states.

Despite differences, however, the assumptions of both systems are fairly similar which is “...the image of the non-disabled, white, heterosexual, male adult...” (Priestley, 2000, p 426) who is also highly individualized and independent of others. Dependency is one distinguishing feature of those who benefit from welfare policies; however, while Priestly hints at reasons for

legitimacy of exemptions from independence, I refer back to Marshall's conception of citizenship. Children are future citizens. Mothers are nurturing future citizens. The elderly are reaping the rewards of successful citizenship. In these cases, dependency is a privilege of citizenship and understood to be temporary or of greater benefit to society. The essence of this compact is that dependency is a reward of independence; those always already dependent cannot therefore experience full citizenship.

It is the disabled, in this scheme, who are excluded, and historically, this is quite true. Foucault describes the exile of the mad, followed by the confinement and institutionalization. For autistic adults with significant impairment, this period of confinement lasted until quite recently; de-institutionalization in the United States occurred in the 1960s through the 70s, but was essentially replaced for many with new forms of institutionalization, such as group homes and nursing facilities. However, as Priestly discusses, it is those on the margins of these categories which cause the most trouble for social policy. My participants, not disabled enough for most social welfare programs, but too disabled to reap the benefits of full citizenship, were on this exact liminal space. This is why the question of legitimacy had importance inside of the communities I studied. If the normative assumption is to be successfully heterosexual, entering into a heteronormative marriage which in turn produces offspring, the impairments in deploying masculinity is not simply an issue of coming across as creepy or representing potential danger, but actual a deeper connection to the citizenship of those on the autism spectrum. If the normative assumption is to be successfully employed across the life course, in a career, then the serial, horizontal, employment of my participants also prevents access to citizenship's benefits, while at the same time, disqualifying them from the benefits of the welfare state.

The way in which our system is designed, adults with disabilities are either too disabled to work, and the welfare state will kick in to cover most of the cost of their care and upkeep, or they are only somewhat disabled, who with some degree of accommodation can enter and participate in the workforce. When adults with significant disabilities wish to work, however, they often earn their way out of the system, which caps the amount a person can earn while receiving disability related income and services, on the assumption that productive work leads to the ability to afford the kinds of services that might otherwise be provided through Medicaid or Medicare. Full retirement benefits are associated with a life history of productive labor; to enter old age without a continuous record of employment means leaving the work force (or more accurately, being forced out of or excluded from the productive work force) without the full benefits of those who did work, and worked continuously. This includes not only an inability to participant in private retirement schemes (pensions, health insurance for retired workers, various savings and investment plans), but a limited access to public resources, the main one of which is tied directly to the total contribution over the life course. Even Medicare, available at limited or no cost to the elderly poor, is tied to a great degree on work history; the ability to afford private supplemental and bridge coverage is, of course, related to retirement savings and income. There is also a significant disparity between those who were working and became disabled and those who entered adulthood as already disabled.

For adults with disabilities, a person is either able to ‘overcome’ their disability enough to enter and fully participate in the workforce, or they are too disabled and are therefore dependent upon others for their upkeep. There is, of course, a huge amount of liminal space within this, a primary contention of the disability rights movement. The move towards reasonable accommodation recognized not only the structural and physical barriers to workforce

participation, but the fact that disability requires a degree of interdependence, as accommodation often means a capital investment in removing or adapting physical barriers, or in making social accommodations around normative behaviors (e.g. extended or more frequent breaks for physical or mental health reasons). Accommodations, in this sense, refer back to Tantom's concept of affording, which he defines in relation to being able to step away from the intangible normative to provide the kinds of accommodations requested by autism on society writ large (as discussed in chapter 1). While employment accommodations are therefore usually seen as a break in welfare policy towards the disabled, by moving the already disabled from actually receiving welfare benefits to earning income, they can be seen as an extension of the welfare state through curtailing the liminal space between dependent non-citizen and productive citizen, moving more from one category into the other and extending the responsibility of the state to ensuring citizenship for certain classes of the disabled.

And yet, as discussed by Tantom,(2009) autistics remain liminal. As Allison Carey (2009) records, the history of citizenship for those with developmental disabilities is not clear cut. Those who were severely impaired were often institutionalized, first in mad houses and later in asylums. However, even displaying a modicum of independence allowed for participation in civil society and other aspects of citizenship. This was, of course, patterned along social structures, and white men were given more latitude for independence than other groups. Added to this history is the institution of eugenics. Asylums served not merely as warehouses for those deemed unfit for society, they also served to destroy one primary right and responsibility of the active citizenry: reproduction. Not merely denied the right to raise their own children, those who were institutionalized during the late 1800s through the 1970s were always at risk of being sterilized, particularly women of color.

Carey connects deeply the relationship between liberal political theory, which espouses a theory of citizenship based upon active participation, independence and rationality, and eugenics, as this concept of citizenship "...allows for and even encourages the exclusion of many people who are not seen as meeting these standards." (p217) She argues that, despite the letter of the law, rights are not automatic provisions and are instead subject to negotiation. The degree to which disabled people, especially individuals with intellectual disabilities, are subject to negotiation demonstrates the marginal location that these individuals have with regards to citizenship. While Carey is focused on intellectual capacity in particular, she states "...the social norms dictate particular ways to look, act, speak and move, so that a slow gait, flailing of arms, atypical speech patterns, or "mismatched" clothing provokes confusion, anxiety, and fear. For rights to be effective... a person must be able to claim them, and other people and social institutions must define that individual as an appropriate rights bearer." (p 215) That most autistics do not have intellectual disabilities is moot, as the social presentation of autism is confused, often, for such a disability. Autistic communication, and the patterns of impairment thereof for those on the spectrum, can mimic or seem to be in some way related to a problem intellect, when it is, as Bogdishina points out, a problem of cognition and/or perception (as discussed in Chapter 1). That intellect isn't even firmly defined in our society contributes to the marginalization of those who are defined to have intellectual disabilities, claims Carey, and I extend that argument to those merely perceived to have intellectual disability by virtue of their social communication, perceptual, or sensory impairments or differences, which often results in the same kinds of deviations from normal that Carey lists for intellectual disability. The tension between autism and intellectual disability was present in my fieldwork, as well, with words like "feeling stupid" and "retarded" with regards to understanding social situations or other people's

social interactions, as well as those same words to describe what they were not but yet felt judged to be by others, so this tie is not just theoretical but also enacted.

Further, according to Carey, the liminality of rights for individuals with cognitive disabilities is exacerbated by the dichotomy in what disability rights advocate for, who can advocate on whose behalf. On the one hand, there is a tension between segregation and inclusion or assimilation as preferred options. There is also the related issue of informed choice, a basis for the liberal citizen, but which is assumed or documented to be curtailed in individuals with intellectual impairments. For some advocates, including self-advocates, segregated environments are the ultimate expression of citizenship and free choice, while for others, it is supported inclusion. For Carey's subjects, the issues here are slightly different than for my own. My participants could hold "valued" jobs given the proper accommodations, or perhaps better using Tantum's scheme, 'affordings'. Whereas Carey's subjects needed supports and had some degree of 'natural' limitation on the capacity of work, my participants generally did not have capacity for labor issues in so much as they had capacity for social norms issues. Of course, more impaired autistics, who were not in my participant group, might need more of the same provisions as those with significant intellectual disability, again as the case is that their social impairments mimic the disability of intellect, despite intellectual capacity. Intelligence may be secondary if the degree of communication impairment is significant. Indeed, communication capacity for autistics is problematic, on the one hand because it may be somewhat impaired, but on the other, it might not be as impaired as expected, which in turn may undermine the credibility of those who are able to advocate. This underscores what I spoke of earlier, of how those with Asperger's are often accuse of not speaking for those with more significant disabilities. Representation among self-advocates is a continuing issue, as those who can speak

are dismissed as not disabled, those who cannot are dismissed because they cannot, and those who use proxies (facilitators, parents) are displaced as focus is on the proxy, with non-parent communication facilitators often dismissed as fraudulent.

My participants, except for a literal handful of exceptions, were not in the disability support system; only one was in disability-related institutional care. All others lived independently, semi-independently, or with family, or in institutional settings unrelated to disability. While a few received Social Security Disability Income or Supplemental Income, the sheer majority were members, attempted to be members, or were former members of the working population. Serial employment was common, as was underemployment relative to education level. A hesitancy to enter a management position was typical through the career, which limited many prospects. One participant had refused management positions for so long, that despite his seniority, during a round of lay-offs, he was considered expendable and let go, just a few years short of retirement age. Others I have already mentioned, like (that guy) who was let go for inappropriate jokes, or Jose who mastery of one set of job skills did little to get him a new job, where he struggled to learn a new set of skills. My participants neither drew extensively from the welfare systems for adults with disabilities, nor could they derive full benefits from being productive workers. They were stuck in a liminal space; while it is certainly against the law to discriminate on the basis of disability, personality or the ephemeral 'fit' are still fair game, and it is in this realm that pervasively works to keep autistics out of gainful and long term employment.

One significant barrier to employment was the difficulty in navigating social situations. Yolanda was in her mid-40s and lived with her mother in a Section 8 apartment in a poorer area of the city. She was often rolling her eyes as she spoke, dismissive of her life's troubles and casting the blame for them squarely on the stupid neurotypicals. Listen to this, she said,

recounting her story of being on work-fare. In order to qualify for public assistance, as she did not qualify for Social Security disability (a whole other story, she explained), she had to go on a certain number of job interviews, or participate in a job training program. So she did this internship with the city government, doing filing in one of their offices. She showed up every day, on time. She worked four hours straight. She broke for lunch and ate at her desk. She was finished with the tasks they assigned her every day by two. At first, she asked the supervisor for more work to fill the time until five. And at first, the supervisor gave her some more work. But eventually the supervisor told her that there wasn't more work, to stop being so productive. So she sat there for three hours, every day, reading her books or going on the internet. She asked if she could leave early. No. Just had to keep sitting at that desk. At the end of the internship, she was not given the job, as indicated in the internship program, which implied that a month of internship would probably convert into a job. The explanation given by the supervisor is that Yolanda's personality just didn't mesh with the office environment. She didn't socialize with the others in the office. She didn't chit-chat. She was too productive instead of spacing out her work day. Yolanda recounts this story with a sense of disbelief. She knew the ideology of work – you went in, did your job, productivity was rewarded. That wasn't actually true, and she couldn't figure out how to reconcile that. When she reported back to her caseworker why she had failed to get a job out of the internship, the caseworker assumed that Yolanda wasn't telling the truth, and refused to place her in any more of the internship programs. Instead, she was left to bounce around from one interview to another, simply to quantify her existence in the workfare program. She was giving up, though. She was going to try to seek another diagnosis, one that could qualify her for disability, as her autism diagnosis failed to do because, as she put it, she wasn't retarded.

Yolanda, it is clear, was not disabled so significantly that she was unable to articulate for herself, express her needs or desires, or fulfill basic social interactions. Instead, what disabled Yolanda was the clash between her autistic impulses, to avoid or minimize neurotypical interaction, to avoid confusing work and friendships, to expend energy performing a social role she found draining, and the neuro-normative expectations around work, gender, and interaction, namely that women who work together will engage in chit chat or gossip. Given a more conducive work environment, Yolanda would likely make an ideal worker, at least, on the job. She lived with her mother because she found it exceptionally difficult to maintain a house by herself, as she struggled with routine tasks of self-care (at one point specifically mentioning taking out the garbage as something she almost never did). Yolanda, like most of my participants, had a constellation of independence skills coupled with dependencies. This inconsistency, as I noted in the first chapter, is a significant aspect of the problem of autism.

### **Biosociality and Biomedical Citizenship**

Keeping a degree of Marshall's lens on the rise of the welfare state, a significant aspect of this relationship came about not just through a new enumeration of rights and responsibilities vis a vis the state, but through emergent forms of power. Prior to the Second World War, states in the geopolitical West began to use mass population techniques to affect the status of their citizens in order to maximize productive labor potential, including community level public health campaigns. Health became an organizing ethic, and with the rising individualization and individuation of ethics and citizenship, forms of citizenship in relation to health status, risk, and maintenance emerged. Stepwise with this was the eugenics movement, which sought to improve population health not through individual health practices as we see now, but the improvement of

population health through the removal of certain groups from reproduction and participation in both state and civil life. Combining both Marshall's and Carey's analysis, we see how the revelations of World War Two demonstrated the horrors of the logical end of eugenic practices while cementing the logic of individualism. Eugenic practices like state sterilization and forced/coerced adoptions in the United States didn't fully end until the 1970s, but they became increasingly isolated and limited after the outrage of the Holocaust and the general turn against eugenicist thought.

Similarly, the practices of health turned from populations into individuals, following a Deleuzian move from mass to individual, and now to dividual, to be addressed later in this chapter. With origins in the turn of the century populism and anti-tuberculosis campaigns, the idea of an active citizenry in charge of personal health became increasingly the norm in the post-war era. Public health campaigns were directed at changing individual behavior, not breaking well handles. As Rose (2007) points out, "the citizen here was not merely a passive recipient of social rights, but was also obligated to tend to his or her own body..." Indeed, that nationalized health care is the dominant example of Marshall's citizenship concept is exactly because of the biologicization of citizenship.

Rose continues, suggesting that "we are increasingly coming to relate to ourselves as "somatic" individuals... as beings whose individuality is, in part at least, grounded within our fleshly, corporeal existence, and who experience, articulate, judge, and act upon ourselves in part in the language of biomedicine." Governmentality, which suggests practices of self-discipline in lieu of absolute state power, has adopted the ethics and narratives of scientifically derived medical discourse, even when or perhaps especially when the science itself is in dispute. This is not just for bodily health practices, as Rose argues "...somatization of ethics extends to the

mind... New sciences of brain and behavior forge direct links between what we do – how we conduct ourselves – and what we are.” He argues that the move towards understanding psychic space as “deep” was replaced by understanding it on the molecular level, as “neurons, receptor sites, neurotransmitters and... the human genome.” Of course, as I refer to in Chapter 4, the neuroscience of autism is deeply unsettled; recent psychiatric literature suggests that the entire neurotransmitter deficit model of affective disorders is junk science constructed mostly to explain and sell particular classes of psychotropic medication. However these models have served governmentality and an ethic of neuro-somatization well. Rose sees his “ethopolitics” as a move beyond mere biopolitics; I find his ethopolitics to be a useful understanding of the specific forms of biopower and biosociality that create an ethic of vitality, but a clear indication from my field work is that ethics of vitality are techniques of governmentality, reproducing power along embodied lines. My participants had certainly internalized the politics of vitality but in many ways struggled explicitly with this call to improvement. They could not improve. They were stuck. Brian lost a significant amount of weight. Adrian set about a program of improvement of social skills. But they were still autistic, and knew themselves through this lens of biomedical rhetoric that forever doomed them to the margins.

My quibble with ethopolitics aside, the ironic location of autistic biosociality is an important factor in understanding the marginalization of autistics under biomedical citizenship. Whereas others whose health identity claims are recognized and interpellated may then gain access to citizenship, autistics remain liminal because they lack treatment, fix, cure. There is no molecular manipulation to alter the fundamental issues of autism, especially for adults whose ‘real’ problems are both mundane and extraordinary. Autism is exclusively known through a medical lens, despite it being very fundamentally untreatable through medical means, and the

health impacts on my participants were more results of stigma and isolation. Indeed, biomedical citizenship instead implies a new eugenics; if a gene for autism is found, then the likely result is fewer born with propensity for autism, just as the case for other genetic conditions like trisomy 21 (Down Syndrome) and fragile X.

There is also a resistance to the rhetoric of vitality when it comes to issues of a 'cure' for autism. I refer my readers back to my discussion of the language of the cure in my previous chapters. Sean desperately wished for a cure, assuming if his autistic tendencies and difficulties were removed, he would not have barriers to getting what he desired (which for him was generally sexual attention from women). On the other hand, that guy whose parents were psychologists had declared him cured, but yet, he was not and still experienced sensory, perceptual, and social differences and difficulties. He had an obligation, he felt, to remove those difficulties and improve, but could not. Still, the dominant rhetoric in the groups was knowing oneself through the diagnosis, emphasizing the formal diagnosis as a key to the truth of the self. Thus autistic identity was firmly biosocial, but a functional identity seemed to hinge not on an ethic of vitality, but of acceptance of limits and management of difference. Autism activism hinged on moving these differences into the realm of acceptably diverse difference, but that rhetoric ignores some of the more problematic differences between 'neuro-diverse' and neuro-normative individuals. Even mundane problems were known through autistic difference, which served to separate autistics and marginalize them further. The individualized problem of autism meant that any difficulties experience by my participants were not only framed as autistic problems, as potentially medicalized and therefore imminently curable or bio-manipulatable, but as highly individualistic, with no onus on the normative others to create any space for tolerance, much less affordance. So long as autism is seen as a problem through biomedicine, even

including rhetorics of neuro-identity, it will be individualized instead of systemic, and liberal activism will fail to provide ease to the burdens of autism for autistic individuals.

### **Autistic Civil Society**

When I began this project, I sought to demonstrate that despite being marginalized as both state citizens and as biomedical citizens, autistics were still capable of participating in civil society, and in fact, did so. My environment of study was an explicitly autistic space and of the kind of volunteer organization that forms the basis of civil society in American society, dating back to de Tocqueville's early documentation through Putnam's evidence of their general demise. While the groups had different emphases, all contained aspects of voluntary action and identification with the group. One group that ran a general support meeting also planned numerous social activities, such that I actually attended more of these informal activities than I did formal meetings (including a potluck, a picnic, a hike, a lunch outing, and a dinner outing, compared to just two formal meetings, in a period of three months). Another group, whose model employed peer-to-peer support, had numerous off-spring groups that met for socializing, including groups for playing board games and watching movies (unrelated to meetup.com groups mentioned in an earlier chapter attended by one participant in a different geographic location). And while yet another group formally emphasized political action, the fact of the matter was that at the time of study, they were relatively inactive in that regards, and the group functioned mostly as a form of socializing where political speech was encouraged, though not exactly routine. An offspring group of that was formed to specifically support individuals seeking or having difficulty with maintaining employment. My in-person groups were not very different than the realm of online civil society documented by Rocque during the course of his dissertation

research, documenting the culture of a main autistic website, [wrongplanet.net](http://wrongplanet.net). In conversation, we established similar findings related to both identity claims making (see chapter XX), as well as engagement around interests, including politics, though especially perhaps, what is colloquially known as geek culture.

Geeks, nerds, and dorks are all pejorative terms for individuals who, for some reason, do not fit socially within the accepted hierarchies, especially in adolescence and young adulthood. While there are varying definitions thereof, it is generally accepted that both geeks and nerds have some degree of perseverative interest in an arcane or highly technical realm. Some argue that the difference between geek and nerd is social skills, the geek being in possession of good skills while the nerd remains marginalized from others. Others might argue that social skills aside, geeks manage to parlay their technical or arcane abilities into social power; whereas nerds must seek revenge, geeks simply outpace their peers in terms of earning potential via special abilities in highly paid fields (engineering, computing, etc). Clearly groups defined by their perseveration and/or skills in certain fields are groups that may have an overrepresentation of autism in the ranks, as perseveration and unique ability in technical or visual fields is a hallmark of autistic being. Indeed, analyzing the various definitions of those terms on crowd-sourced media [urbandictionary.com](http://urbandictionary.com), the behaviors ascribed to both nerds and geeks (and dorks) clearly applied to many of my participants, and for good reason. A number of my participants self-identified as a form of geek or nerd, either identifying with an academic discipline or form of employment (math, engineering, etc), or with a fandom. Being a fan of a television show, comic book or manga series, or entire universe which included some combination of movies, shorts, shows, and novels both text and graphic (e.g. Star Wars), was common, though I did not track this specifically in the field. Far too into my work to investigate this line of autism culture, one

participant bemoaned the increasing cost of being a fan. Those others, he implied, are invading our space. In relation to the high cost of attendance of a major comic book convention, the increasing crowds, and the limited space for fan-generated material, the increasing popularity and corporatization of the comic book space this participant read as an invasion of neurotypical individuals into a previously autistic space.

Not all individuals with poor social skills are autistic. Not all autistics have poor social skills (though all have some degree of impairment, the manifestation of this impairment, especially in adulthood, varies considerably). And certainly not all those who participate in geek cultures are autistic or even “cousins on the spectrum” (participant slang for those who simply don’t meet the diagnostic threshold for autism, but who may have traits similar to or mild forms of autistic traits). However, as arenas where the common denominator was an esoteric perseveration, geek culture allowed for participation in civil society for many autistics. As that culture has moved to the mainstream (e.g. the *New York Times* covering Comic-Con<sup>22</sup>, the supposed phenomenon of the “brogrammer” – hegemonically masculine person who is adept at computer science<sup>23</sup>), my participants reported feeling excluded from these areas, as social impairments became less tolerated and fandom became an expensive hobby.

So why report on a phenomenon not extensively documented in my field notes? The loss of geek culture as autistic space reinforces my arguments about the limitations placed upon autistics in both state and biomedical citizenship. State citizenship is predicated in part on full employment; being priced out of participation in geek culture is also a result of less than full employment or otherwise marginal economic status. Further, older adults on the spectrum could find in geek cultures others whose profile of skills and impairments matched their own. This

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<sup>22</sup> <http://topics.nytimes.com/top/reference/timestopics/subjects/c/comiccon/>

<sup>23</sup> <http://www.motherjones.com/media/2012/04/silicon-valley-brogrammer-culture-sexist-sxsw>

mean a primary identification with others in a fandom or geek culture, instead of the biosocial identity of autistic. With commodification and popularization, the chances of others engaged in a fandom being autistic, a cousin, or at least tolerant of autistic traits are lessened, furthering marginalization. Autistic space has been colonized by capitalism as autistic being has been medicalized and autistic difference fetishized. Autism is being reassembled through identity politics, capitalism, and the risk society.

### **What is to be Done?**

In arguing against identity politics, Jasbir Puar (2007) asks us to consider the possibility of affective politics (p 215). She offers us instead the concept of the assemblage, which “allow[s] us to attune to movements, intensities, emotions, energies, affectivities, and textures as they inhabit events, spatiality, and corporeality... [it] underscores feeling, tactility, ontology, affect and information.” This politic of affect serves autistics much more coherently than a politic of identity, for identity is representational and is thus ostensibly that with which autistics struggle, connecting perception to representation, especially in the realm of the social, in addition to Puar’s and Chow’s (2002) critiques of identity politics. A politic of affect could note the affective disjuncture that underscores autistic difference, as I argue in chapter 4, which assembles into the figure of the creep for many autistic men. While Puar is particularly talking about terrorism and queerness, her use of assemblage is useful in understanding how to reconceive autism away from biomedicine, as assemblage in and of itself that has become a monstrosity.

As opposed to Rose’s ethic of vitality, of ethopolitics, Puar’s assemblage is based on an understanding of necropolitics, the forms of biopower that will not to death, but to life.

Ethopolitics is really a form of necropolitics, considering the limited access autistics have to vitality. Emphasizing an ethic of vitality, therefore, is a form of willing to life. Biomedical citizenship and biosociality, as forms of identity politics, produce intersectional identities; psychology is another form of knowing oneself through claims making on established social parameters:

Intersectionality demands the knowing, naming, and thus stabilizing of identity across space and time, relying on the logic of equivalence and analogy between various axes of identity and generating narratives of progress that deny the fictive and performative aspects of identification: you become an identity, yes, but also timelessness works to consolidate the fiction of a seamless stable identity in every space....As a tool of diversity management and a mantra of liberal multiculturalism, intersectionality colludes with the disciplinary apparatus of the state – census, demography, racial profiling, surveillance [adding in: cures, forced treatments, disability welfare apparatuses] in that “difference” is encased within a structural container that simply wishes the messiness of identity into a formulaic grid... (p 212)

Identity politics simply fails to address autism at all levels; autism fails to map neatly onto these grids, and cannot be understood in positive identity claims, as those reify the Otherness of the autistic while denying humanity and citizenship by limiting possibilities on the basis of an autism identity. Further politics based around autism awareness or tolerance fail to account for the complexities, where by autism does not merely intersect with other status claims, but disrupts a person’s capacities with regards to claims making itself, at least in a legible way.

Puar writes that “displacing visibility politics as a primary concern of queer social movements, assemblages demonstrate the import of theorizing the queer affective economies

that impact and engrave but also announce, trail, and emblazon queer bodies...” (p 222) which she then lists to include the bodies of her analysis. I humbly suggest inclusion in this list that of the autistic body, who by virtue of autistic neurology queer cognition, challenging the normative assumptions of cognitive science, which Bogdishina suggests is reminiscent of the quantum (as discussed in the introduction to this dissertation, but which I argue is possibly a fetishization of queer autistic neuro performance). The parallels between how Puar writes of race and sexuality are reminiscent of my own analysis of autistic embodiment, yet at a level of affect simultaneously deeper and more overt than either race or sexuality (and clearly, which assemble together at the affective level, as in chapter 4).

The question begged at the end of Puar’s work is of moving forward with assemblage analysis. Affect theory asks us to look at corporealities, and thus to corporeality I turn in the form of Bryan Turner’s ruminations on vulnerability. While I disagree with his conclusion of cosmopolitanism, his conception of the corporeal body as vulnerable, that precariousness and management of embodied risk, not in numeric risk but in organic risk, is distributed among the social order at the level of the body, is an important aspect of assemblage missing from Puar’s work. Indeed, she admits that queer theory has a difficult relationship to the biologic (p 209), which always seems to be one the edge of essentialism. As Turner points out, “an aspect of human frailty, our ontological vulnerability includes the idea that human beings of necessity have an organic propensity to disease and sickness, that death and dying are inescapable...” (p 29) While certainly cyborgization and biomedicalization has changed individual and population relationships towards frailty, death as ontologic inevitability remains. Indeed, Turner seems almost fearful of these biomedical advances, worried about the status of the human, especially in regards to citizenship and protection from frailty, in post-humanity. He is unable to bridge from

corporeality to assemblage the way Puar is unable to incorporate actual bodies into the assembling. Still, what is fruitful to understand is the conflict between post-human vulnerabilities and assemblage, as vulnerability becomes one more aspect of temporality and juncture (or disjuncture). I theorize that the increased marginalization, the ever increasing focus on interventions for normalizing autistic or potentially autistic children, and the lack of affordances, accommodations, and respect for autistic adults stems from the uncanny valley of autistic being, one that throws into relief the possibility of the uber-rational, affect-less (again, due to either hyperstimulation of affective exchange which produces a body unable to engage with affect, or a body which requires a higher level of stimulation for recognition), computational figure. Vulnerability in part becomes a manageable aspect of a biomedical citizenship, following from Turner to Rose, but becomes an unknowable aspect of affect when moving to Puar. Still, the body, a leaky, bleeding, reactive body, remains, and remains as such vulnerable to the immanency of death, of the corporeal body and by extension culture as we know it.

Autism directly confronts the ideal of the liberal subject, especially the heteronormative, white, masculine, productive worker who engages in regimes of self-care and vitality, by presenting instead a constellation of abilities, capacities, and impairments, including sensation, perception, and affect unmitigated by socialization, which in and of itself may be a source of impairment and self-care. My participants were exceptional and mundane, exceptionally mundane, nonexceptional, both the source of their problems and the embodiment of social problems with regulations of affect. It is the nonexceptional, Puar says, that is the contagion, the disruption, the terrorist. Autism speaks back to that subjectivity.

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