THE POLITICS OF AUTISM:
EXPANDING THE LOCATION OF CARE

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Abstract

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This project examines the identity of autism as well as its relation and subsequent effect on theories of justice and an ethic of care. Theories of justice and care are both equipped with thick conceptions of being human that potentially exclude different identities, in this case, autistic people and their families. Both theories establish the home as the ideal and primary setting for dependents, but autistic people and their families may require an expanded and alternative location for care. Rather than embed an alternative perspective in a universal “view from nowhere”, I adopt a sibling perspective to analyze the meaning of autism as well as the consequences of long-term care. Siblings of people with profound disabilities represent the theoretical and contradictory locations of autonomy and interdependence. Analyzing how siblings maneuver in relation to disability may provide better insight into developing alternative inclusive strategies for marginalized disabled families.

Approved:

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For my brother.
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Chapter 1:
Introduction

This project began on a warm spring day – the kind of day that seems preordained for idyllic college campuses and long philosophical discussions – and there I sat with a professor discussing John Rawls, human rights, and my brother’s autism. Our discussion was facilitated by the ice cream that my professor had treated me to and its sweetness must have inebriated my brain as I described my brother’s most violent and unexpected manifestations of autism. Part of understanding the complexity of autism is realizing its multiplicity and recognizing that many images of autism are based on the high functioning autism whereas my brother had a much more severe and lower functioning variety. It is the severity of Matt’s autism that is sometimes hardest to explain and which I attempted to relate to my professor on that warm spring day: a complete loss of language, self-injurious behavior that has often resulted in trips to the emergency room, an erratic desire for socialization, and an inability to register normal feelings of pain which, at his worst, had rendered him almost indestructible and unstoppable. And yet I was determined to configure him within a rights community even though he lacked many of the primary attributes that moral status seemed to require.

It was at this juncture between reconciling my brother’s disabled identity with a full spectrum of rights that my professor interjected a suggestion: since my brother lacked a normal range of human abilities, perhaps it would be more conducive to think of him as having the same rights as the most intelligent ape or a beloved domesticated dog. She continued to make parallels between my brother’s low functioning autism and highly
intelligent dogs: neither dogs nor my brother could speak through language, but they could both establish emotional bonds through a limited form of communication with others. Even though the association between autism and canines has been made before, it was not the answer to justice for which I had been searching. For me, the assumption that my brother could be accommodated within a schema of rights more easily as a dog or at least dog-like said something irretrievably wrong – not about my brother, but the way we do justice.

This thesis is then the work that followed behind the question of how justice can incorporate the needs and rights of severely low functioning autistics. More specifically, it is an exploration in the way in which we conceptualize being human and how that conception can exclude alternative ways of being in the world like autism. My focus has been on the lower end of the spectrum of autism because I believe it represents a “hard case” for justice because of its core traits. In chapter one I explore the meaning and manifestations of autism which has been primarily constructed by a medical model of deviance. Chapter two attempts to ascertain whether or not autism can be assimilated into a liberal theory of rights that is predicated on autonomy, reason, self-determination, and sameness. Specifically I look at Rawls’s theory of justice and its construction of being human. Chapter two finds no resolution between a community of rights-holders that is constructed out of autonomous rational atomistic agents and autism in its more severe and dependent manifestation. Establishing autism in conflict with liberalism’s individualistic aspirations also sets autism in an uncomfortable relation with some disability rights rhetoric, especially the Independent Living movement which prizes autonomy and self-determination as inclusive criteria for disabled people. Autism becomes a deviant category even within the Americans with
Disabilities Act which maintains self-sufficiency and productivity as legitimate aspirations for all disabled people.

Unsatisfied with the incomplete answers left over from liberalism and rights rhetoric, chapter three looks at an ethic of care to establish better accommodation for autistic people and their families. An ethic of care originated out of (1) women’s experience as caregivers and (2) the realization that liberalism’s division between private and public spheres is a political divide that exacerbates the injustice of long-term dependents and their caregivers. Since care theory begins with a rejection of atomistic autonomy, it could potentially de-stigmatize severe autism. Upon scrutiny, however, care theory projects prescriptive roles for caregivers and care receivers that assume a level of reciprocity, attentiveness, and at times affection, but some autistic children deviate from this model by their aloofness and aggressiveness, straining the ability of the caregiver to maintain attentiveness. Autism may be even harder to reconcile with care since the core traits of the disability can prevent associational ties from forming.

In chapter four, I attempt to propose a strategy for autistic inclusion within a schema of justice, but in no way am I offering an alternative grand theory to liberalism nor a third principle to add to Rawls’s original position. Instead I turn to queer theory with its elucidation of the epistemology of the closet, the insidiousness of shame, and its counter-narrative of coming out. In chapters one and two, severe disability connoted enough stigma that it trumps theories of justice; autism can become the exception outside of ethical constraints. The problem becomes autism’s deviant identity. Thus a possible solution is a reconceptualization of being human, but this process must recognize the inability of the autistic person to formulate their own coming out process that is then rendered silent by a
construction of identity politics that bases authenticity on the speaker’s identity with the group. At this point, I then interject a sibling perspective which can potentially alter the way we do disability by analyzing how siblings are socialized differently to disability. The final objective of a sibling perspective is to establish local coherence for autistic people rather than an assimilationist account of justice. Local coherence recognizes that there is a multiplicity of autistic behavior that cannot be bound by one solution, but instead requires a dedication to recognizing and dignifying alternative ways of being in the world. Realizing that justice and autism can both be contextual, historical and situational is the purpose of local coherence.

The embeddedness of a sibling perspective as well as a commitment to local coherence also distinguishes my own situatedness in relation to justice, human rights, and autism. Often this project has launched me into the heady dialogue of theoretical principles of justice waged across disciplines and politics. But just when I think I have found the answer, I visit my parents’ house where the commitment to my brother has led to my father’s early retirement, my mother’s constant exhaustion, and my younger sister’s delayed independence as she continues to reside at home to help care for Matt. At those times I am harshly reminded that eloquent words and my theoretical musings have no currency in the immediacy of their dilemma. What they need is a version of local coherence that can recognize their needs, their fears, and the entirety of their familial disabling condition bred out of a desire to keep my brother in the privacy and safety of their home as long as possible.

This project then continues the feminist principle that the personal is political; that perhaps my experience as well as my family’s is a commentary on the insufficient and at times ridiculous way we do (or don’t do) justice for severely developmentally disabled
people. Disclosing my position as a sibling and secondary caregiver to a severely disabled person, I invite a dialogue about the complexity of dependency which is not just about siblings, autism, or my own family. I echo the sentiments of Eva Feder Kittay by recognizing “the urgent need to formulate a globally pertinent ethics of long-term care,” however I believe that we will be unable to construct an ethical theory of care while our conceptions of disability are closeted, concealed along with our dread of disease, death and shame.

Finally this project revives and modifies a former feminist’s concern with our narrow conception of being human which is then complicit with the exclusion and prejudice of stigmatized groups. From that warm spring day I’ve been mulling over the comparison of my brother with the most intelligent of dogs and however I frame it, I reject the proposition. This project refuses to situate human rights upon the status and rights of non-human animals. The tactic of justice that suggests the devolution of human rights into a substratum of animal rights is, for me, unsalvageable. This project seeks to theoretically configure a world in which my brother and my family and other families may discern a world of freedom and joy regardless of severe disability. I believe that justice shouldn’t be compromised due to disability. The belief in justice is the belief in a possibility without prejudicial compromises and because I am convinced of my brother’s humanity. This project asks, ain’t he a human?
Chapter 2:
The Circle of Competence

Since the 1970s, the Independent Living Movement has demanded equal rights, an end to discrimination against disabled Americans, and proclaims the same individualistic values for themselves that the dominant non-disabled class has enshrined: dignity, autonomy, and competency. Instead of “emphasizing fixing the individual, the independent living paradigm places the problem in the attitudes of society and stresses changing the environment.”¹ Using a civil rights model of empowerment, the 1990 Americans with Disabilities Act targeted “unfair and unnecessary prejudice” as the primary cause behind people with disabilities’ exclusion.² The ultimate goal of the ADA is self-sufficiency: first because it is the right of every American to be free and independent and secondly because dependency and unproductivity costs the United States billions of dollars of unnecessary expense.³ Using person first language, the ADA emphasizes that people with disabilities shouldn’t be defined by their impairment, but rather by their (non-disabled) personhood. The burden of assimilation shifts, under this model, to the non-disabled person under the premise that disability will cease to be stigmatized when the non-disabled population recognizes their own harbored prejudice as the cause of disabled injustice.

Popular culture mirrors this perspective, for example, the 2006 film The Ringer describes itself as an “uplifting…story about an ordinary man who discovers what it truly means to be special when he attempts to ‘fix’ the Special Olympics.”⁴ Johnny Knoxville’s character Steve passes at the Special Olympics as “Jeffy,” assuming an intellectual disability primarily by mimicking a child-like demeanor. He fools the non-disabled volunteers, but his
co-competitors discern his forced personae as false and unconvincing. After Jeffy comes out as Steve to six other mentally challenged adults, they decide that they should help Steve train in order to beat the six time returning gold medalist. In the process of training, Steve learns that he and his six new friends are more alike than different: they cuss, joke, develop friendships, fall in love and are competitive just like him. The process of assimilation is evident in a commercial advertising the Special Olympics, in the film, in which the former gold medalist is seen running, eating, and working out. The commercial ends with Jimmy, the star athletes, bench pressing weights. When he rises off the bench, he looks straight into the camera and declares: “I’m just like you” to the presumed non-disabled audience. At the end of the film, the cast dances and sings along to Aretha Franklin’s “Respect” and the moral of the story is obvious: people who are intellectually challenged deserve respect because they are just like the rest of us. Specifically, their commonality is primarily enabled through two share characteristics: the way they think and the way they interact with one another which I will refer to as the qualities of reason and association.

The Independent Living Movement, the ADA, and The Ringer are all engaged in the same story whose strategy is simple: if we give disabled people respect, it will enable them to have equal rights, which will then guarantee justice. The strategy’s linchpin is that we as non-disabled people recognize that mentally disabled people are just like them, that in fact, it is only prejudice that erects any barrier. While I agree with the goal of justice, I contend that the strategy of rights based on sameness will inevitably build a barrier between Us and an Other. All three examples’ success is contingent upon high functioning disabilities that do not impede the person qua disability, but whose exclusion must be caused by society. Referred to as the social model of disability, it posits that impairment is distinct from
disability: impairment refers to the bodily or mental “handicap” whereas societal prejudice leads to disability and is assumed to be more disabling. Wheelchair users are often invoked as an example: if all buildings had ramps and were accessible, being in a wheelchair wouldn’t be a disability, but only a difference. The social model and civil rights approach are preferable to the former medical model which emphasized the individual’s physical/mental disability as an illness. The medical model portrays the disabled person as dependent on health professionals for cures or maintenance and ignores any disabling features or attitudes in society.  

The social model theory and the civil rights approach to empowerment also protect the status quo of individualism and the goals of modernism. The Enlightenment produced the modernist worldview which believes

that human nature is rational and self-interested; that each individual has inherent human rights regardless of his or her culture of origin; that capitalist development is good because it leads to progress; that such development will benefit all humans in the long run; and that human ethics and knowledge are capable of being developed from a universal, impartial standpoint.

From this description, the primary values of Western culture are rationality, individualism, progress, a belief in universalism, and human rights rhetoric. Modernism constructs the individual as rational and productive while creating a capitalist society that upholds productivity as progress. While it purports to guarantee individual rights, it may actually thwart its own universal aspirations, specifically in regards to people with severe disabilities, like low functioning autism. Since the model assumes rationality and self-interest, it encounters difficulty with dependency and mental incompetence. The Ringer’s strategy is to render incompetence as merely stigma, making mental disability no longer a bar to rationality
or self-interest. On the other hand, some forms of autism cannot be rendered as competency no matter how equitable it would seemingly appear. Martha Minow refers to this as the dilemma of difference uncovering the conflict that recognizing difference is at times necessary for fair treatment. Under liberalism, however, equality implies sameness whereas difference leads to stigma. “If to be equal one must be the same, then to be different is to be unequal or even deviant.” However, ignoring difference and presuming sameness can lead to injustice as well.

In this chapter, I will challenge the practicality of rights based on sameness in the case of autism and posit how this strategy continues to exclude people, particularly low functioning nonverbal autistic people. In so doing, I will reject many of the premises of the ADA, particularly the goal of self-sufficiency. Under the ADA, dependency is depicted as a dysfunction of the person or society that needs to be fixed, but I contend that as long as dependency is seen primarily as a problem, stigma will inevitably follow leading to marginalization. My choice of autism as a tool to challenge rights rhetoric is threefold. First, autism is increasing: in diagnoses, media attention, and public awareness, and yet, the scope of understanding is still inadequate. As the autistic population grows, particularly amongst adults, public policy should shift its attention to developing long-term strategies for developmentally disabled people and their families. If the government and activists persist in their assimilationist approach, this shift might not occur, leaving some autistic people and their families ignored and excluded. Second, autism challenges our conception of being human as an autonomous, self-determining rational agent. This thesis refuses to see autism as the problem, but argues instead that our construction of being human is charged with being incomplete, unrealistic, and masks the private injustice that disabled families face. Third, as
a sibling to a low functioning nonverbal autistic adult, the rhetoric of autonomy, rationality and self-sufficiency is in stark dissonance to the reality of my brother’s life. For my brother, the assimilation as pictured in *The Ringer* is impossible. Under the paradigm of independence, his life is nothing but an anomaly, a medical tragedy that science has yet to eradicate.

In order to challenge the paradigm of autonomy using autism, the following chapter is divided in three sections. The history and meaning of autism will be explored, with an emphasis on the medicalization of deviance and has been rendered an Other. In the second section, the concept of a rights community will be uncovered as a system of conferring human status to some while marginalizing others. Rights carry an aura of universality, but under critical inspection, they are unmasked as rules, defining the appropriate construction of behavior. In the third and final section I will unpack rights rhetoric’s assumption about being human, sub-divided into two categories which premises assimilation upon (1) reason and (2) association. By uncovering norms of behavior, I will challenge the idea that we are all “just like” one another. I will show how the universality of being human was constructed during the Enlightenment, was revived in John Rawls’s *A Theory of Justice*, and continues to define rights rhetoric. The exclusion from the rights community is not an anomaly to the rhetoric, but is a direct consequence of constructing a system of justice whose entry and membership is based on the presumption of sameness. By using autism, this chapter contests autonomy’s power, seeking to build an alternative construction of being human.
The Autism Epidemic

Autism’s “discovery” in 1938 by psychoanalyst Leo Kanner correlated with the wider societal phenomenon of the medicalization of deviance, a “process whereby more and more of everyday life [came] under medical dominion, influence, and supervision.”

Previously, mental disabilities had been classified as either idiocy or insanity, but at the turn of the nineteenth century the medical community and government census bureaus initiated new categorizations. Medicalization and the expansion of disabilities helped to disassociate disability from criminalization, but it did not disconnect disability from stigma. Erving Goffman’s seminal text *Stigma: Notes on the Management of a Spoiled Identity* describes how difference is rendered deviant by being constantly compared to an invisible and unrealistic norm. The deviant person “is thus reduced in our minds from a whole and usual person to a tainted, discounted one.”

In the ensuing eighty years since autism’s discovery, it continues to be situated within a medical model and resisted political analysis under the social model theory of disability.

The medicalization of deviance probably helped drive eleven sets of parents to Leo Kanner, a child psychoanalyst, with what would become the first children to be diagnosed with classical autism. After studying the eleven unique children, Kanner published the authoritative text *Autistic Disturbances of Affective Contact* in 1943. He identified three primary and enduring traits of autism. All eleven children that Kanner examined exhibited (1) an indifference to inclusion, (2) an obsession with sameness, and (3) a range of communicative disorders. Three children were completely mute, others were only able to repeat nonsensical phrases (referred to as echolalia), and a few were able to grasp most of language, but had trouble with pronouns, reversing you-and-I. Kanner wrote that the
“fundamental disorder is the children’s inability to relate themselves in the ordinary way to people and situations from the beginning of life.”\textsuperscript{11} For instance, parents considered their children unaffectionate since they seldom took notice of their parents’ entrance or exit out of the room. Likewise, Kanner noted that when a child came into his office, he or she would spend the same amount of time looking at Kanner as they would a filing cabinet. Kanner described five year-old Donald T.’s behavior paradoxically: “he seems to almost draw into his shell and live within himself” and yet he “seems to be self-satisfied.”\textsuperscript{12} Parents, however, were devastated by their children’s aloof and withdrawn demeanor which Kanner referred as \textit{autistic aloneness}. The aloofness so defined the children that Kanner designated the entire condition as autism, symbolizing its obsession with self, but he was not the first professional to apply the term “autism” to a type of disorder. In 1911, Eugen Bleuler used it in reference to a particular stage of schizophrenia and up until the mid-twentieth century, Kanner’s classical autism would continue to be associated with childhood schizophrenia.

Today, Kanner’s version of autism is referred to as “classical autism” to differentiate it from other forms of autism. Currently, autism is classified as a pervasive developmental disorder and is referred to as Autistic Spectrum Disorder since it can affect individuals over a range of functioning and severity. Despite the disability rights rhetoric and the ADA, autism is firmly rooted in the medical model rather than the social or civil rights approach. Categorized as either low or high functioning, autistic people placed on the high end of the spectrum are able to engage in communication and social interaction. High functioning autism is often referred to as Asperger’s Syndrome and there is debate over whether or not it should even be considered autism for all of its differences. While mental retardation is not integral to autism, it often accompanies it, as can seizures, aggression, and “stimming”.
Stimming is shorthand for self-stimulating behavior that can range from hand-flapping and twirling to more violent forms such as biting and head-banging. Most of this project is concerned with more severe manifestations as autism for multiple reasons. First, people diagnosed at the low end of the spectrum are less likely to fit themselves into the Independent Living paradigm and therefore are more at risk of exclusion and discrimination. Second, low functioning autistics offer more of a challenge to our assumptions being human. Autistic behavior begins to contest primary assumptions about being human that The Ringer used to foment integration: communication, interaction and rationality. Finally, the few representations of autism in the media are usually based on high functioning individuals that work to silence lower functioning populations.

The term autism derives from the Greek word for self, "autos" and represents the excessive focus of self by the autistic person as opposed to being (normally) engaged with others. The implicit norm of human association works to define autism. Not being interested in others is considered pathological, even though the autistics themselves seemed unperturbed by their aloofness that so disturbed their parents. Ironically, autism’s Greek translation displays a marked similarity to autonomy. Autonomy, an integral concept to Western political theory, shares the Greek root word for self, but then is followed by the Greek word *nomos*, meaning rule or law. Jennifer Nedelsky, a feminist theorist, translates autonomy as governed by one’s own self. The difference between autism and autonomy is that the former is unregulated; it is not controlled by rules or reason. However, Nedelsky notes that autonomy too can have pathological results similar to autism: “The most perfectly autonomous man is thus the most perfectly isolating.” It is as if autonomy has the potential to become distorted into autism: that without rule or law, a focus on self becomes detrimental
and pathological. Some researchers even hypothesize that autism is triggered by too much autonomy, suggesting that Westernization’s focus on self in a fast-paced consumerist society has actually caused autism. Autism, according to these researchers, can be seen “in the child’s desperate, frustrated attempt at socialization combined with constant and intense fear... [a] victim of our stressful environments, so different from a primitive hunting and gathering society.” Autistic people become embodiments of Nedelsky’s perfect isolation and pathological autonomy.

Not only can autism be read as an overabundance of autonomy, but it also shares the duality of self that Western philosophy has established as mind/body, authentic/inauthentic. Autism may not manifest itself until children are 18 to 30 months old which propels the idea that autism is something that happens to a child’s real identity. The late onset of autism correlates with the time frame of childhood immunizations, fueling the controversy of whether or not mercury in vaccinations causes the developmental disorder. Parents often describe this period as the point of loss, when their children slipped away into autism. Treating autism takes on an aura of a search and rescue mission in which professionals and parents try to find the lost child and autism becomes the kidnapper. Goffman described stigma as a spoiled identity and in the case of autism, it is as if the child actually spoils before their parents’ eyes, losing language, affective contact decreases, and toddlers seem to slip off into their own world. Bruno Bettelheim, another psychoanalyst and pioneer autism researcher thought that autistics were an “empty fortress,” prisoners withdrawn into their own minds. He presumed that the autistic child was escaping from parental abuse. Bettelheim’s analysis was based on a comparison of autistic withdrawal with the experience of Jews in Nazi death camps who similarly mentally withdrew from torture. Although the
linkage of abuse with autism has been rejected, the duality of selves, authentic/autistic, persists. The belief in an authentic self residing somewhere within the body of a malfunctioning, autistic self is a key component to much of the medical literature as well as integral to many autistic advocacy groups. The website of Cure Autism Now (CAN), an American advocacy group, describes “children [who] seem to develop normally for their first year or so and then begin to slip away,” similar to Bettelheim’s version of autistic withdrawal.¹⁸

Today, autism is no longer associated with schizophrenia, psychoanalysis or Nazi death camps, but in the past few years, the increasing number of diagnoses along with the association with vaccinations has transformed the developmental disorder into an epidemic. The creation of an epidemic is not merely a mathematical equation of diagnoses per population, but according to Foucault, it is a political determination.¹⁹ Linda Singer notes that the transformation of a disease into an epidemic begins when health officials realize its increasing toll on medical resources and is then used to mobilize additional support.²⁰ But as professionals and advocates portray autism as an epidemic to demand additional resources, it also creates an atmosphere of fear as witnessed in the spring of 2002 at a hearing before the House of Representatives. Representative Dan Burton, whose grandson is autistic, has equated autism with tragedy and attributes it to the level of thimerosal and mercury in childhood vaccinations, even though numerous scientific studies dispel the claim that vaccines cause autism. During the hearing, parents of autistic children, autistic people and doctors testified to the horror of autism, referring to it as an “economic and emotional burden to the country for the next seventy years.”²¹ Another person testified that the onset of autism
is like being “suddenly hit with a bomb that spreads its shrapnel from the child to the family, to education, the community, and humanity at large.”

Despite the inconsistent data in regards to Thimerosal and autism, parental groups and advocates continue to launch a national attack on drug makers for causing the "greatest catastrophe that's ever happened." Amidst the demands for funding and retribution, the representation of autism as a burden, catastrophe and childhood epidemic goes largely unquestioned. Consequently, the attribution of autism to twentieth century vaccines, the history of the developmental disorder is erased; likewise, thousands of autistic adults are neglected as the debate circles repetitively around young pre-pubescent children. Meanwhile, the assumption that the high level of mercury causes autism has led to numerous high-cost treatments purporting miraculous cures, a few which have resulted in death. If autism has spread, so too has its media coverage. In the summer of 2005, Rolling Stone published an article entitled Deadly Immunity by Robert F. Kennedy about autism and the role of mercury. Some argue that the increasing rates of autism are due to expanding diagnostic criteria, better diagnoses, and public awareness, rather than mercury. Nevertheless Kennedy persists in the vaccinations conspiracy and refers to an apparent authority on mercury toxicity as saying, "If the epidemic is truly an artifact of poor diagnosis […] where are all the 20-year-old autistics?" However, Kanner’s diagnosis of autism in 1938 guarantees that there are older autistic people; furthermore there is no proof that autism didn’t pre-date his “discovery”. Several researchers have traced autism at least into the nineteenth century. Waltz and Shattuck analyzed a doctor’s notes taken from a Children’s Hospital in London that described three cases of autistic-like behavior in children and Uta Frith and Wing have also predated autism.
Ironically, I read Kennedy’s article shortly after my brother’s twentieth birthday that passed rather unceremoniously since he doesn’t eat cake, celebrate or consistently understand how to open presents. Matt’s history parallels much of Kanner’s description of classical autism. My brother’s language developed normally at first and I am told that he had mastered around forty words before they gradually began to disappear roughly at the age of two. At the time, I was nine years old and vaguely remember performing the song “Eensy Teensy Spider” with him: him laying on the carpet, my body above his, showing him how to gesture along with the song. He had performed the song reasonably well and then it seemed to become more difficult and I thought that with more practice he would remember. His language and behavior continued to degenerate, and finally disappeared.

Over the years I absorbed the books, films, television specials and newspaper articles that all told about autistic children who had made a miraculous recovery as teenagers who had resumed language. I assumed that my brother would too; thinking that somewhere in him was his real self who would introduce himself to me one day. As a child I imagined my adulthood, overfilled with transformations: my brother would not only be talking, but he would be a genius, an autistic savant. I imagined that when he came out from his autism, he would stun the world with his brilliance and mastery of several languages, not just English. By age sixteen, he would already be enrolled in medical school. I thought that any day, he would discard his autism faster than it had appeared. And I waited. In my mind, I had given Matt a deadline: I thought that if he didn’t begin talking in his teens, he would never talk at all.

Recently, researchers confirmed my adolescent confusion: they reported that siblings’ understandings of autism are often underdeveloped and delayed, especially in regards to its
etiology and trajectory. At the time I didn’t know that savants only account for about five percent of the total autistic population, confused by their overrepresentation in media. In reality, over half of the autistic population will remain completely nonverbal, like my brother, or possess a small vocabulary which is seldom used in accordance with conventional communication patterns. Currently, the most successful form of treatment for autistic children is Applied Behavioral Analysis (ABA) which is an intensive, forty-hour a week program whose success is predicated on early intervention, ideally beginning treatment with two and three year old toddlers. ABA began in the 1960s at UCLA under O. Ivar Lovaas who focused on behavior modification to eradicate autistic behavior. When children exhibited autistic behavior they were given an aversive stimulant, either “a slap or painful electric shock” or food was withheld. Like Kanner, Lovaas noted that no child in his experiments “had any awareness that he was considered abnormal.” Lovaas interpreted autism, not as a neurological disorder, but rather a series of behaviors and believed that autism was a “hypothetical construct” which was altogether “shaky.”

Part of ABA’s appeal can be attributed to the fact that autism is still firmly lodged within a medical model of deviance rather than a social or civil rights model like some other disabilities. Peter Conrad describes four effects of the medicalization of deviance: (1) the problem of expert control, (2) medical social control, (3) the individualization of social problems, and (4) the depoliticization of deviant behavior. The first two effects cause the deviance to become privatized, removed from public discourse, and subject to supposedly neutral medical authorities who can offer cures and treatments rather than social adaptations. The individualization of social problems has the tendency to look for “causes and solutions to complex social problems in the individual rather than in the social system.” According to
Lovaas, ABA “focused on those behaviors that made the child easier to live with, such as friendly greetings and other indications of affection, as well as dressing, good table manners, brushing the teeth, etc;” with an “emphasis on making the child look as normal as possible.” Alternatively, we could question why it is so important to have children conform to normalcy. Could there be other solutions to this problem located outside of the autistic individual? Finally, the fourth goal takes the deviant behavior out of the political realm. In this respect, autism is gaining political prominence, but usually in regards to parental demands for more medical intervention rather than a mobilization to de-stigmatize its meaning.

Despite ABA’s association with aversive stimuli and its annual cost hovering between 50,000 to 70,000 dollars, it has continued to gain appeal. Recently, a research group in Wisconsin replicated the original ABA treatment used at UCLA by replacing the aversive stimulus with positive stimuli; the results proved identical to the original (which had been the most successful) results. Fifty percent of the children were able to attain a high level of functioning which allowed them to be integrated into school, however, just as many did not make any improvement. The fifty percent who did not respond successfully correlated with the children who lacked the most language skills to begin with.

While Lovaas may have interpreted autism as merely a series of behaviors, it’s likely to be permanent into adulthood. The evidence surrounding autism suggests that it is a permanent disorder rather than a childhood epidemic; however there has been relatively less research into the trajectory of autism. Kanner and associates performed a follow-up study to the first eleven children diagnosed as autistic and found that the results varied drastically. The children who had the most developed use of communication in 1943 were the most
successful as adults. They lived in the homes of their parents or other guardians and a few were able to maintain employment, although none seemed interested in developing long-term interpersonal relationships. Out of the remaining children, a few were unable to be found, and the rest had spent almost the entirety of their lives in mental institutions. Once in an institution, all of the remaining autistic adults had regressed even further.\(^\text{37}\)

More recently, a group of researchers published *Trajectory of Development in Adolescents and Adults with Autism* and determined that few autistic adults are able to amass enough substantial improvement to move them into an independent living setting.\(^\text{38}\) Instead of improvement, some adolescents and adults reach plateaus or even have periods of aggravation and regression.\(^\text{39}\) Despite my childhood belief that my brother would overcome autism, Seltzer’s et al research posits “that few, if any, individuals who receive a diagnosis of autism in childhood recover fully and achieve levels of functioning typical of their age peers” and for those that do, they were more likely to have been diagnosed with Asperger’s Syndrome.\(^\text{40}\) Seltzer et al describe the typical trajectory of autism:

> Few adults with autism live independently, marry, go to college, work in competitive jobs, or develop a large network of friends. The majority remain dependent on their families or professional service providers for assistance with tasks of daily living. Even among those who work, jobs are often poorly paid and do not provide a living wage. Furthermore, adults with autism tend to have poorer outcomes than others with disabilities.\(^\text{41}\)

Lovaas’s “emphasis on making the child look as normal as possible” remains an unlikely result. If the trend continues and almost half of autistic people remain impervious to intervention, advocacy might well turn to the development of long-term care settings.

Low functioning autism begins to look very different from the assimilated characters in *The Ringer*; the lack of language, a disinterest in social interaction, and atypical patterns of
behavior like stimming render Knoxville’s assimilation approach dubitable. Recalling *The Ringer*, mentally disabled athletes were given respect because of their similarity to non-disabled people, or as some autistic advocates classify non-autistic people as “neurotypical.” How would *The Ringer*’s plot have changed if all athletes were nonverbal autistic adults? Could the strategy of rights as sameness still work? My brother participated in local Special Olympics and I remember ribbons proudly displayed on the refrigerator. The ribbons were only for participation because he never did understand the idea of competition. At one event, when the gun was shot off to begin the race, Matt just put his hands over his ears and screamed. When all the other competitors had finished the race, Matt skipped sideways to the finish line, the crowd cheering and Matt laughing wildly. Next to a the ribbons, I remember a picture taken of Matt and my father at one such tournament: a fifteen year old boy sitting on my dad’s lap, his hands splayed out in an act of stimming, both of them laughing. When I think of Matt possibly encountering the fictitious Steve/Jeffy I know that he has the same probability of biting Steve as ignoring him. In this hypothetical situation, the idea of integration based on similarity and social interaction is impossible; thus there will have to be alternative methods of guaranteeing respect and integration for low functioning autistic people. For ABA advocates, the best method to integrate autistic people into our communities is to eradicate their autism, but the research results prove that the majority of autistic people will still be excluded from a rights community. In the next section I’ll first explain how a rights community is constructed and how that construction is premised on inclusion and exclusion; secondly I’ll explain how low functioning autistic people would fall outside of the community if the boundaries are constructed along Western core values.
Rights-as-Sameness in the Circle of Rights

“Legal boundaries in Western societies have drawn a boundary between normal and abnormal, or competent and incompetent,” Minow contends, using mental disability as a classic example of mental incompetence. The significance of being labelled different is that law treats “as marginal, inferior, and different any person who does not fit the normal model of the autonomous competent individual” and thereby excludes them from the rights community. Recognizing that people with severe disabilities have rights can be integral to the quality of their treatment. Despite the Independent Living and deinstitutionalization movements, many mentally disabled and autistic people continue to reside in institutions, often as a result of transinstitutionalization in which they have been moved from large institutional facilities to nursing homes. Long-term care facilities provide “significant use of antipsychotic medication and physical restraints, a fostering of dependence, and a loss of initiative and control of everyday life among their residents” which would easily be construed as rights violations to competent individuals. In The Rights of People with Mental Disabilities: the Authoritative ACLU Guide to the Right of People with Mental Illness and Mental Retardation, the authors conclude that people with mental disabilities have faced a long history of exclusion, stigma and rights violations. They argue that “inclusion and integration can be achieved only if the law recognizes that people with mental disabilities are fundamentally like other people and hence entitled to equality as well as fairness” (emphasis added). Ironically, the book never mentions autism.

Other minority groups have had to coordinate strategies to gain entry into rights communities, primarily by eliminating the stigma that is associated with their identities. Gayle Rubin in Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality defines
different types of sexual behavior and the people who practice them as being outside or within “the charmed circle.” In the center of the charmed circle are straight, monogamous married couples who practice the most socially acceptable form of relationship and therefore given the most legal protection. On the other hand, “deviant” sex practitioners are on the periphery and suffer legal and societal consequences, such as same-sex and sadomasochistic sex. Rights communities are similar to the charmed circle in which those in the center are accorded the most access to rights, while those in the periphery are accorded less. Rubin concedes that the center of the charmed circle is expanding to incorporate more types of sex; similarly, rights ethics have continued to embrace more and more people. But just as transsexual, sadomasochistic and intergenerational sex remain hard cases to incorporate, abnormalities or an absence in reason and association may prove inconsistent with the central tenets of rights philosophy. Instead of the charmed circle of sexual rights, we can begin to envision a Circle of Competence.

In the twentieth century, the courts have attempted to curb discrimination that rests upon stigma, but “equal protection jurisprudence in the twentieth century was strongly assimilationist.” Accordingly, oppressed classes who are able to assimilate into the silent norm have better chances of acquiring legal protections and equal status. Like Rubin’s Charmed Circle, entry into the center is based upon the idea of rights-as-sameness: monogamous homosexual sex can approach the center of the circle to the degree that it resembles heterosexual monogamous sex more than the other types of deviant sexuality. For developmentally disabled people, their path to the center of the Charmed Circle of Competence can only be made if their rational capacity and social behaviors resemble the neuro-typical class. They are not the first group to be denied entry based on their presumed
mental faculties. Women and people of color were denied rights often based on the argument that they possessed inferior intelligence, were portrayed as child-like, and naïve, a similar description still applied to mentally disabled people. However the discrimination against women and African Americans based on limited rational capacity has been declared unconstitutional and illegal, but developmental disabilities prove much more salient in court.

In *Cleburne Living Center, Inc. v. City of Cleburne* a residential home for mentally retarded adults sued the city for discrimination after the city refused to allow them to occupy a house in a residential neighbourhood. The majority opinion struck down the city’s refusal, but they only applied a rational basis test in the case, failing to put disabled people in the same historically discriminated class as women or African Americans. According to the court, “mentally retarded persons, who have a reduced ability to cope with and function in the everyday world, are thus different from other persons.”51 Since these differences are considered to be relevant to the State’s interest, Justice White struck down the quasi-suspect class that the Appeals Court had applied and negated any claim that mentally disabled people are politically powerless. The two dissenting opinions disagreed, however, Justice Stevens opinion illustrates the tendency to extend heightened scrutiny to the case based on rights-as-sameness. “I cannot believe that a rational member of this disadvantaged class could ever approve of the discriminatory application of the city's ordinance in this case.”52 Stevens imports rationality and competency into a class that is defined by their cognitive limitations.

The above example testifies to the success and failures of an assimilationist approach; in the next section I’ll explore the parameters of the Circle of Competency. What determines the competency of an individual and how does this then configure their ability to garner rights? Specifically, low functioning autism will be compared and contrasted to the
requirements of competence. While distinctions like race, sex, and sexual orientation are or are becoming less significant in regards to full personhood status, autism may represent a harder case. Autism’s difference confronts the core of the circle: rationality and association. Modernism has constructed being human as individualistic, self-sufficient, self-governing, and progress driven; these characteristics are possible based on the capacity to reason and to associate with one another according to rational and atomistic principles. Whether or not we can reevaluate autism in order to conform to the center is doubtful. In the first section I’ll look at the relationship between reason and rights; in the second I’ll consider how association and interaction determines entry into the Charmed Circle. Like Minow, I’ll argue that insisting on sameness is ultimately more exclusionary to autistic people than recognizing difference.

**Humans as Rational**

Human rights are interdependent with reason, but reason also constitutes the conception of the Western self. Binary relationships pervade Western political thought; these binaries hierarchically dichotomize the world. The self also becomes dichotomized into mind/body in which the mind is in the subject/I position while the body is relegated to the position of object. In reference to the rights of disabled people, Justice Benjamin Cardozo states that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body.” His statement alludes to several facets of Western thought: first that the mind and body are separated – the body becomes the possession owned by the self. Having a right to your body, however, is not automatic – it is predicated on being reasonable. Reason becomes the mediator of rights and even determines who has control
over their own body. Cardozo’s statement implies that those *without* a sound mind don’t have a right or ability to be self-governing. In a pamphlet organized for teachers of autistic students, the authors warn that students “might be *driven* by strong *impulses* to act regardless of rules or consequences”\(^{54}\). Reason and emotion are another duality in Western political thought in which the latter signifies impulsive, erratic and irrational tendencies, the same impulsivity that apparently drives autistic behavior.

The ascendancy of reason was facilitated by the Enlightenment, driven by the political philosophies of Hobbes, Locke, and social contract theory. In order to design a theory of governance, philosophers conceptualized a state of nature which presumable was a time and place before the government, organized society or law. Without law or socialization, mankind was imagined to be governed by a primordial human nature, an instinctual and universal conceptualization of being human. Locke described his state of nature as:

> A state also of *equality*, wherein all the power and jurisdiction is reciprocal, no one having more than another, there being nothing more evident than that creatures of the same species and rank, promiscuously born to all the same advantages of Nature, and the use of the same *faculties*, should also be equal one amongst another.\(^{55}\)

For Locke, all men could be considered equal due to their identical “faculties,” i.e. their reason. At first, Locke’s state of nature appears to be the scene of tranquility; however the peace and order is jeopardized by “noxious creatures.”\(^{56}\) Reasonable men may punish those who have quit the “common law of reason, have no other rule but that of force and violence, and so may be treated as a beast of prey, those dangerous and noxious creatures.” Accordingly, the foundation of modernism was premised along the lines of reasonable men and unreasonable men; the lack of rationality dehumanized individuals. Thomas Hobbes
state of nature, renowned for its quality of life as nasty, brutish and short was similarly
egalitarian:

Nature hath made men so equal in the faculties of body and mind as that, though there be found one man sometimes manifestly stronger in body or of quicker mind than another, yet when all is reckoned together the difference between man and man is not so considerable.  

The state of nature socialized men [sic] into conformity and this conformity allowed men to be equal. Rights as sameness is predicated on the idea that men are basically the same thus differential treatment is considered unjust. However as Locke’s conception of “noxious creatures” suggests, the rigidity of identity only seemed universal; rights were bestowed on a minority of men, rather than the multitude. Reason only seemingly created equality. It’s hidden purpose was to segment people into hierarchalized groups with each ordered in relation to its supposed measure of reason.

Surprisingly, what some consider the first documented case of autism, Victor the wild boy of Aveyron, corresponds with the conception of the state of nature in the era of the Enlightenment. Lingering beyond the theories of the state of nature lurks the question of what human behavior would resemble if humans could be created outside of socialization, assuming that left in the wild, humans would develop according to their natural instincts. Coinciding with Rousseau’s notion of natural man, in 1800 in the Aveyron district in Southern France, a wild boy roamed for several years until he was caught and given to a local doctor.  

Dr. Marc Gaspard Itard, now considered one of the founders of special education, began to work with the twelve year old boy who had been found wandering naked in the woods outside of town. The wild boy, named Victor by Itard, exhibited many behaviors now associated with autism: he was nonverbal, insensitive to extreme heat or cold, he used others’
limbs as instrumental, and possessed an obsession for sameness. Using educational theories and influence by Locke, Itard worked with Victor for six years, but the boy never made significant improvement and eventually died within the confines of an institution. Itard’s conviction in Victor was not enough to transform the wild boy into a normal reasonable man. Whether or not Victor was actually autistic is definitely debatable, however, his case is not alone in linking feral children to autism. Victor’s case raises the question of whether he was abandoned because of his abnormal behavior, or if his abandonment caused his abnormalities. Either way, Victor proved little hope for the belief in the success of education.

Social contract theory was revived in the twentieth century by John Rawls in *A Theory of Justice* which once more places reason as the most fundamental and universal human quality. Justice could be correctly attained during the original position in which mutually disinterested moral agents designed a world from behind a veil of ignorance. The veil of ignorance blinded agents to their own and others’ identities whose purpose was to ensure fairness. The lack of identity amongst agents, for Rawls, necessitated equality because agents would be unwilling to design a system that discriminated against gender, race, sexuality or disability out of fear that they themselves might embody a “spoiled” identity. The only requirement for moral agents is to be rational and mutually disinterested, both enabling them to impartially determine the principles of justice. Reason is defined by Rawls in a narrow economic sense in which rationality is seen as “taking the most effective means to given ends.”59 Rawls moral agents are therefore not mentally disabled, but he does allow them to make provisions for others who by “misfortune or accident are unable to make decisions for their good, as in the case of those seriously injured or mentally disturbed.”60
By constructing moral agents as autonomous, mutually disinterested, and rational in the original position, Rawls can then import these values into the real world as primary tenets of being human and just governance. Furthermore, he continues the tradition that equality is based on sameness in which disembodied reason becomes the facet of identity that makes people most like one another.

Rawls’s concept of redress would seemingly force the moral agents to design a society which provides for severe disability. On the other hand, Rawls limits the moral agents’ ability to discern severe disability claiming that “hard cases” can “distract our moral perception by leading us to think of people distant from us whose fate arouses pity and anxiety.” Rawls assumes that “hard cases” are not “us” thus implying that moral agents’ veil of ignorance is penetrable: their rational capacity assures them that they are not mentally disabled. Since their self is only defined by their ability to reason, they could abstract themselves from the identity of severe mental disability. Even if they would discover their “selves” in mentally disabled identities, the difference in mental functioning would render their former rational self a new and distinct incompetent self. In fact, cognitively able moral agents may find disability a “state unthinkable for oneself” and “so different as to be unimaginable.” Moreover, Rawls assumes that hard cases are “distant” and foreign to us; and by defining the original position as mutually disinterested, agents wouldn’t be interested in their own potential to be caregivers to permanent dependents. The danger of focusing on severe disability like autism is that it could potentially upset the fairness of redress. Rawls’s “idea is to redress the bias of contingencies in the direction of equality.” He gives the example of providing more money to educate the disadvantaged “at least over a certain time of life.” By not looking at severe disabilities seriously, Rawls doesn’t have to contend with
long-term dependents and extreme redress that could potentially distort the well-being of others. Redress is “not the sole criterion of justice” for Rawls. Instead, it is weighed “against the principle to improve the average standard of life, or to advance the common good”.65 Attending to the educational and caring needs of severely autistic individuals might drain too many resources from the “average” standard. Rawls concept of disability also assumes that the response of pity and anxiety is natural rather than socially constructed. However, it seems quite plausible that Rawls himself could have designed the original position with the regulation that pity was an unacceptable response to disability, especially with the interjection of mutual disinterestedness.

Rawls doesn’t deal with dependency or disability very well because he has a conception of being human that completely ignores the realities of an embodied life which then affects his conception of Justice. Rawls assumes that “the desire to act justly derives in part from the desire to express most fully what we are or can be, namely free and equal rational beings with a liberty to choose.”66 Liberalism creates a conception of being human that is contingent on competency and self-determination, but how are people read as rational or irrational? Reason and freedom must be interpreted through action. My contention with liberalism and autism is that the former excludes the latter due to an insufficiency in reason. If autistic justice is my aim, I have several options. First, following the wisdom of The Ringer, I could only use high functioning autistic people to prove that they really are all reasonable. Secondly, I could accept that some autistic people are incompetent and then I could either accept their exclusion from a full spectrum of rights, or I could find alternative strategies of empowerment. My first objective is to prove the incompetence of some autistic dependents in order to justify the creation of alternative methods towards a just society. To
do so, I assume that reason can be understood in several ways, among them three abilities: to communicate through language, to be productive, and to strategize methods of empowerment. Finally, our willingness to extend rationality to formerly stigmatized groups may be linked with our ease at conceptualizing them as sexual beings. To some degree, low functioning autistic people will fail at all four categories; and not only is it an absence of reasonableness that pushes them away from the center of competence, but also the manifestation of irrational behavior. Thus autistics may be denied entry into the center and even the periphery of the Charmed Circle of Competence.

Disaggregating reason and language may be impossible and it is this that makes autism such a hard case on the periphery. In Hobbes’ *Leviathan*, he begins by describing being human in terms of its most basic function of sensory perception and then gradually adds characteristics which will lead to Reason. Between sense and reason is imagination and speech; it is in this process that autism fails to mature into an authentic state of being human.

The imagination that is raised in man (or any other creature endued with the faculty of imagining) by words, or other voluntary signs, is that we generally call understanding, and is common to man and beast. For a dog by custom will understand the call or the rating of his master; and so will many other beasts. That understanding which is peculiar to man is the understanding not only his will, but his *conceptions and thoughts*, by the sequel and contexture of the *names* of things into affirmations, negations, and other *forms of speech*: and of this kind of understanding I shall speak hereafter.67

It is not enough for humans to respond to language; they must simultaneously produce it and order their conceptual world around language: the demarcation of languages separates humans and dogs. Conversely, Temple Grandin, a college professor and autist, describes her consciousness as a series of images that she then must tediously translate into language.
which for her isn’t a natural process. For Hobbes, nonverbal autistic people might seem more similar to dogs than humans. Even Grandin assumes that it is her autistic mind that enables her to read the thoughts of animals on the assumption that her brain functions in a non-human animal-like manner. Rawls’s original position also necessitates common language; justice is derived from consensus reached through discursive strategies. Fifty percent of the autistic population is nonverbal. Even amongst those who possess speech, it might be nonsensical to almost everyone. Language does not necessarily have to be verbal, but an informal communication system based on gestures might convey certain needs, but not necessarily reason.

An inability to communicate through language creates two problems for reading reason into autism: first because the autistic self without language contradicts notions of reasonableness and second because others will be unable to understand the desires, needs and concerns of the autistic person. For instance, even when my behavior appears unreasonable (moodiness, erratic anger, etc.), I can use speech to explain my conduct to import reason into it. After living around an autistic person for twenty years, I still ask what motivates some of his behavior, questioning his changing dispositions. The lack of language accentuates at times how distant we can be from one another, especially when I or my family perceives that he may be in pain, but can’t discern if it is a toothache, headache, sickness, or just depression. The nonverbal person is rendered less rational and emotionally distant, accentuating the foreignness of the Other that suggests non-human status. For example, when I thoroughly explain my brother’s nonverbal state to others, they often draw a parallel to animal rights rhetoric, again suggesting that his status is more akin to a dog than my own.
Alternatively, people with disabilities can interject reason into their identity if they can prove that they are productive. Conversely, they can also be excluded on the basis of their unproductivity. Some autistic people are highly credited for being productive and autistic, for example, Temple Grandin. Recently, a teenage boy was visited by the President of the United States for scoring a record number of basketball points at the end of a high school game and for being autistic. In fact, being productive, successful and developmentally disabled is considered awe-inspiring; President Bush cried when he met the young basketball star. Disability studies recognizes this as the Super-crip theme in which disabled people’s achievement is read as amazing “in spite of their disabilities.”

This narrative functions to normalize the person as productive at the same time that it renders them extraordinary for that production.

For instance, in *Freedom through Flight: Performing a Counter-Narrative of Disability*, the authors explore how Passion Works, a non-profit organization that supports artistic collaborations in my local area, provides employment and therefore political mobilization to mentally retarded and developmentally disabled adults. Although the authors seek to provide a counter-narrative to people with disabilities, they only choose to interview non-disabled staff workers, volunteers and family members who then offer interpretations of the disabled artists’ works. According to the non-disabled interviewees, the act of producing the artwork for the artists accomplish a “freedom through flight” in which artistic productivity enables them to “surpass limited understandings of mind and body, and to function as holistic human beings.” Performing authenticity as a whole human now dictates not only reason, but instrumental rationality that produces objects that non-disabled others can read as valuable. Echoing *The Ringer*, a non-disabled staff artist describes the act
of producing artwork as revealing a “whole complex person working inside them just like everyone else” (emphasis added). The article supposedly offers a counter-narrative that worth is a result of producing, however, the interpretation of the product remains in the domain of the neuro-typical. The staff and volunteers read the artwork as if it signaled a hidden rationality. Like the social model theory, it is not the disability that it is disabling, but it is only the stigmatization of mental disability that makes the neuro-typical assumption of the other’s inferiority. If we took the time to study the lives of developmentally disabled people (and provided them with an art studio with assistants), we’d realize that they’re not really impaired. Incompetence becomes merely a myth. When I voiced my skeptical concern for Passion Works to a colleague, saying that not all disabled people can participate in roles that require motor skills, like my brother, she suggested that perhaps I was unaware of hidden potential in my own brother.

Despite Passion Works seemingly inclusive attitude, the assumption that developmentally disabled people have hidden talents or need to be productive may be more threatening than the rule of language for entry into the Circle of Competence. First, it thrusts people with severe disabilities into the same mold that non-disabled people are expected to fill. Martha Nussbaum, while recognizing the limits of severe disability, insists that society should focus on finding them vocational outlets. According to Nussbaum, some “citizens with many mental impairments are capable of employment. If [they] cannot find a job, well, what other ways might there be to give [them] some measure of control over [their] social environment.” Alternatively, we may question whether people with severe cognitive disabilities, like autism, are even socialized into valuing ideas like control, work ethic, or productivity.
Furthermore, vocational centers may be of secondary importance compared to parental concerns for the establishment of trustworthy residential centers disabled children. Examples like Passion Works are vocational facilities offered through the Ohio Department of Mental Retardation and Developmental Disabilities (ODMR/DD). Currently in Ohio, two of the twelve residential centers for people with developmental disorders are being closed; at the same time, parents and legal guardians are demanding more specialized services for certain disabilities, among them autism. In a report about the current situation of ODMR/DD, parents’ major concern was not the establishment of additional vocational centers, but rather the closure of residential facilities. “Parents indicated that their greatest fears were that more centers would close and their children would be forced to move into an unsafe residential center.”

When my family approached our local board of MR/DD to find an appropriate day placement opportunity for my brother, the severity of his behavioral disorder compounded with the idiosyncrasies of his autism prevented him from any vocational prospects. Vocational centers assume a level of skill that for Matt was unattainable. A counter-counter-narrative could recognize that the limited capacity in some developmentally disable people prohibits them from participating in vocational training, and yet, they still require special services. The narrative of developmental disability as able-oriented and productive masks individuals whose disability is disabling. Garnering rights for disabled people, under the ADA and Passion Works, amounts to abilitizing disability. When impairment is constructed as a societal prejudice, people with severe autism whose behavior and disorder prohibit functioning and productivity may become further stigmatized.

Real incompetence forces us to rethink traditional empowerment strategies. Although liberalism creates a bounded community that excludes deviant groups, it also presents the
tools for inclusion. The rhetoric of universalism has enabled marginalized groups to challenge their enforced subordination, such as women, African-Americans, colonized indigenous people, and people with physical disabilities. However, as previously stated, the empowerment process is one in which oppressed groups develop a group consciousness and then demand rights based on the same fundamental core of being human that makes people equal. Disability rights rhetoric mirrors this tactic when they base their moral personhood claims on autonomous, self-determined consciousness and action. In response to the ADA, Justin Dart, a disability activist proclaimed, “Empowerment is the issue of the age…. Nobody is going to give it to us. We have to empower ourselves.” Anspach insists that the first step of a successful disabilities movement is to convince others by their actions that they are “independent, rational beings, capable of self-determination and political action.” Anspach and Dart assume that empowerment necessitates competency, independence, and self-awareness as disabled, but as Kanner and Lovaas noted, many of their autistic patients were incompetent, dependent and unaware of their disabling condition.

In Nothing About Us without Us: Disability Oppression and Empowerment, James Charlton uses a Marxist framework to analyze disability discrimination concluding that it is the inability for people with disabilities to be productive members in a capitalist society that excludes them. Following Marx, Charlton accuses people with disabilities of false consciousness, claiming that they have internalized feelings of shame and alienation. Assuming that “everyone has a consciousness,” he simultaneously remarks that his book lacks the perspectives and stories of people with cognitive disabilities, even though they represent the largest portion of the disabled community and suffer from the most oppression. He can’t see that the model of empowerment is itself disabling to people with
severe developmental disorders. Consciousness-raising as an integral aspect of empowerment demands the ability to reason; conversely, the inability of a group to reason masks oppression as paternalism. The same strategy that enables empowerment enforces the subjugation of irrational citizens.

Extending instrumental rationality to severely developmentally disabled people in regards to Special Olympics, empowerment and artwork, however, is drastically different from conferring the same ability of self-determination in relation to sexuality. Exclusion from the Circle of Competence based on inferior reason can be accompanied by assumptions about uncontrollable sexualities, as in the case of African American men, women, and the mentally disabled – all of whom have been labeled incompetent. Uncontrollable sexuality, in men, is then also linked to violence. American novels such as *Of Mice and Men* and *The Sound and the Fury* explore what happens when mentally disabled men are sexually enticed. In *The Ringer*, the male athletes were attracted to women, but only women who were also mentally disabled. When Johnny Knoxville’s character fell in love with Lynn, the neurotypical volunteer, he was only able to express his desire legitimately when he came out as non-disabled Steve. When he had attempted to kiss Lynn while in the personae of Jeffy, she immediately protested. She was so remorseful over the incident that she renounced her status as volunteer. People with mental disabilities are then rendered *not* just like us. Part of the discomfort related to sex and mental disability is that it contradicts the image of the mentally disabled person as permanently child-like. Uta Frith, an autism researcher, characterizes the life of autistics as “permanent immaturity” because of their incomplete development.77 Thus the rhetoric that people with developmental disabilities are just like us masks our unwillingness to extend them all the rights and responsibilities associated with being “free
and equal rational beings with a liberty to choose.” Neurotypicals, like Lynn, police the boundaries of appropriate behavior for mentally disabled people while simultaneously cloaking their exclusionary gaze as falsely-encompassing.

Finally, autism can be accompanied by traits that appear completely irrational; rather than the absence of reasonableness, irrational behavior may be why Rawls thinks hard cases are so distant from “us” – autism can evoke a feeling of foreignness in non-autistic people unaccustomed to its traits. Among autistic behavior that could easily be construed as irrational are self-injurious behavior, no real fears of danger or pain, tantrums, and an obsession with sameness. Conversely, Rawls’s moral agents are constructed to be risk-averse. They are endowed with the ability to envision the fear of danger and pain. Reason then becomes further defined away from autism: the inability to process danger/pain as fear is irrational. Instead of being risk-averse, autistic people can be fear-averse.

Katharine Beals, mother to a six year old autistic son, explains the challenges of raising a child who is fear-averse. “Try taking him out,” she warns, “and watch him run straight for the street, looking gleefully over his shoulder at your scurrying feet as you desperately try to catch him before it’s too late.” Similarly, when my family moved out into the country, our house was alongside a state highway. Matt, like Beals son, developed an impulse to run out into the road. We tried to always know his whereabouts in the house, but sometimes when the house would fall eerily silent, my mother would ask, “Where’s your brother?” My older sister would quickly begin to search the house while I hot-footed it to the highway. I still remember the slap-slap-slap of my bare feet hitting the hot pavement as I bolted down the road seeing the cars that had quickly careened to the side of the road to avoid the blond-headed little boy, no more than nine years old. Growing up with autism, I
sometimes forget how strange my brother’s behavior can be, but when outsiders enter my family’s home, we all become hyper-sensitive to the fear of what Matt may do.

I have attempted the reverse of the Independent Living strategy by pressing the incompetence of severely autistic people because of their inability to manifest reasonable behavior. By being unable to communicate and unproductive, severely autistic people lack the skills that have typically been used to organize empowerment movements as well as losing the ability to argue for rights based on sameness when the sameness refers to rational capacity. Insisting on the reasonableness of being human also affects the methods of our association. When severely developmentally disabled people deviate from normal patterns of interaction they become further positioned from the Center of Competence. Liberalism constructs an organizational pattern for public justice and private interactions. Association has been implicated by reason in this section in the discussion of communication, sexuality and empowerment strategies. In the following section, I want to unpack some of these assumptions about how people perform association and further how autism continues to disrupt the conventions of being human.

**Human Association**

Liberalism divides the world into public and private spheres; in the dichotomy of spheres, each represents polarized characteristics. The public becomes the sphere of men, rationality, equality, justice, and law. The private sphere then becomes associated with women, emotion, care, and uneven power relationships are often masked as natural and beneficial. Autism problematizes both worlds. Incompetence bars low functioning autistic people from full participation in the public realm and atypical patterns of association can also
disrupt the care in the private sphere. Kanner’s autistic aloofness also adds additional challenges to political empowerment since mobilization is often strategized for self-identified groups who recognize their own oppression. Rawls’s description of fully human being as equal, rational, and self-determined not only models personhood, but affects association. Even though the original position was mainly concerned with designing the social structures for public policy, his description of human beings would seem to permeate both realms. Furthermore, if the state imagines its citizens as free, rational and competent, it’s unlikely that public policy will adequately address the needs of permanent dependents. Surprisingly, Rawls depiction of mutual disinterest may prove more autistic than autonomous. In the following section I want to address how our implicit assumptions about human association further propels severely low functioning autistic people away from the Center of Competence and rights.

Liberalism’s construct of autonomous rational agents leads to the construction of association in terms of contractual relationships in which people deliberate and can consent or dissent. The equality of reason in the original position allows each moral agent an equal standing in deliberation: one moral agent, equals one voice, equals fairness. Language is integral to our normative concepts of being human not just because it serves as proof to an inner rationality, but also because it forms the bonds of interaction and provides rules for association. The loss of language not only is interpreted as a progression of withdrawal into the self, but also as a process of distance between the child and parent. The return of language is also a return to association with others. In an article entitled *I Love You says Miracle Boy* the author describes the return of language as a return to interaction:
They were the precious words a devoted mum had waited four years to hear from her little boy. As Kimberly Mason tucked up son Spencer in bed he whispered: "I love you." - in a show of affection he had been unable to give till then because autism had trapped him in his own world.81

By upsetting language, autism upsets the ties of association, in part because of what Kanner referred to as autistic aloneness. Another family of an autistic son, Aaron, explained how his aloof manner not only isolated the young man, but it also isolated other family members away from him. "I don't think he likes to play with me," one of Aaron's brothers said. "When I touch him, he goes away."82 As Aaron’s father poignantly confessed, "You don't realize how important a conversation is until you don't have one." Language cements the bonds between autonomous and isolated individuals. Language becomes the answer to Nedelsky’s fear of autonomy devolving into isolation. The words we speak become rafts, tossed out into the vast ocean, hoping that another will hear the spoken words and pull us from our remoteness.

By not communicating in a typical manner, autism jeopardizes the bonds that people establish between one another. The autistic person, failing to interact in a normal way, can then be rendered deviant again, not only for the way that they act, but for their lack of engagement. “We must recognize,” insists D.H. Kelly, “that deviance and the deviant emerge out of a continuous process of interaction among people.”83 Underlying interaction are unspoken codes of behavior that are slowly ingrained during development, but for autism, these processes may never be learned. Kelly concludes that the “probability of rehabilitating someone who does not view his or her activity or career as deviant is poor.”84 What Kelly refers to as rehabilitation could also be termed assimilation.

Thus the ability of autistics to assimilate is only partially related to language; it is also
predicated on the ability to follow implicit notions of conduct, like tone of voice, spatial distance, the voice’s volume. Among the half of autistics who are able to comprehend and utilize language, their inability to relate in a normal way to neuro-typicals still sets them apart as different. Lorna Wing, autistic specialist, divides children with autism into sub-types based on their particular type of deviant interaction: aloof, passive, or active-but-odd, although the categories are not strict and autistics may fluctuate between them at different times. The aloof type avoids interaction, the passive type will respond to interaction but will not initiate it, while the active-but-odd autistics will engage with others but only in an odd, repetitive and, often, inappropriate manner. Wing generally associates active-but-odd mannerisms with high functioning autistics, such as those with Asperger’s Syndrome, while the aloof personality is more likely to be a trait of someone nonverbal. Beneath Wing’s division of autistic deviant behavior, an idea functions silently, suggesting to us that there is a normal, stable and socially acceptable method of interaction.

For instance, some autistic researchers refer to a theory of mind called “mindblindness” that apparently affects autistic people differently than neuro-typicals and therefore results in a very dissimilar style of association. Some studies have maintained that autistic children are unable to comprehend another person’s internal thoughts. Researchers note that autistic children have problems with the “Sally-Anne task.” Autistic children observe Sally placing her doll in a box, then see her leaving the room. While she is gone, Anne moves the doll to another location, for instance, under the bed. When Sally returns, the autistic child is asked, “Where will Sally look for her doll?” They consistently reply that she will look for her doll under the bed where Anne placed it. The term mindblindness is used to designate how the autistic mind is unable to grasp the perspective of another, like Sally, who did not see the doll
move. Other autistic people themselves attest to the fact that it is hard for them to read nonverbal cues, thus they may have the idiosyncrasy of being long-winded because they cannot read the nonverbal cues that the other person is sending, alerting them that they are uninterested. Others offer accounts that they are not able to recognize faces in different circumstances creating a much longer duration between someone being construed as a stranger or acquaintance. Critics argue that the experiment is meaningless, insisting that it proves little. The Sally-Anne-Task is built upon the false belief that neurotypical people do have the ability to mind read, which of course, is not always true. Why autistic minds process information differently from non-autistic minds is unknown, but what it does suggest is that difference does exist and these differences may correlate to some assumptions made by liberalism and rights-as-sameness.

Liberalism assumes that our universal identities will render behavior comprehensible and further postulates that social cooperation exists. Human nature’s drive towards social interaction, for Rawls, manifested itself in its most reasonable form as reciprocity which guided just associations between humans. Rawls refers to it as the “criterion of reciprocity” when reasonable citizens, “viewing one another as free and equal in a system of cooperation over generations, […] are prepared to offer one another fair terms of social cooperation” while under no constraints of domination or manipulation. The process behind the original position assumes that power originates amongst collective rational activities. Empowerment strategies to enter into the circle of rights are also organized around self-identifying with a group and then collectively bargaining against the dominant class.

For autistic people and advocates, this strategy of empowerment may prove problematic. Anspach proclaims that “the new activist groups,” unlike their predecessors,
“are composed of the disabled themselves, seeking social change through their own efforts, rather than through others acting as surrogates.” But for low functioning nonverbal autistic people, how would they organize to seek social change? Furthermore, social protest is often organized around a desire for inclusion which may not exist within some autistics. Judy Singer, an autistic advocate who diagnosed herself late in life, argues for an alternative political consciousness organized with the traits of autism in mind:

A challenge to the disability rights movement materializes: how do you include people who may need the benefits of inclusion, but cannot bear the physical and emotional presence of it? The answer from their/our point of view is that we don’t want to be included, we want mutual understanding, clear boundaries, appreciation of our gifts, based on what we can do, not what we can’t. Perhaps as the voices of the ‘neurologically different’ are heard more loudly, a more ecological view of society will emerge: one that is more relaxed about different styles of being, that will be content to let each individual find his/her own niche, based on the kinds of mutual recognition that can only arise through an ever-developing sociological, psychological, and now neurological, self-awareness.

While I agree with some of the premises that Singer lays out, I have trouble with her version of autistic needs. First, Singer’s own position as a self-identified high functioning autistic person arguing for the rights and needs of all autistics is less than self-critical, especially when she uses the medium of “voice” to express all autistic needs. Furthermore, Singer’s claim that she is definitively autistic because she has had a life-long problem with being a part of groups minimizes the ostracizing affects related to severe autism: that for some autistic people, being a part of a group is not their choice to make. Singer wants to differentiate autistic needs from the larger disabilities framework by arguing against forced inclusion, but she maintains the identity of the autistic person as a self-determining autonomous agent.
Perhaps problematically, I’m contesting Singer’s ability to be an authentic voice speaking on behalf of the autistic spectrum. The way that we have imagined group formation is that individuals with particular identities identify with one another as the same. As a group member, that individual in some ways becomes associated with the entire community. In *Globalizing Feminist Ethics*, Alison M. Jaggar confronts many of the difficulties associated with discursive communities and their strategies for empowerment, notably the process of becoming a community member and then how that community polices its borders to maintain its identity. Concerned with “who is able to participate and who is excluded, who speaks and who listens, whose remarks are heard and whose dismissed,”88 Jaggar asks, “Who is entitled to speak for a group as a whole and whence derives her authority?”89 The problem with traditional forms of empowerment is that it assumes that an authentic speaker must have the identity of the group that he/she is defending. Ed Roberts, a prominent disabled activist contends, echoes Singer’s concerns when he insists that disabled activists must speak for themselves and cannot risk trusting the opinions of non-disabled people.90 However, the insistence that the authenticity of the speaker must be based on similar group identity further marginalizes nonverbal low functioning autistics.

On the other hand, liberalism has too often relied on paternalism when it assumes that the oppressed are unable to speak for themselves. Rawls argues that, in the original position, moral agents decide that the principles of paternalism will suitably apply to people with developmental and mental disabilities.

Others are authorized and sometimes required to act on our behalf and to do what we would do for ourselves *if we were rational*, this authorization coming into effect only when we cannot look after our own good. Paternalistic decisions are to be guided by the individual’s own settled preferences and interest insofar as they are not irrational… As we know
less and less about a person, we act for him as we would act for ourselves from the standpoint of the original position. [...] We must be able to argue that with the development or the recovery of his own rational powers the individual in question will accept our decision on his behalf and agree with us that we did the best thing for him. (Emphasis added)\textsuperscript{91}

Rawls maintains that to the degree the other person becomes more foreign to ourselves we must act for them as we would act for ourselves, ignoring their differences insofar as we regard them as irrational. But assuming that another person’s needs are identical to our own can be too much of a presumption, especially when the other is autistic and may have very different needs and desires that might be construed as irrational. Singer is arguing for neurodiversity: an acceptance of different cognitive ways of being in the world, but Rawls suggests uniformity in deciphering the needs of others as if cognitive difference were irrelevant. Rawls maintains a duality between the authentic normal self and the inauthentic disabled self, referring to a process in which the person recovers their rational capacities. The needs of the Other and the needs of the normal moral agent are, for Rawls, assumed to be identical.

The problem with association and autism is that we have yet to design a method for dealing with difference. We insist that the Other is really the same. When the Other does fail at assimilation and self-determination, their needs become the property of another to decide. Theories of mindblindness and Wing’s interpretation of the three personalities of autism suggest two things: one is that autistic difference does exist, but two, it also suggests that there is a norm somewhere for comparison. In The Ringer, the problem was solved by denying that it was there: neuro-typicals and mentally challenged interacted along typical patterns of behavior mediated through language. In my first chapter, I have begun to question the limits of rights-as-sameness. If autistic people’s identities don’t conform to the
norm and if their manners of association do not engender similarity, what is to be done?

Liberalism relies on stability born from the sameness that exists uniformly across all individuals, in spite of their particular differences. Autism contests this belief in sameness, stability and rules of association.

**Conclusion:**

My objective in this chapter has been to illustrate the difference of some forms of autism; my project has therefore been antithetical to many forms of empowerment in relation to liberalism since I have attempted to accentuate the foreignness and alienation of autism when situated against neurotypical behavior. I have not done this because I believe that autism represents an inferior way of life that therefore doesn’t necessitate rights; rather I contend that the demand for assimilation which is predicated on rights-as-sameness will render nonverbal low functioning autistic people as excluded. Instead of arguing about how autism could be seen as reasonable, self-sufficient, autonomous or competent, I want to dismiss the rhetoric surrounding liberalism’s construction of being human as well as the strategy for inclusion. Nor do I intend to rely on an argument based on animal rights as the surest way to integrate autistic people into a rights community. If liberalism can’t integrate all individuals into a *universal* scheme of rights, then there might be something wrong with liberalism, not autism. Autism never promised to be like non-autistic behavior, but liberalism has offered the assurance of a world premised on equality, universal rights and dignity.

Other authors attempting to integrate autistic people into the nondisabled population contend that the best strategy of inclusion is to assume competence, but this chapter has
attempted to render that suggestion as dangerous. Not every autistic person will manifest all of its most atypical behaviors, but if competency is set as a standard to judge all persons, there will undoubtedly be some mentally disabled stranded on the outskirts of justice. Rather than sifting through autistic experience to prove productivity, we might question the alliance between full human status and reason. This chapter has also unearthed ways in which the belief in autonomy is only partially true: autistic aloneness, a state of being which is resistant to outside desires, is construed as pathological, tragic, and deviant. Perhaps it is not autonomy after all that constitutes our identities.

If autism is a burden and a tragedy, as was argued before the House of Representatives, the remedy is to find a cure in accordance with the medical model of disability. While the social model and civil rights approach to disability may not be able to grapple with the real differences of autism, the medical model is surely not the best answer either. The ADA is problematic because it is predicated on assimilation, individualism, competence and self-sufficiency. It refuses to acknowledge disability as disabling or as an issue of dependency. Liberalism attempts to base dignity and rights within each atomistic individual, but we may begin to ask if there are alternative ways of valuing being human. In the next chapter, I’ll look at an ethic of care which focuses on the interdependence of people and mutual care, rather than individualism, autonomy and competence. Can care imagine alternative ways of being human that refuse to devalue an autistic way of being in the world?
Chapter 3:
Is Care The Answer?

In the summer of 2005, a news story began to emerge from a rural town in Northern Ohio: eleven adopted children were removed from their foster home when it was discovered that nine of them were being kept in wooden cages. The horror of the story was quickly mitigated when it was further revealed that all of the children had special needs, ranging from fetal alcohol syndrome, HIV, Down’s syndrome to autism. Suddenly, the couple’s behavior, normally construed as child abuse, became questionable: did the wooden and chicken wire cages amount to barbarity or was it admirable that they had adopted so many disabled children that nobody else had wanted. The confusion illustrates how the value of care transforms when the charges are severely disabled. The children’s disabilities overshadowed their abuse: several news articles seemed just as surprised that one child was diagnosed with pica, a disorder which is characterized by eating dirt, as to the arrangement of cages as living quarters. Arguing that the enclosures protected the children from one another and themselves, the Gravelles maintained that as soon as they were found innocent, they would fight for the return of custody of all eleven children.

Amidst the criticism of the Gravelles, several parents of autistic children came to their defense, contending that the story only appeared inhumane to people who had never had the burden of caring for autistic children, some of whom are prone to wander away from home and engage in aggressive behavior. One mother in Texas said that the Gravelles should be applauded rather than condemned; the foster parents were doing all that they could do to care for eleven special needs children. In an article entitled Children in Cages? So what’s the
Problem?, another desperate mother explained how her family was on a vigilant watch over their autistic son after they discovered that he was wandering in the neighborhood about to expose himself to a younger child. “There aren't exactly people lining up to take care of these kids,” she remarked, raising the dilemma that if it weren’t for the Gravelles, where would these eleven children be?95

Regardless of the eventual verdict of the Gravelles, it is apparent that autism and other severe disabilities raise new implications for caregivers, issues that may be unfathomable to people who have never experienced profound disabilities. What is the moral response to children with no communicative skills who are apt to wander from home without the knowledge of dangerous consequences? Autistic children who have wandered from home have been found killed after walking in front of oncoming trains or drowned in backyard shallow ponds. Autism is a hard case for moral reasoning, not only because it defies assumptions about typical human capabilities, but also because it threatens the ideal relationship that people have with one another. In my own family, my younger brother’s autism has changed my conception of appropriate care and has led me to question the ability of one family to care for a dependent in their own home. Rawls argued that issues related to disability were barred from the original position because it threatened to burden the disinterested moral agents with pity, implying that their emotional response would cloud their judgment.96 In effect, Rawls agents were guaranteed to be neurotypical (a term created by autistic advocates to refer to non-autistic minds) and ignorant of the possibility of profound mental disability, but for those of us not privileged with the ease and comfort of disembodied agents, issues related to disability, dependency and ethical care are at the center of moral reasoning as well as our lives.
In response, care ethicists explore the questions that previous theorists assumed were too private or too complicated for general moral principles, paralleling many of the concerns that were raised in the first chapter. An ethic of care could problematizes the private sphere because of feminist theorists who had politicized the personal. Feminist theorists also grounded their theory in experience as a starting place for ethical consideration. Unlike Rawls who began with an abstract original position, feminists looked at their own experience as women to uncover different aspects of power and oppression. Christine A. Littleton differentiates between two primary methodological questions in feminism. First, what constitutes women’s lived experience, and secondly, which aspects of that experience have been ignored in dominant moral paradigms? Care work then becomes a principal object of a feminist revision of experience and ethics. Care work had previously been rendered invisible by theories that had previously only focused on the public sphere, especially in regards to rights and responsibilities. But care constituted the lives, experiences and moral dilemmas of many women, thus it could no longer be ignored as marginal or private to theory. The methodology of experience expands the boundaries of political theory.

For instance, how do we expand the Circle of Rights to encompass people with all levels of capabilities and needs? From chapter one, we know that rights rhetoric of universality only masks the bounded-ness of the circle. What principles of justice guide the behavior between unequal persons, such as dependents and their dependency workers? By focusing on dependent relations, often by using the mother/child dyad as a point of reference, care ethicists tackle dependency, exposing autonomy, competency and the self-sufficient nature of families as destructive myths, especially for women who have predominantly carried the burdens of care and the dependents in their charge. Can an ethic of care help us
understand the moral consequences of autism? What dilemmas does it illuminate and what remains unresolved? In the first chapter, autism rendered reason and inclusion problematic; will an ethic of care be the answer?

In the following chapter, I will explore three aspects of an ethic of care that differentiate it from liberalism and potentially enable the needs of nonverbal low-functioning autistics to be incorporated into a system of justice: the challenge to public/private spheres, the realization of dependency, and the mother/child dyad. I believe that an ethic of care can expose the myths of autonomy and self-sufficiency; however, I do not think that it can de-stigmatize mental disability completely. By politicizing the family, a care ethic can question dependency, but it’s reliance on the mother/child dyad as a model of care potentially recreates the problems of liberalism. First, early approaches to care reinforced women’s gendered role as mother/caregiver, but the dichotomy between mother/child becomes controlled by Western Thought’s construction of binary categorization. By focusing on the benevolent maternal bond between mother and child, a care ethic creates a normative relationship, posing a risk to low-functioning autistic people who deviate from the appropriate “child” role. Will care maintain justice if the dyad is rendered problematic by disability? In the following chapter I will argue that an ethic of care should challenge liberalism’s public/private distinction and its reliance on reason to begin moral debate about dependency. However, the reliance on the mother/child dyad prohibits a care ethic from dismantling the home’s private status and its normative construction of benevolence maintains the exclusion of low-functioning autistics. I contend that the well-being of autistic dependent adults necessitates that we go beyond the home and beyond care to render justice complete.
An Ethic of Care: Underlying Themes

I will first begin by describing some of the basic principles of an ethic of care. Care ethicists begin by questioning liberalism’s primary attention to moral discourse situated between autonomous agents. This construction of justice privileges the public sphere, historically the realm of men; meanwhile women and dependents are assumed to be beyond justice because of the family’s “natural” arrangement in the private sphere. Maintaining the ethos of binary thinking, the public domain is masculinized and its attributes of individualism and impartiality are advantaged. Consequently, femininity as embodying desire, care, weakness and the body, is relegated to the home and devalued. For care ethicists, women and dependents are subordinated and devalued in the home; however, liberalism insists on this public/private division so that the home’s privacy becomes a haven from the impersonal public domain, guided by women’s different moral nature constituted by care and affection.

The denigration of women’s moral nature and the masculinization of morality were challenged by Carol Gilligan, a psychologist and student of Lawrence Kohlberg. Kohlberg’s moral development culminated in the rhetoric of universal rights’ principles similar to Rawls’s original position which privileged masculine perspectives. According to Gilligan, Kohlberg misinterpreted women’s different moral voice when he positioned it as underdeveloped and inferior to an abstract rights discourse. Instead, Gilligan saw women as responding to their gendered socialization which had prepared them to be primarily responsible for the preservation of relationships and child rearing. Specifically, daughters’ relationships with their mothers and their own capacity for mothering created a morality
embedded in interdependence, a necessary precondition of women who would most likely have to subvert their own interests when they assumed care for dependents. An ethic of care, therefore, was not a replacement for justice, but an alternative perspective for different concerns that were typically associated with women’s experience.

Relying on Gilligan’s new moral voice, feminists disputed the hegemony of liberalism’s moral discourse that had consistently devalued women, care, and partiality. Liberalism’s ideals of formal equality and universal rationality not only create a masculine bias towards the qualities of being human, but the discourse of reason and equality has failed to produce universal justice. According to Iris Marion Young, women and other subordinated classes have relied on rights-based discourse for two hundred years to demand equality, but relationships of domination and subordination persist. Liberalism is fundamentally flawed because the focus upon equality and universal rationality merely masks subordination; unfortunately, the invisibility of inequality does not make it disappear. Subordination is not quarantined in the home, but continues to affect the public discourse of justice, contaminating its supposed impartiality. Liberalism patrols the divide between public and private because it needs the equality in the public sphere to be unaffected by private relations of domination and subordination as if difference could be “bracketed” and inconsequential to justice. Under this policed divide, issues surrounding permanent dependency and autism are contained to the privacy of the home and considered “irrelevant” to the common good. The repercussions of this divide are apparent in the Gravelles’ example. Neighbors questioned how so many children were kept in such a small house and a few outsiders were even aware of the children’s cages, but the home’s aura of privacy combined with the children’s deviant disabilities created a situation in which care was left to
the private discretion of parents. In effect, the home can remain unjust, but liberalism hopes that the injustice will not filter into the public arena of law and policy.

Marginalizing dependency is in accordance with liberalism’s construction of autonomous agents and self-sufficient families: under this construction, families are responsible for managing the dependency needs of all its members. Being human in this discourse is controlled by autonomy, competency, and reason; these values also permeate conceptions of appropriate familial dynamics. According to Martha L. Fineman, the individual and the family are both regulated by the ideals of autonomy and self-sufficiency. Dependency is first rendered invisible because it is seen as unnatural for individuals and secondly because it is regulated to the private sphere of families. The construction of an ideal self-sufficient family works to marginalize permanent dependents, constructing them as deviants to the hegemony of autonomy. Rhetoric masks dependency: the ideal self-sufficient family and the autonomous individual are both myths that work to stigmatize members of society who are dependent and the dependency workers who care for them. Low-functioning autistics are stigmatized for their incapacity to be autonomous and their families become a burden upon society if they are unable to manage their dependency needs. Some public policies recognize these needs. Public education and IDEA provide families with an outlet for their special needs children until the age of twenty-one, but adult dependency needs are relatively forgotten. Although the ADA promised that small residential facilities would be created locally to cater to the long-term dependency needs of mentally disabled adults, it has remained an unfulfilled promise as many incompetent adults languish in large institutional settings, like nursing homes, and their “care” is controlled by anti-psychotic medication. This empty promise garners little protest from the dependents.
silenced by their powerlessness and reflects how the entire debate of dependency is rendered silent by its “private” nature.

Conversely, if mentally disabled adults remain in the home the autonomy myth is even more damaging as the needs of the disabled member can be more physically, emotionally, and financially burdensome and can jeopardize the stability of the entire family. Instead of making more demands on the public state to provide care, the autonomy myth also works to silence “deviant” families. In my own family, my autistic brother’s needs have increased as his toilet training and bathing skills have regressed and his aggressive behavior necessitates more physical restraint. Nevertheless, my family’s response is to isolate, withdrawing out of fear that outsiders would label my brother unfit for the home and our inability to control him would be construed as inefficient and deviant to the ideal self-sufficient family. In a culture that enforces autonomy, families may be unwilling to make demands on the state because they would be forced to expose their own incompetence, but families cannot always contain dependency needs, even if the rhetoric of self-sufficiency argues otherwise.

For these reasons, dependency remains hidden, but the needs of autistics and their families can be uncovered by a feminist ethic of care. Contesting the demarcation between public and private spheres as a distinction of pure physical space, feminists recognize that the division constructs the level of importance accorded to each realm. According to Nancy Fraser, political discourse deploys the terms “private” and “public” to “delegitamate some interests” and to “valorize others.” Care concerns and long-term severe disability are two important issues that are ignored by political discourse under the rhetoric of privacy, even though they have ramifications outside of the home. Rhetoric hides the concerns of
permanent disability, but an ethic of care uncovers these concerns. Familial relationships that were considered natural and impervious to universal principles of justice become new locations for debates of justice. Beginning their analysis with private relationships of dependency, care ethicists avoid liberalism’s lack of critical engagement with the effects of private inequalities upon the public discourse of justice. Long-term dependency needs appear to have a better chance of visibility with care rather than traditional justice rhetoric.

In the remaining chapter, I will ask if a care ethic can adequately incorporate the needs of low functioning autistic adults. I believe that an ethic of care exposes many of the dilemmas of liberalism’s insistence on autonomy, self-sufficiency and competency, but I maintain that relying on care as a method of justice for low functioning autistics calls into question certain assumptions that may prove to be problematic, such as:

- the assumption that the mother/child dyad is the primary and benevolent model of care;
- the assumption that maternal care is universally necessary; and
- the assumption that care can replace justice to create just relationships between neurotypical adults and autistic people without a dramatic shift in disability discourse.

I will approach each one of these concerns separately.

1. The Mother/Child Dyad: Beyond Power?

In the first chapter, liberalism’s insistence on reason and social cohesion prohibited the entry of low-functioning autistics into the Circle of Rights; we can see how dependency workers, usually women, would also be excluded because of their apparent lack of autonomy
under the constraint of their charge. In response, some care ethicists, notably Virginia Held, Sara Ruddick and Eva Feder Kittay, replace mutually disinterested moral agents with the mother/child dyad that is premised on interdependence and empathy over autonomy and reason. Maternal thinking can be universalized into a system of justice by acknowledging that we are all “some mother’s child,” even if we may not be mothers ourselves. However, some care ethicists replicate the same avoidance of power that traditional liberals’ project, with the same negative result. In liberalism, universal reason seemingly enforces equality thereby barring concerns of domination; similarly, care ethicists construct a mother/child dyad based on benevolence that protects the relationship from abuses of power. However, not all care ethicists employ the mother/child dyad. Theorists like Joan Tronto, Daniel Engster and Josephine Donovan construct moralities that are based on care while rejecting the mother/child dyad as their normative model. Care ethicists could argue that exceptions like the Gravelles do not jeopardize their theory because the mother/child dyad is only meant as a general way of being rather than an enforced rule of universal conduct. One of care ethics strengths, however, is that it draws upon women’s experience to construct its theory, rather than relying on philosophical mind experiments that do not replicate reality. If an ethic of care is to be a valid alternative to rights discourse, it must struggle with the invidious nature of power. For permanent disability, this section will want to question how an ethic of care can theorize, and even valorize, dependency relations without succumbing to unjust dynamics of domination and subordination. In fact, by theorizing about mother child relationships, some care theorists inadvertently create a normative system of motherhood that becomes associated with benevolent mothers and innocent children that masks the realities of long-term dependency and low-functioning autism. Just as liberalism uses reason to
engender consensus and avoid manipulation, an ethic of care assumes that the mother/child dyad will prevent negligence and abuse of power. In the remaining section, I will first inquire how the dynamics of power permeate into care even within a framework of benevolence, potentially harming dependent and dependency workers. Secondly, I will examine how the construction of a mother/child dyad enforces certain rules of conduct that exclude certain deviant identities, like autism. Third, in response to the shortcomings of an ethic of care bound by maternal roles, I’ll examine alternative models of care in relation to autism.

I first want to discuss the imbalance of power between mother and child; in order to be just, it must be controlled by benevolence just as liberalism must rely on universal reason to enforce equality; however, the history of care discourse illustrates that it has had ulterior motives of domination. Uma Narayan situates an ethic of care alongside liberalism in its attempt to subordinate different classes,\textsuperscript{114} she refuses to read it as benevolent as Sara Ruddick who developed a theory of maternal thinking that drew upon the benign wisdom of mothers.\textsuperscript{115} Relying on a postcolonial critique, Narayan explains that care discourse can “function ideologically, to justify or conceal relationships of power and domination.”\textsuperscript{116} Imperialism situated the colonized similar to an ethic of care’s permanent-child dyad, constructing the colonized as childlike and inferior and the colonizers as paternalistic superiors.\textsuperscript{117} Depicting native cultures as child-like, the discourse suggested that their oppression was only temporary and would cease once the colonized reached maturity; of course, only the dominant class was able to define mature and reasonable behavior. The idealization of motherhood makes the unfair marginalization of children unlikely, especially since mothers are not permanently powerful over their children who will eventually mature
into adults, but permanent dependency complicates this situation. The assumption that caregiving is benign further masks instances of abuse like the Gravelles in which caregivers are assumed to possess special knowledge of their charges’ needs: the Gravelles defended their behavior and objected to the intrusion of the law. An ethic of care attempts to control this imbalance of power by creating normative roles for mothers and children to embody. Contrary to these roles, permanent disability and low-functioning autism fail to conform to this model.

For instance, care ethicist Sara Ruddick constructs motherhood and maternal thinking as “benign, accurate, sturdy, and sane,” creating a new way of being human as opposed to an autonomous, competent and impartial demeanor. Ruddick addresses mothers’ relationship to power, explaining how they are simultaneously constrained by and exercise power, but her description of maternal thinking implies that mother’s power, even if it exists, is secondary to her primary qualities of benign care. Further, she implies that any malfeasance of power is most likely due to the patriarchal society in which a mother practices care as if maternal thinking is developed outside of the hegemonic discourse of subordination. Even though maternal thinking arises out of an oppressive gendered system that subordinates women and their emotional qualities to the home, Ruddick maintains that maternal thinking is still valuable and worth salvaging.

In the discourse of care, mothers and children are not beyond power, but within its boundaries. In fact, one of mother’s primary responsibilities and sources of power is to socialize her children according to her culture’s rules of behavior. On the other hand, this discretion is constricted to her own societal cleavages that necessitate that she indoctrinates her children into the same imbalance of power that acculturated her into the subordinated role
of dependency worker. Amidst Ruddick’s analysis of maternal thinking’s relationship to power, her description of the child’s role is almost completely ignored and considerably inadequate. This dialogue suggests that mothers are the agents of maternal thinking while children become empty receptacles of care. Since the child is “radically different” than the adult that he/she will eventually become, Ruddick suggests that a mother is both necessary and meaningless: it is her role to socialize her child, but the eventual adult will be unusually dissimilar to the child it once was. This mother and child dyad replicates Western Thought’s binary categorization: mothers become agents, powerful, in control, while children occupy the former category of women: inferior, weak and subordinated. Just as women’s subordination appeared “natural” under men, children’s inferiority is beyond rebuke under the benevolence of their mothers. Children’s powerless condition is not threatening to societal justice because of its impermanence: it is escapable through adulthood, but permanent dependency disrupts this expectation. As a result, permanent dependents must assume a child-like demeanor and innocent dependence if they are to garner benevolent care, but autistic adults threaten this assumption.

Mentally disabled dependent adults often bear the repercussion of the assumption that dependency necessitates child-like personas. Under this model, care constantly emanates from the symbolic mother, and in return, her charge reciprocates with mutual love. For instance, the affectionate and compassionate nature of Down syndrome mitigates its disabling affects; DS has even been used to propose alternative ways of being in the world that reject our culture’s insistence upon competition and “success”. Eva Feder Kittay describes her mentally and physically disabled daughter Sesha desires and reciprocates in the “coin and currency of love” exemplified by her moist and messy kisses, implying that Sesha
trades affection for care. Mother and child become symbolic as constant love and affection. Mother’s love is attributable to their experience as mothers, while children’s and permanently mentally disabled person’s affection is a state which has yet to be spoiled by the knowledge and failures of maturation as if they are suspended in compassion that would be contaminated by reason. Conversely, as the parents who came to the defense of the Gravelles testify, autism may not be as sweet as the kisses of Sesha.

I often confront this assumption when I explain to people that I have an autistic brother; they insist that his childlike innocence and joy must be an inspiration, apparently confusing autism for the compassionate and good-natured demeanor of Down syndrome. I explain that my brother possesses a variety of emotions not limited to joy, but also incorporating sadness, depression, and rage. In response, people feel bound to uphold the dignity of my brother by suggesting that he must have some exceptional talent, assuming that all autistics are savants. In a culture that prizes success almost as much as individualism, exceptionality would appear to make up for a lack of innocence, as if their difference can be mitigated by talent. Instead, unaffectatione and aloof demeanors are symptomatic of autism and it is far more likely to be accompanied by mental retardation rather than savant abilities. In response, Kittay acknowledges that autism may contest her assumption that care relationships are characterized by reciprocal love and trust. Autism’s deviation from reciprocity jeopardizes Kittay’s paradigmatic relationship between mother, child, and doula. Nevertheless, she quickly dismisses her concern, reasoning that mutual affection is just as difficult to sustain amidst profound physical disabilities. I would argue, however, that autism’s deviation from child-like affection and joy is more threatening to reciprocity then Kittay acknowledges.
For instance, Katharine Beals describes how autism challenges ideas of mutual trust and love in familial relations. When her son was four and a half years old he picked up two new habits: “slapping and eye poking.” Beals explains, “Suddenly we had a child who was harming the people who helped him; a child who was hurting other people’s kids; the kind of child that I thought I’d never have.”

In this dyad, both parties deviate from their assumed role: the autistic child manifests violent behavior while the mother/caretaker finds it continually more difficult to maintain an affectionate and loving attitude. Perhaps even more difficult is the difficulty that Beals had with establishing the ideal type of mother/child bond that Kittay assumes can be achieved amidst any disability. Instead of attachment, Beals experienced profound loneliness. “Spending such long hours with someone so socially remote makes one crave the company of others.” Not only was the ideal unreachable, but any type of bond became difficult to attain. Kittay doesn’t take seriously enough the specificity of autism’s manifestations, but Kittay is not alone. Sophia Isoka Wong in an article about Down syndrome (DS) also admits that autism can make it difficult to establish relationships, but then goes on to insist that “parents’ attitudes toward the child are equally if not more influential.”

I can attest, on the other hand, how difficult it is to maintain a positive attitude to the dependent person when that person habitually spits on you, pulls your hair and screams in your face, often accompanied by laughter.

Regardless of the positive attitude of the caregiver, autism is difficult to configure within the mother/child dyad premised upon benevolence and innocence. The primary traits of autism sever this projection. Autism is a spectrum disorder which means that the following traits are not universal, but neither are they unique among autistic children and adults. Self-injurious behavior often can accompany autism, including biting, pinching,
hitting, and relentless head-banging that can require helmets. Aggressive behavior can often be directed outward; for caregivers, aggressive behavior, impaired social functioning and unpredictable mood swings can be the most difficult to accept and cope with.\footnote{130} Uta Frith who studies autism describes some of the core traits such as irrational conduct and indifference to social conventions; these traits may disrupt the normative association of the mother/child dyad.\footnote{131} Also, some autistics need very little sleep which can also lead to a frustrated and over-tired caregiver who does require adequate sleep. To illustrate how disruptive these behaviors may be to social conventions, I’ll sketch a few of my autistic brother’s behaviors. Puberty shattered any lingering hopes that he would remain innocent as his public fascination with erections became a new source of consternation to my family, especially amidst company. Nudity may be a frustrating habit of children, but becomes alarming when the “child” turns twenty. Definitely the largest schism between autism and innocence is my brother’s strength and aggression which, as a child, could be restrained, but as an adult it becomes threatening and uncontrollable. An ethic of care should reckon with these anomalies of cruel caregivers like the Gravelles and deviant children because it is a feminist ethics grounded in experience, not abstraction. While liberalism may escape particular incidents by relying on its abstract position to moral questions, a feminist ethic of care positions itself as using experience as its foundation and should therefore attempt to inquire into adult dependency. Developmental disorders can’t be lumped together as if all developmentally disabled people share a static demeanor. For instance, Down’s syndrome is “mysteriously associated” with acting out of empathy instead of self-interest, but autism is not Down’s.\footnote{132} As the first chapter discussed, autism is more aligned with the polar opposite: an obsession with self to the extent that others are ignored. Autism should not be
conflated with Down syndrome as if DS could represent all developmental disorders. Principally, as autism rates appear to be increasing and becoming much more prevalent than DS, it is critically important that autism is established as its own category.

Recent statistics regarding autism suggest that it affects anywhere between 1 in 500 to 1 in every 166 children and research also reaffirms that it is often a life-long debilitating disorder. Seltzer et al acknowledge that many dependent autistic children grow up to be dependent autistic adults and most will rely on their parents for care. The dependency of children is substantially different than permanent dependency because relationships of power are generally clear in the former, but when autistic adults exhibit aggression and self-injurious behavior, it is doubtful that they can still fill the role of powerless children. The realities of autism must be rendered real; quaint assumptions about disability work to disable families in need of outside assistance because the discourse generally depicts them as children or at least child-like. Moreover, it’s doubtful if the mother/child dyad can sustain itself amidst these deviations away from benevolence and mutuality. According to Seltzer et al,

Improvements are not seen for all [autistic] individuals and, even in those who do improve, changes are seldom substantial enough to move the individual into the normal range of functioning. […] Additionally, although the overall trajectory for many with autism is improvement during adolescence and adulthood, there can be plateaus or even periods of symptom ‘aggravation’ along the way, and for some individuals, symptoms may not abate or even may worsen.

Their proposal to substantially increase social services to cover the entire trajectory of the autistic person’s life, not just childhood, is driven by the permanency and severity of autism. Accordingly, parents in a study in England agreed that finding adult care for their autistic children/adults was their most stressful and primary concern.
Returning to the challenges of the mother/child dyad, this structure poses significant risk to the mother as well. If mothers’ primary goal is successful socialization, she is likely to fail amid low-functioning autistics. Bad mothering is a familiar theme to autism: frigid mothers were previously assumed to cause autism as their children withdrew into themselves away from maternal frigidity. While parental advocacy as well as research has countered this hypothesis, the mother/child dyad threatens to increase mother’s likelihood of assuming control for their child’s disorder. In fact, a care ethic that privileges the special knowledge of maternal wisdom can potentially cause mothers to feel primarily responsible for their child’s well-being, even if it may be more dependent on their disorder. This feeling may not inherently be misplaced, but autism may necessitate a specialized type of knowledge outside of maternal thinking. Due to autism’s communicative dysfunction that causes half of autistics to possess little or no language, caregivers are forced to develop their own private method of communication with autistic dependents. This particularized knowledge may increase mother’s sense that only she can understand the need of her child; however this reinforces them as being the sole guardians of their child’s well-being. Idealizing motherhood can have adverse effects.

For example, the day before my older sister’s wedding, my mother refused to attend because she was too afraid to leave my brother in the care of a professional dependency worker who was not a member of the family. Supposedly, only she knew his needs and only she could anticipate his wants. Even though my brother’s care had consistently been dispersed among a six member family, my mother maintained that she was the only person that could be trusted. Consequently, this also necessitates that she is responsible for his regression if she insists that she controls his well-being. After my father threatened divorce,
my mother agreed to attend the wedding and my brother was left to the responsibility of an outsider with no adverse results. An ethic of care does not postulate this type of maternal sacrifice, but I believe that it is complicit with it. Perhaps my family’s ordeal is unique and meaningless to an ethic of care. On the other hand, it may be more common, but generally hidden as families carry their burdens alone and in private. One possible solution to avoid a hyper-reliance on mothers/families is to disassociate care from the private realm and instead place it in the public discourse as a universal model of association.

For example, care ethicists have disaggregated care from the practice of mothering to better imagine universal principles of association and justice. Josephine Donovan maintains an allegiance to care as the primary principle to justly relate to the world without relying on a maternal model. Under her perspective, care is not a matter of maternalism, but instead is a practice of listening to others, “paying emotional attention, taking seriously – caring about – what they are telling us.” Donovan’s article pays particular attention to extending fair treatment to non-human animals, thus she assumes that care can take place without mutual language relying instead on intuitive notions of universal needs. On the one hand, she seems determined to recognize an emotional obligation for fair treatment across difference without reducing the difference into sameness. However, she goes on to describe how a “dialogical” ethic of care occurs when we are able to see “the other as a creature who suffers in a manner like oneself,” assuming that all animals seek life and avoid pain. Our intuitive knowledge that all creatures want to avoid pain thus becomes the foundation of care as it then propels us to become morally responsible to deter pain and promote life, although Donovan suggests that teaching people how to respond in a compassionate manner may be a prerequisite to some caring practices.
The problem detectable in Donovan is twofold. First, she has actually performed the opposite of her original intentions by reducing difference to sameness in her assumption that all humans and non-humans universally avoid pain. Donovan insists that nonverbal language across species is similar and can counter the feelings of foreignness that we may confront in addressing the needs of non-human animals. However, the nonverbal language of autistic people may not so easily assuage feelings of alienation, especially when the nonverbal language is self-injurious behavior is in sharp contradiction to the universal principle that all humans are pain-avoidant. Many parents of autistic children recount having to drag their children away from oncoming traffic when the children repeatedly insist on running straight out into the road; apparently autistic children experience terror, anxiety, and pain differently than Donovan’s universal assumption that all humans “shrink away from sources of pain.” 141 Perhaps we could insist that even though some autistics may induce situations of pain and terror, we should respond as if they should; i.e. even though they may want to run into traffic, it should be our moral response to stop them. My contention, however, is that if pain-avoidance is supposedly universal, autistic traits may inhibit connection and induce more of an alien response amongst neurotypical individuals. Donovan reaffirms sameness while assuming that she is recognizing difference.

The second problem that Donovan creates is that she simplifies the ability to communicate nonverbally across difference, assuming that we can intuitively know the other’s needs by applying a model of pain-avoidance. According to Donovan, “lions do speak, and it is not impossible to understand much of what they are saying.” 142 Since autistic people at least share human status with nondisabled people, it should be even easier to know their needs, but my experience complicates this scenario. For instance, my family has six
members, one of whom is autistic. When my brother cries, we each try to decode his nonverbal cry into some sort of substantial need. With five translators of nonverbal language, we often reach five different conclusions. One person insists on taking him a ride in the car, another wants to fix him something to eat, while another insists that taking him somewhere or feeding him is exactly what he does not need. My scenario is overly simplified, but my point is that interpreting needs is not easy.

On a national level, many autistic advocacy agencies regard their own understanding of autistic needs as the authentic source of autistic knowledge. For example, Autism Society of America (ASA) describes itself as “the voice of autism.” In response, autistics.org, a group that rejects many of the premises of ASA, countered with its own new slogan as “the real voice of autism.” Finally, Autism Speaks begins its website with the statement that “Autism Speaks…for those that can’t.” Just as my family squabbles over the needs of my brother, national autistic advocacy agencies quarrel over the meaning of autism and subsequently advocate for very different types of possible public policies. It is actually quite difficult to understand nonverbal language – insisting that care can overcome these differences actually inhibits the process when we automatically assume that our needs are identical to all others. Further, in the next section, I’ll question if care is really the best tool to try to decipher needs. It may be that care actually prevents us from establishing autistic understanding.

Donovan is only one example of extending care to relationships without relying on a mother/child dyad. This is scarcely an exhaustive account of alternative models of care, but we can see some potential problems of an ethic of care even outside maternal bonds. Just as autism jeopardizes normative assumptions about mother/child relationships, it also
complicates assumptions about universal needs and knowledgeable responses. Perhaps autism is an aberration which should be ignored or, as Kittay attempted, quickly tucked away as a possible difficulty without adequately addressing its ramifications on care. On the other hand, autism can be used to challenge theory, to question if the theory genuinely accounts for difference. Implicit in this section has been the belief that care is the answer and the best mediator between dependent and dependency worker, but autism challenges such an assumption. In the next section I will question if caring for autistics is necessarily just. Care ethicists like Ruddick and Joan Tronto have developed an ethic of care characterized by the quality of loving-attentiveness, but the next section questions the validity of loving-attentiveness to care for dependent autistics.

2. Maternal Care: Is it Necessary?

Feminists may question whether or not women gain from the embrace of motherhood within a care discourse, but in this section I will question what autistic dependents gain from the privileging of care. In the previous section, I demonstrated how some care ethicists attempted to base care on the relationship between mother and child while simultaneously contesting the natural isolation of the home, but these two concerns would appear to be contradictory. If feminists are “to join in articulating a theory of justice shaped by and incorporating maternal thinking” which is premised on the public/private divide, are care ethicists emphasizing women’s regulation to the home? Similarly, if care is positioned in the home with women, dependents must also be relegated to its domain, but is this just? In the following section, I will first ask if autism requires an ethic of maternal thinking that embodies loving acceptance and attentiveness and present evidence that suggests otherwise.
In the latter half of the section I will explain the consequences to the assumption that the best care is located within the home. Readdressing how liberalism masks dependency needs by privatizing and naturalizing care, I will elaborate upon the positive aspects of professional knowledge and care and the disadvantage of associating optimum care within families. In essence, is care within the home preferable to other long-term care options? Is care as loving-attentiveness always necessary?

First, how do we conceptualize care? Daniel Engster, by analyzing other care theorists, describes a moral directive to care that can be applicable to maternal care, but also can extend beyond the maternal dyad. We care for others when we (1) promote their survival, (2) help them sustain their basic capabilities, and (3) help to relieve suffering. Profound disability, however, can complicate these basic assumptions about care, specifically the second aim of caring. Engster first criticizes Martha Nussbaum’s list of capabilities for endorsing a view of life that is overly bourgeois and Western. He minimizes Nussbaum’s original list to the most “basic of innate capabilities.” Consequently, innate capabilities are limited to the “ability to sense, feel, move about, speak, reason, imagine, affiliate with others, and in most societies today, read, write, and perform basic math.” Engster’s list threatens to position some autistic people beyond innate capabilities, thus his conception of being human may persist in being overly narrow and normative, especially when he further insists that the possession of all these capabilities are necessary to “pursuing any conception of the good life.” This perspective is already laden with normative levels of functioning built into the conception of being human. Care, like liberalism, seems to have assumptions that exclude low-functioning individuals.
According to Engster, the “first virtue of caring is attentiveness” and further stipulates that “caring will usually be most effectively and excellently performed in particular personal relationships.” Engster posits that care theory endorses partiality meaning intimacy leads to optimum care. On the other hand, studies related to autism contest traditional conceptions of appropriate care. Hendricks studied autistic children and adults in a residential facility in Europe and postulated that “autistic people occasionally experience greater comfort from imposed routines than from a yielding form of love and understanding.” Hendricks agrees with care theorists like Kittay who argue that the process of caring must be mutual, but Hendricks asserts that non-autistic people cannot base their perception of adequate care on “unquestioned assumptions about universal human needs.” By analyzing the behavior between autistic people and the staff, he noted that methods that relied heavily upon routine, rules and rigidness provided the best environment to moderate the excessive repetitive and destructive behavior of autistic people. Loving attentiveness may offer acceptance to repetitive behavior, instead of discipline, that actually would work to aggravate its worsening affect upon the autistic person. This difference can’t be ignored argues Hendricks: “There is a danger of ignoring the differences between autistic and non-autistic people, there is a risk of being uncaring, even hurting autistic people, precisely by treating them as fellow human beings.” Unlike Hendricks, I would argue that assumptions about being human should be questioned, rather than arguing that autistic people should seemingly be treated as sub-human. However, his contentions about what qualifies as quality care and who has the power to impose their type of care on dependents are both valid concerns that potentially contest universal claims of maternal knowledge. Following Engster, families of dependent autistics may first feel a sense of failure since the quality of care they provided was unable to
produce the sufficient list of capabilities, thus excluding their autistic child from achieving any sort of good life. Secondly, family members may consider themselves overly bound to permanent autistic dependents, even when the level of need surpasses their own level of skill and ability. Since some autistics are nonverbal, parents and families may feel even more partial as the autistic person’s traits heightens the outsider status of non-familial others. Under Engster’s model, care is a by-product of partiality and families may then come to fear leaving their children with others, even if they possess more professional knowledge.

In fact, Hendrick’s postulations undermine how well any universal assumptions can be transmitted to autistic individual’s authentic desires. Liberalism and an ethic of care both assume that the desire for social inclusion and reciprocity are universal characteristics of being human; however, some autistic advocates argue against the forced inclusion that society insists upon. Judy Singer, a high functioning autistic advocate challenges the benefits of inclusion especially since inclusion can be physically and emotionally upsetting. Autistic people are often highly sensitive to things that would generally be considered unnoticeable: the texture of fabric and food, sounds, and certain types of touch. Singer contends that many autistics “cannot bear the physical and emotional presence” of others and simply do not want to be included. Autistic claims for distance challenge an ethic of care’s loving attentiveness as well as liberalism’s tenets of public deliberation and private familial association. Even though the first chapter associated the idea of rights-as-sameness with traditional forms of liberalism, we might see how care concerns are equally premised on mutual needs and same interests. Mothers often express their desperation over their autistic child’s lack of affection, but this does not require that autistics have a mutual desire for love
and acceptance. In effect, autistic minds may challenge the family’s currency of love as its foundation.

Normative conceptions of families lead me to the second set of issues concerning the consequences of associating optimum care with the home: the prospect of residential long-term care. The reality of permanent dependency is a prospect that many families never consider before disability, blinded by the powerful myths of autonomy and self-sufficiency. When families realize the long-term care needs of their disabled members, their potential options are marred by the autonomous discourse that was earlier discussed in reference to Martha L. Fineman. By privatizing the family, care needs are assumed as the responsibility of families, particularly maintained by female members. Furthermore, care provided by families is assumed to be of better quality than professional services. When individual members fail in their pursuit of autonomy, parents are held responsible for that care. Adults with mental disabilities are less likely to be able to turn to spouses or children for care; thus parents will be held primarily responsible even though this arrangement leads to the almost guaranteed conflict as adult children outlive parental caregivers. Long-term residential facilities become one of the few options that families are able to consider, but society’s focus on autonomy implicates this decision as well. The deinstitutionalization movement “affirmed the family model of care as the appropriate policy goal” even though “care within the family is not necessarily loving nor in the best interests of the disabled persons.” I would argue that an ethic of care, in some ways, also reaffirms this family model of care. By privileging the mother/child relationship and partiality, care ethicists inadvertently reinforce the family as the location of long-term care since mothers and families are presumed to
possess more knowledge and love for their children as compared to health professionals or paid caretakers.

Families that consider residential care also face being stigmatized for “failing” in their caring responsibilities. When families are constructed as private and necessary to the state, they are “rewarded” with noninterference; in the liberal tradition, privacy is cherished as the landmark of freedom away from the state.\textsuperscript{162} Not only is state intervention into families seen as undesirable, “[resort] to the state is considered a failure.”\textsuperscript{163} Parents, and especially mothers who are held responsible for care, may resist public support to maintain the integrity for themselves and their families, even when it threatens the well-being of all of those involved, like the example of my mother’s unwillingness to hire outside assistance. According to Hooyman and Gonyea,

Our cultural values on individualism and personal responsibility also underlie the widely held belief that institutional or residential care is the least desirable care alternative for individuals and groups who are viewed as weak and deserving. When privacy and independence are regarded as goals to be prized and achieved, they are best secured by remaining in one’s own home, even at the expense of other members’ well-being.\textsuperscript{164}

Although maternal thinking has been constructed by feminists like Ruddick as “benign, accurate, sturdy, and sane,” we must question if the care relationship between mother and child is the most beneficial arrangement in all situations. The level of care required for severely disabled dependents may overwhelm the capabilities and knowledge of caregivers, but the myth of autonomy and self-sufficiency works to mask these relationships. When families do experience these difficulties, they are likely to construct their circumstances in terms of private demands, rather than to see their condition situated in the public discourse of state responsibility.
More pragmatically, families are constrained by financial considerations; while mothers and female family members may provide unpaid labor to maintain dependency needs, outside sources of care are hardly free. Even though families are expected and encouraged to care for their adult dependents through the discourse of autonomy and self-sufficiency, the State spends much more money maintaining large residential institutional settings for adult dependents rather than assisting families with dependents. As mentioned earlier, public education ends at age twenty-one, but if mentally disabled adults are in residential facilities, they are legally due a method of treatment. On the other hand, they have no such rights if they remain in the privacy of their family’s home. Even if the discourse of the State privileges private care, the flow of money suggests otherwise. Of course, Hendricks’ article suggested that autistics would benefit in professional residential settings, but his study was not referring to nursing homes or other large institutional settings. The professional care that he witnessed was in a small residential home specifically modeled for autistics in which the number of paid staff outnumbered residents. Obviously, there is a radical distinction between care based on routine and regulation and care maintained by anti-psychotic medication.

I am not suggesting that more adult dependents should be shipped to residential facilities, but autistic adults would benefit from an expansion of care as well as by the specification of appropriate care. Ideally, families could work with the State to educate themselves about the best type of care to provide and what type of outside sources could be used as adequate alternatives for care. In order to do so, an ethic of care must go beyond the mother/child dyad for multiple reasons. First, we must recognize that privileging mothers with maternal thinking might bind them to unrealistic expectations in confronting children
and adults with permanent special needs. Secondly, while some aspects of maternal care
may be “natural” or, more likely, women are heavily acculturated to fill that role, we must
realize that specialized knowledge into the needs of autism is not. If we do not prioritize
education, we risk discovering more children being cared for in cages. Care must be
expansive as well as individualized if it is to respond to hard cases like autism. To
accomplish these tasks, however, the identities of low functioning autistics and other
profoundly disabled adults must be rendered human enough to care for and to care about.
Liberalism’s insistence on reason forced mentally disabled adults to either become competent
or remain hidden. Furthermore, as discussed in the first chapter, the disability rights
movement failed to incorporate dependency needs into a rhetoric fighting for independent
living. Can an ethic of care produce a shift in the disability discourse that incorporates the
lives of permanently dependent and autistic?

3. Maternal Care: A Shift in Identity?

In the last section, I want to address whether or not care can bridge the difference of
mental capabilities in order to demand that autistics be integrated fully into conceptions of
being human. The mother child relationship contests the belief that justice must be impartial
in order to be just. Instead of relying on a disembodied view from nowhere, care ethicists
take us into the most intimate relationship to begin theorizing justice. This embeddedness
implies that we are more likely to be guided by ethical principles when we are interdependent
with one another instead of mutually disinterested. While care may make us more attentive,
it makes us question if that attentiveness can expand beyond our immediate relations. Joan
Tronto, a care ethicist argues that “until we care about something the care process cannot
As Tronto confesses, “Whether we can conceive of a way to think of morality that extends some form of sympathy further than our own group remains the fundamental question for contemporary life.” Amidst the mother/child dyad, care is assumed to be motivated by maternal thinking which, by itself, will be shown to be problematic, but what motivates care when it is projected as a universal ethic? Can we care about someone who remains invisible? In the case of autism, how would non-family members respond to someone whose disability inhibits them from expressing typical patterns of association and reciprocity?

Liberalism bypasses this debate by falling back upon the universalism of reason in which human differences are “bracketed” in order for principles of justice to be ascertained. Of course, in the history of liberalism, we know that differences weren’t bracketed and they remained salient: women were denied rights and people of color were enslaved. The relationship between neurotypicals and autistic people embody this dilemma in which the difference is not caused by space or physical difference, but is engendered through the distance of minds, which may prove to be a far deeper schism. Will non-autistic people recognize that autism is an alternative way of being in the world, or will they insist on its marginalization? In the following section, I’ll discuss a series of examples, both historic and current, that suggest that autism and mental disabilities may bar attentiveness.

The history of mental disability reveals that parental love may not be benign and suggests that parents will likely construe their children’s lives just as defective as outsiders would perceive. Before Nazi Germany began exterminating Jews, they practiced their methods on disabled children and adults, especially those already residing in institutions. The creation of a master race precluded the existence of disability. Disabled people, also
known as “useless eaters,” who resided in residential homes became targets of governmental officials, intent on freeing up hospital space for the soon to be wounded military. In 1920, Binding and Hoche, a lawyer and psychiatrist, questioned if the country could afford to care for “life unworthy of life” while facing an emergency; they emphasized the economic burden that disability was making upon German society. In 1925, Edward Meltzer, a physician, objected to the contempt for disabled life, recognizing that handicapped people and their caregivers could experience joy from their relationship. To prove his point, Meltzer conducted a poll of parents of disabled children to rally around their worthiness. Unfortunately, parents and society did not agree with Meltzer: seventy-three percent thought that the mercy killing of incurable idiots was humane and just. There is no exact number of disabled persons slaughtered during Nazi Germany, but it is estimated around 300,000. The history reveals that having a mentally disabled child does not protect a parent from contempt or discrimination. Partiality, as earlier described by Engster, does not readily lead to an obligation of care.

More recently, statistics about selective abortion suggests that the relationship between mother and potential child is mediated by disability. Even amidst Down syndrome’s association with compassion and affection, eighty percent of fetuses that are diagnosed with Down syndrome are aborted. In research cited by Adrienne Asch, prospective parents experience discomfort with the possibility of mental disability and retardation. Current autism research projects searches for a “cure” by finding the responsible gene involved, but genetic engineering suggest that the cure being sought is selective abortion. Selective abortion of disabled fetuses can be compared to the systematic abortion of female fetuses in regards to sex selection. Sophia Isako Wong, a sibling to a DS brother, sees “no sharp line
between the difficulties of being a woman in a patriarchal society and those engendered by having Down syndrome in a society focused on cognitive ability.” Wong asserts that people with DS, and perhaps other people with developmental disabilities, shouldn’t be looked upon as deficient, especially as improved medical care extends and improves the quality of their lives. While Wong’s perspective suggests that personal relationship with disabled people can engender mutual respect, the Congressional Hearing discussed in the first chapter suggests that parents of autistics compare the disability to a bomb, spreading shrapnel among humanity and maintain that autism is a fate worse than terminal cancer. Wong’s position as a sibling may account somewhat for her response, an idea that will pursued in chapter three.

The final example, Gail H. Landsman’s article Reconstructing Motherhood in the Age of “Perfect” Babies: Mothers of Infants and Toddlers with Disabilities, resuscitates Binding and Hoche’s question: “What constitutes a life worthy of living?” and “Who counts as being fully human?” The mothers interviewed expressed anger, rage, disappointment, self-pity, and devastation upon delivering a disabled child. In order to continue mothering, the women were forced to construct new narratives about life, reevaluating their old priorities. Landsman argues that the disabled child “becomes a lesson, sometimes delivered by God, to reassess priorities or to learn true values.” Accepting disability requires a complete transformation of prior ideals, but it is unclear what type of transformation actually takes place in Landsman’s mothers. They awkwardly inhabit two worlds of rage and acceptance. Particularly, the reconstruction of personal narratives of strength and success are individually based; mothers construct narratives that stress the individuality of their own child over their disability. In effect, mothers’ rewrite their own personal life trajectory; they do not reconfigure the category of disability.
In these examples, we can see how all three assumptions related to care and disability interconnect to maintain barriers of exclusion. Mothers’ difficulty to connect with their disabled children is predicated upon an imbalance of power, the non-benevolence of care, and the category of disability as a “spoiled” identity. As Narayan suggests, “social relationships of domination often operate to make many who have power unable to genuinely care about the marginalized and the powerless.” However, it is not only the imbalance of power that marginalizes disabled children, but the fear and dread of the meaning of disability. The discourse of maternal love suggests that maternal care is universal and constant, but the opening example of the Gravelles as well as this section’s illustrations, depict relationships that are not controlled by care. The level of care is not only manipulated by domination and the identity of disability. Parents of autistic children who defended the Gravelles attested to the difficulties of caring for their children. The above examples examine how the social construction of disability impedes care, but in the specific analysis of autism, we can question how autistic traits themselves jeopardize care.

Disability complicates and may even impede the practice of care, but what exactly is the practice of care if decentered from the practice of mothering? Joan Tronto divides care into a four stage process: (1) caring about, (2) taking care of, (3) care-giving, and (4) care-receiving. One mother who defended the Gravelles reasoned that most people would be unwilling to care for a child whose behavior was erratic and aggressive, and who required vigilant supervision. Her reaction implicitly contests the simplicity of Tronto’s four stage process. Tronto imagines that individuals can (1) recognize care needs and simultaneously feel compelled to respond to that need. Secondly, the care-giver will know how to respond and will (3) follow through with that action. Finally, the care-receiver should respond to the
care that she/he receives as a sign of recognition and mutuality. Autism challenges each stage.

In regards to *caring about*, one of the examples that Tronto uses is starving children (presumably from another country) as seen on television used to motivate viewers to make donations; in essence, the sight of need triggers “the recognition in the first place that care is necessary.” She herself recognizes that not all people will automatically recognize a need, like the person who ignores the homeless person they pass. Tronto’s use of comparing a starving child to a homeless man might warrant information about how we actually care about, especially in relationship to the last stage of care if we (the care-giver) expect recognition, gratitude, or improvement. Stage one most directly addresses the ways in which the social construction of disability may deter the recognition of need if that category of disability has regressed to being considered non-human or sub-species. Just as we may feel more compelled to save a drowning person over a drowning raccoon points to the ways in which we can dangerously assess the “human-being-ness” of others. Further, when we consider autism, an autistic person might willingly inflict pain on his self, or precariously dodge into traffic: are we as motivated to recognize a need for care when the harm is self-inflicted? Tronto’s homeless man is a good example in that we may be unwilling to recognize a need for care when we assume that the person is capable of responding to his own care needs.

*Taking care of* assumes that we, as care-recognizers, first feel compelled to respond and secondly, assumes that we know how to respond. Autistic people who exhibit self-injurious behavior might resist a traditional prohibitive response. Sue Rubin, an autistic woman, describes banging her head against a bus window as a method of expressing
frustration that can actually be “pleasant.” Further, Katharine Beals admits that the only method she has found successful in blocking her six year-old’s violent behavior is a quick, smart slap in the face. Tronto assumes that need is universal, but she also assumes that others can translate that need. In fact, first we must categorize another’s actions, identity, or location as a need. In effect, it is as if we each become a need-signaler or a need-recognizer. We know that meaning can get “lost in translation” even when it is text that it is translated and yet care theory, if it is to be an adequate moral and ethical system of principles, has to rely on the belief that needs, locations and identities are translatable. The challenge of autism is its obdurate foreignness, its resistance to translatability. In these instances, the person acting as “recognizer” may become more alienated with the autistic person as they strenuously and constantly must translate codes that are indecipherable. When we take what parents say seriously about the difficulties of caring for their autistic children then we must recognize that the motivation of care can be jeopardized by the identity and behaviors of the care-receiver. The indecipherability of need problematizes the delivery of care.

Finally, the last stage necessitates that we recognize the effect of caring in the care receiver; this assumes that the care receiver will be responsive to stage three, the care-giving, whether that response is positive or negative. Nel Noddings describes how “receptivity” must exist in the caregiver and is also required in the care receiver. Likewise, Kittay insists that the relationship between carer and cared-for profoundly effects both parties, suggesting again the ability to respond to the care provided. Autism demands care, and yet, contests responsiveness. Jason B. Konidaris, an adult sibling to an autistic brother, attests that there is little or no feedback to a caregiver when the charge is autistic. Other siblings report less intimacy and nurturance from autistic children, again stressing the lack of
typical bonds of reciprocity. If we imagine care as ongoing, Tronto’s four stage process may be more aptly defined cyclically as stage four leads to a feedback loop to stage one in which caregivers are more apt to continue to acknowledge need when they experience the effects and response to that need. On the other hand, if caregivers fail to receive a response, does the cycle continue? If so, does it continue in the same quality of care given? What seems most definitive is the way in which autism upsets Tronto’s four stage process. While she acknowledges that there may be conflict, she doesn’t adequately question if the inevitable conflicts associated with care disrupt the practice of care. Rather than describing optimum stages of care, care ethicists might develop stronger theories by examining the duress of real care practices.

The inconsistency between theoretical processes of care and dependency relations between caregivers and autistic charges threatens not only the full integration of autistics into ethic of care, but care itself as a universal practice and theory. Low functioning nonverbal autistics are unable to defend their own worth within communicative discourse. This chapter has explained how they may not be able to rely on their caregiver’s discourse of care. Are we forced to fall back on to liberalism, maintaining that concerns over autism are unfit for public discourse, sending it back into the confines of the home? Alternatively, can there be another solution?

**In Conclusion**

In this chapter I analyzed whether or not an ethic of care was better able to incorporate autistic needs into the theoretical debate related to personhood and rights; my conclusion is somewhat mixed. Feminist challenges to public/private spheres and the
exposure of autonomy and self-sufficiency as myths are both required to provoke critical
debate as to the demands of autistic people and their families. On the other hand, the
mother/child dyad may not be as useful in upholding the moral personhood of autistic
children. Mothers may not be able to resist the damaging interpretations of disability nor
maintain perfect benevolence; this negative version of dependency and disability may
undermine mothers’ ability to establish healthy maternal bonds. This chapter also uncovered
how care as loving-attentiveness might be an inappropriate and damaging response to
autistics; this evidence suggests that maternal wisdom is not absolute as a method of
universal care. Most importantly, the mother/child dyad projects normative roles for both
members that are unrealistic and ultimately damaging for both. Daniel Engster and
Josephine Donovan extend care beyond the mother/child dyad, but both theorists rely on
thick conceptions of being human that may be overly burdened with normative conceptions
concerning the level of functioning as well as universal responses. When Engster positions
optimum care according to partiality, he re-erects the same limitations of maternal care
insofar as the home and the private realm become heavily rooted to care with the dangerous
side effect of ignoring potential public services to aid in caring. If care is to work, it must
expand, especially when the dependency needs of low-functioning autistics overburden any
person’s singular capacity for care. Further, it privileges a belief that proximity promotes
special knowledge, but families may need to rely on outside sources to properly know the
needs of their autistic family members.

When Sara Ruddick constructed her image of maternal power, she recognized that
“Obedience is largely a function of social powerlessness.” In regards to long-term
dependency and autistic needs, we cannot afford to be so uncritical and obedient. As
Narayan noted, rhetoric valuing care has been utilized to marginalize and stigmatize the Other like mentally distant autistic subjects; caring relationships must be subjected to the same scrutiny as traditional liberal theories of rights. In both theories, power operates, often silently, to maintain oppressive social conditions. On the other hand, an ethic of care should not be abandoned since it importantly politicizes relationships that formerly had been considered natural; this confrontation is integral to autistic people and their families. Dependency concerns that have been relegated to the private sphere continue to be marginalized and yet long-term care potentially becomes more and more important on public policy as the population continues to grow older. Care ethicists sustain the political location of the family and home, challenging the assumptions of care and power. Tronto believes that care may be able to overcome these differences, but severe disability may be a hard-case for care theorists as well as traditional liberals. The perception of disability may trump seemingly a priori conditions like rights or care. As several accounts suggest, permanent disability may impede theoretical principles.

In the next chapter, I will consider another method of incorporating the needs and personhood of mentally disabled individuals and low-functioning autistics. Before principles of justice can be applied and prior to the establishment of maternal bonds, disability requires a redefinition of values, ideals and, most importantly, a new idea of what constitutes being human. Liberalism and an ethic of care positioned disability on the periphery while moral agents and mothers/caregivers constituted the center; I believe that disability should be the new center that can effectively de-center the debate away from universal codes of behavior of reason and care. Obviously, centering the debate on nonverbal autistics is complex since the agent is by definition non-communicative and silent. I will first rely on queer theory to begin
de-centering the debate, relying on its multiplicity of identity as well as its strategy of coming-out. Secondly, I intend to unravel some of the impediments within an ethic of care by replacing the mother/child dyad with my own construction of a sibling perspective, which I think could potentially expand care and facilitate justice.
Chapter 4:

Autistic Counter Normativity

In the article *Taking the Basic Structure Seriously*, Iris Young turns to the problem of “normativity” in relation to Rawls’s theory of justice, elaborating on the work of Michel Foucault, Judith Butler, and Michael Warner to illustrate how injustice is deployed regardless of distribution patterns. Young describes normalization as a “set of social processes that elevate the experience and capacities of some social segments into standards used to judge everyone.” People who fail to meet such a prototypical standard are constructed as “abnormal, problematically different, or despicable.” Disability exemplifies normalization as disabled people are rendered deviant against non-disabled norms irrespective of the effect any effect that the disability may or may not have upon the disabled individual. Young criticizes Rawls for perpetuating able-bodied normativity when he brackets people with disabilities outside of the original position. He bases this exclusion of disabled presence on the assumption that it would contaminate the identity of non-disabled citizens, assuming that disability prohibits contribution-potential of effected populations. Rawls fails to interrogate societal barriers, able-bodied standards, and prejudice as the causation of disability’s disenfranchisement. Young uses the example of a person in a wheelchair to demonstrate that readdressing mobility devices, such as stairs and feet-operated machines, could alter the contribution-potential of disabled populations to the public. With inclusive attitudes and accessible spaces, the supposed disability would cease to exist.
Young challenges the marginalization of disability, but she implicitly assents with Rawls’s construction of human behavior in the “usual sense” as being practiced by “contributing” to society as an autonomous agent. Her analysis of being human is surprisingly public, even though earlier in the essay she criticized the marginalization of care to the private realm. She inadvertently extends this invisible divide when she turns to the wheelchair user, asking how that person navigates around stairs, curbs, and feet-operated machines. Her description of the world is weighted towards the public realm when she fails to address the private maneuverability needs in the home, such as getting in and out of bed, bathing, and toileting that may require human assistance, not just structural or attitudinal change. In effect, Young gingerly tiptoes around disability, refusing to jump into its cavernous and messy implications, thus she reaffirms that the usual way of being in the world is autonomous, productive and capable. She succumbs to her own resistance: she aptly recognizes the stigmatizing force of normalization when all people are held up to one standard, like productivity, but then she de-stigmatizes disabled people by arguing that, if the world were different, they really could be seen as productive.

Young also differentiates her analysis from Eva Feder Kittay’s interest in disability since the latter association with dependency bolsters normative assumptions that disability is disabling. Kittay rests personhood on mutuality. “An individual,” according to Kittay expresses her personhood “through her warmth, her serene and harmonious spirit, and her infectious love of life that enriches the lives of others and who has never acted maliciously or tried to harm anyone.” Kittay stresses personhood in regards to levels of emotional participation. Thus, both Young and Kittay interpret being
human in terms of contribution-potential, but Young’s perspective is centered in the public realm of society/productivity whereas Kittay’s subjects participate in mutual care and affection. While their analysis differs, they illustrate two primary examples of the residual effects of theorizing from a perspective that begins with a thick conception of being human, whether constructed as overly autonomous or caring, that project standards of normativity. Young and Kittay’s descriptions of human functioning also works to closet other aspects of being human, notably our physical vulnerability, our abjection, and our unwillingness or inability to be contributing or caring members of society. When autism fails to conform to either construction in its resistance to contribution, it acts as a trump to theoretical principles, potentially hotwiring our ethical commitments since the deployment of theory is triggered by the recognition of the thick conception of self, whether that self is overly autonomous or caring. Chapters one and two uncovered the prescriptive roles behind theories of justice and care whose hidden requirements worked to marginalize permanent dependents, regardless of their seeming universality. Young and Kittay both attempt to import disabled people into communities of justice/care, but their attempts may prove inadequate.

The effect of normalization has been a recurrent theme throughout this project insofar as autism has been analyzed against a normative conception of being human, but I hesitate to place my conclusions parallel with Young or Kittay. Young refers to Michel Foucault, Judith Butler, and Michael Warner for her concept of normativity, but her example of disability doesn’t seem exactly what they might have meant in their critique of normalization. For example, Warner stresses the idea of a counter-normative standpoint that “only has the force of critique or resistance insofar as it has its own
normative impulses, which it develops in ways that conflict with the dominant norms.”¹⁸⁷ Rather than prove productivity, postmodern critiques would question how the value of productivity polices the “usual” boundaries of human behavior. Productivity as a measure of worth is incriminated in the discourse of power and domination. Disability also renders productivity meaningful as the two constructions function in a dichotomous relationship in which their essential meanings are created in their contradiction. Disabilities are located in the space of “power’s opposite,” serving as reminders to invisible standards positioned against “those who are fit[,] attractive” and productive.¹⁸⁸ Postmodern discourses surrounding normativity thus do not offer methods of assimilation; rather they uncover the deceptive ways in which power designs standards that work to marginalize segments of society. Can disability offer a counter-normative paradigm to confront overly oppressive rules of behavior?

Paul Hunt, an early disability advocate, did situate disabled people as a counter-force to able-bodied standards. He insisted that severely disabled people occupy an awkward uncomfortable subversive space to remind non-disabled people of vulnerability; a counter narrative against the values of autonomy or control. He rejected the universality of societal values such as work, success, and family, arguing that life needn’t be productive to be considered human. Normativity silences the realities of disability and disease, convincing people that their worth is “bound up with their more fortunate position in life.”¹⁸⁹ Instead of assimilating into norms, disabled people cannot help posing questions about values, about what a person is, what he is for, about whether his work is the ultimate criterion of his worth, whether work in the everyday sense of the word is the most important or the only contribution anyone can make to society.¹⁹⁰
Hunt conceived disability advocacy as a process of disclosure whereby disabled people represent the realities of an embodied life, disputing the mind’s divorce from the body. From behind the walls of institutions, Hunt urged disabled people to come out of their closets of abjection to force non-disabled people to see their selves inextricably woven with their bodies.

Michael Warner’s more recent description of queerness as an unpredictable and unstable transgression against normativity parallels Hunt’s location of disability. Both critique Western conceptions of an “unrealizable utopia without shame” where the mind is no longer tied to the abjection of the body. Replacing disability in the place of queer culture illustrates the transferability of ideas in Warner’s statement: “[disability] at its best deals with intensities of shame without simply trying to climb up the ladder of respectability.” Warner accuses gay advocates of de-sexing queerness in order to make it palatable for straight acceptance. Similarly, some disabled advocates attempt to abilitize disability, but queer and disabled power may reside in its counter-values that contest straight, able-bodied, neurotypical norms. The epistemology of the closet extends to disability and autism, accentuating the dichotomies between public/private, disclosure/secrecy, authentic/autistic. Abjection becomes centrally located in the discourses of shame, secrecy, and disability. Disability transgresses against the norm, resounding with the abjection of the body as it seems to accentuate its frailty, messiness, and imperfectability. In some ways, Western society closets all bodies by locating our identity within our rational capacities. On the other hand, the body is also the location of ceaseless inspection. The idolization of the perfect body resonates against the scrutiny of
bodies-at-risk: legs in stirrups, brains in scanning, autistic people and families enrolled in genetic research, tracking deviant chromosomes and deceitful DNA.

Disability studies can radicalize notions of normativity, expanding the concept of being human, but Robert McRuer warns that the edginess of disability studies is careening gently into the same assimilationist approach that Warner finds so unbearable in queer culture and gay/lesbian politics. Counter-narratives are at risk of being swallowed by the capitalist impulse to devolve counter-culture into consumer products, exemplified by *Queer Eye for the Straight Guy* wherein counter-culture becomes a tool to sell home-ware. Counter-normative values are weaned from their radical past, but theorists like Warner and McRuer attempt to revitalize counter-normativity to challenge dominant power structures. Instead of manipulating deviant bodies into the center of competence, Warner, McRuer, and Hunt contend that subaltern communities banished to peripheries can offer powerful critiques if they are able to resist assimilation. Extending McRuer’s concerns, this chapter asks:

How does our work generate not just solutions but problems? What issues are never identified in our fields and movements as they are currently constituted? Why? Who haunts the margins of the work we do, the margins of the feminist, queer, and disabled world? What would an ongoing commitment to those spectral presences entail?

Rather than questioning how autistic people can be integrated into rights communities or enmeshed in thick conceptions of selves, I look to autism to see what is amiss in our theories of justice, care and human-situatedness. How can the narrative of autism decenter normative values? Can the concept of abjection illuminate the dark crevices of our closets of shame, privacy, and embodiment? And can abjection’s construction tell us
anything about the functioning of families with disabilities? The following chapter
pursues these questions.

**Three Stories of Abjection**

Before analyzing potential political strategies incorporating counter-normative
perspectives, I want to pursue the meaning of abjection and submit reasons why it helps
decipher the mobilization of stigma against disability. The word “abjection” is defined as
“total humiliation,” “brought low in condition or status,” and “a low or downcast
state.” I am particularly interested in the relationship between bodies, abjection, and
disclosure. I submit that abjection is not a natural state of bodies, but is constructed out
of Western theory’s mind/body split wherein the mind is presumed to rule the body.
Unruly bodies are labeled as deviant because the lack of control symbolizes the
inferiority of rationality. The body’s inferior status to personhood is evident in moral
theories that privilege cognitive functioning as a requirement for being human, not bodily
status. The persistent question, what constitutes being human, has severe consequences
for some mentally disabled people when the line drawn between human and non-human
is based on cognitive ability. Martha Nussbaum contends that it is only sentiment that
makes us see severely disabled people as humans: full human status must be
accompanied by basic cognitive abilities. Thus we can see the significance of
abjection on theories of personhood as uncontrollable bodies are excluded. This section
asks why some theorists are willing to enact violence on deviant bodies. What do we
hide from ourselves when we castigate mentally disabled people to the periphery of rights
communities and society? Finally, the process of abjection is not a singular experience,
but, like deviance, it can only emerge in the interaction between people wherein the transgression of rules is witnessed and the burden of shame is shouldered.198

The following narratives explore the relationships between abjection, bodies, and disclosure. Two accounts are scenes taken from personal discussions with other non-autistic people about abjection, the body, and moments of disclosure. The third narrative is borrowed from an article by Kittay. If the reader bears with me, each narrative consists of differing prescriptive roles for (1) the person whose bodily abjection/disability is disclosed and (2) the person to whom that abjection/disability is revealed, who then must conceal their acknowledgement of the other’s debasement. Each story diverges somehow from the others and it is in the discordance between narratives that positions counter-normativity.

The first conversation took place over dinner primarily between a visiting feminist scholar and a group of my department’s professors. Earlier in the evening, the guest of honor had delivered a lecture, weaving personal narrative with theoretical musings, culminating in her account of her dying father and herself acting as caregiver to his frail and malfunctioning body. The pinnacle of her father’s abjection was mitigated by the act of writing, disclosure, seen as a cathartic process. After the lecture, another professor expressed how deeply the death/care narrative had moved her, perhaps affected most by the lecturer’s depiction of having to bathe her father and change his diaper. The dinner table seemed to collectively assent, erupting in nods, head-shaking, and compassion. However, I had recently returned from a disability conference during which a writer had emphasized the disabled writer’s unique position to memoir. For non-disabled people, abjection was more like a moment, followed by the writing/disclosure/
healing, but for the permanently disabled author, abjection and vulnerability were residual and the writing was no longer therapeutic, but political.199

I expressed these concerns to the dinner table, questioning the author’s interpretation of her experience, juxtaposing it with my own family’s relation to my autistic brother. Her narrative had been powerful in part because it disclosed the secrets of her father’s bodily shame, his defecation, his filth, and her position as daughter and witness. I countered that in my family’s home, and wherever else that permanent and severe disability resides, the disabled body is rendered more public as bathing, toileting, and dressing routinely become group activities. How does personal narrative heal this abjection when the writing process is not the finale, but an interlude? Is it still abjection? She replied that, first, the father/daughter relationship was distinct from a sibling bond insofar as the former is less egalitarian resulting in bodies becoming more closeted. Secondly, she insisted that it was her story: other stories, like my own, may have completely different meanings, as they should in a multiplicitous world, but her story was her own. When the guest lecturer had shifted attention to another conversationalist, another professor turned to me, asking for more details about autism and my family. I disclosed some additional information, and this time a solitary head nodded and sympathized: oh how hard that must be, she replied, I don’t know how your parents cope. Somehow the purpose of my narrative, political voice to dependency, had devolved into just another Supercrip story, with my parents cast as heroes, while the listener became the unbeliever, stunned at disabled tales of defecation.

Shifting to the second narrative, Kittay’s article Dependency, Difference and the Global Ethic of Care momentarily explores the relationship between a physically
disabled man and his personal female assistant. During an interview, Kittay noted how he treated the assistant as if she were invisible, exemplified in his refusal to allow Kittay to hold the glass from which he sipped. Kittay’s arm was attached to Kittay, rendering her assistance as an exaggeration of the man’s incapacity. Conversely, the caregiver’s hand and arm seemed disassociated from its original source, instead transforming into a tool, an extension of the man himself and therefore no longer incriminated his body as incomplete or despicable. For him, Kittay’s hand threatened to out his body’s abjection. In response, Kittay was disturbed, interpreting this moment as further proof of the marginalization of dependency workers. It embodied the “quintessential ethical dilemma of caregiving” that situates “two populations, disabled people and prototypical caregivers” against one another in an antagonistic relationship in which vulnerability is masked at the expense of the dehumanization of the careworker. Kittay’s solution is to acknowledge dependency workers and vulnerability, to out the realities of care work.

However, one might question whose body was rendered invisible. I submit that it was his. Returning to the first story, when the woman described changing her father, she said that she pretended not to see his naked body, his penis, or his filth. For her father, she acted as if his body was invisible. If we extrapolate the disabled man and his dependency worker to situations of bathing or toileting, the question of who disappears is complex. Kittay translates the man in a futile attempt to uphold the problematic ideal of autonomy, but perhaps he was hiding his shame rather than announcing his competency. Thus it becomes a dualistic dance in which one body is disclosed in its abjection while another is bound to its secrecy, her spectral presence haunting the margin of the other’s vulnerability.
The final conversation returns to the dinner table, but this time shared by only one professor and myself, but the discussion was hardly academic. Her autistic son engrossed himself in the restaurant’s nearest corner, enraptured by watching (not playing) the screen of a video game machine, occasionally erupting in familiar guttural noises, sometimes his body twirled in circles. Meanwhile we were equally engrossed in our own disclosures, our conversation resembling a contest of whose abjection overwhelmed the other. We traded stories of black eyes, broken windows, frantic trips to Emergency Rooms, the regression of toileting skills, torn off clothes, spat-at faces; and also the battles over bathing, the difficulties of shaving, holes in walls, shaky marriages, and deferred dreams. Unlike the first conversation about dependency, this interchange had been punctuated by hearty laughs, but little sympathy. After the first dinner conversation, I had rebuked myself for my disclosures, feeling the hot flush of shame in relation to my experience, but not so in the latter. The feeling of disclosure was absent for my partner in discussion already knew my “secrets” of shame having also lived with a “low-functioning” autistic person. Between the two of us, abjection was rendered as normative.

The interplay of these stories reveals the reconstruction of abjection as well as its deconstruction. In the previous chapter, Joan Tronto’s four stage process of care was the performance of need in the care-receiver and the recognition of need in the care-provider. Similarly we can see how abjection is signaled by one body in the consciousness of the mind. Just as autism can disrupt the care process, disabled voices and disabled listening alters the story-telling of abjection. Abjection is constructed in the binary between secrecy/disclosure when that which should be kept hidden is exposed. The first two
stories mitigate the abjection by assuming a blinding gaze wherein the observer performs as if she/he cannot see the other’s body/vulnerability. In the third, former abject states are reconfigured as normative situations. What had seemingly shocked the first audience was normalized by the last.

I believe that the feminist scholar was right when she separated her experience to her father as a different relation than what I have with my brother; however, I don’t read that difference as naturalized. Further, as people continue to live longer, more adult children will be performing care work for their aging parents. Being a witness to a parent’s body/abjection may become more familiar to more people, and yet, the moments of vulnerability could easily continue to be constructed as abject and deviant. If shame lingers on the location of the body, as it is apt to do under Western mind/body dichotomies, increasing the prevalence of bodily care will bear no relation on the interpretation of care.

Together, these stories contextualize different moments of care that are not visible under an ethic of care that focuses more on the emotional and mutually rewarding aspects of care work. Expressing the relationship of caregiver and care-receiver primarily along affectionate ties of reciprocity negates the embodied work of care. Kittay attempts to get at the hardship of caregiving in her use of the term dependency worker, but her construction of care as mutual combined with the depiction of Sesha as loving closets the messier moments of dependency and disability. However, the purpose of these stories is not to prove that disability is demeaning, but to elucidate how Western culture closets all bodies.
While vulnerable bodies become central locations of shame, but they do not carry the shame alone. Permanent dependents are not isolated, but instead their bodies become, to some extent, more public as bodily hygiene and care become group activities. On the other hand, the autistic person may be positioned outside of normalization insofar as that they break the rules of closeting shame: they may strip in public, their toileting may regress, and aggressiveness may increase. As several researchers pointed out, some autistic people seem as if they are unaware of their own disability and deviance. However, their families may not be as immune to the power of normalization. Just as the caregiver shoulders some of the shame, families with disabilities may collectively closet the dependent’s vulnerability to protect their familial identity. The rhetoric of autonomy normalizes families as well as dependents; thus one member’s body might threaten to render all of their lives as abject. Kittay postulates that the invisibility of dependents and dependency workers is partly caused by liberalism’s desire to maintain the home/private sphere as the location of care work. If care was made public, dependency could shift to central focus and moral responsibilities would attach themselves to the needs of dependents. Dependency is silenced because recognizing it would upset the supposed equality in the public sphere and could potentially drain public resources if it was acknowledged as necessary to the citizenship’s well-being. While I assent with Kittay that this aspect of care is true, I also submit that dependency is closeted because it symbolizes the realities of an embodied way of life that normative standards usually police. Visible dependency is shaming and the response it to pretend not to see its reality. Under this perspective, delivering care is rendered problematic because the receipt of care is an open acknowledgement of the body’s debasement. Abjection also
problematizes the response to need: instead of interpreting the body’s vulnerability as inevitable, bodily needs often evoke discomfort, not compassion. But how does abjection relate to autism?

Autism illustrates the denaturalization of abjection. As the final conversation exemplifies, abjection does not necessarily follow the disclosure of the body’s vulnerability. Families with disabilities can offer counter-normative values to dominant culture. However a strategy of coming out as alternative locations of vulnerability may seem unlikely routes to empowerment. As my first interchange revealed, disclosing disability may merely result in sympathetic responses, rather than a cognizant challenge to normative standards of human worth. How can the disclosure of disability invoke new constructions of being human? Theories of justice and care primarily define the authentic self by its cognitive functions as either basically rational or emotional. Disability narratives offer a counter-narrative that first recognizes the body as a location of identity.

The stories also illustrate how the expansion of identities can be imagined as a process of witnessing and conversing. The construction of selves can take place dialogically wherein family members can act as translators and allies to nonverbal subjects. We can parallel the dialogue between disability/ability to similar relationships between Third World feminisms and Western dominant culture. Disability dialogue “can yield a vision of coexistence that does not require making other lifeworlds extinct or provisional.”201 Politics of Piety: The Islamic Revival and the Feminist Subject is an ethnographic study of women in Egypt’s mosque movement, and an example of Third World feminism yielding counter-normative values in opposition to Western constructions of identities. Saba Mahmood’s project scrutinizes Western ideals such as
autonomy, agency and freedom – ideals that could similarly be critiqued from a disability perspective. Mahmood uncovers the thick conception of selves that permeate liberalism and Western feminisms: both define the self as rooted in agency with an a priori desire for freedom as embodied by resistance to power and authority. The “naturalization of freedom as a social ideal” elevates it to a universal principle, but for Mahmood, ideals cannot be created outside of power, but are rather the products of power. Thus no ideal is natural; all are constructed. Mahmood questions how a specific subjecthood becomes a normative standard for all subjects. We can extend her analysis to disability discourse where non-disability has been naturalized as the normal way of being in the world even while the realities of the body symbolizes its vulnerability.

Lila Abu-Lughod asks if Muslim women really need saving and we may apply the same logic to autistic people and their families. Like other Third World feminists, Abu-Lughod seeks to create a mutual dialogue between locations wherein Westerners are aware of the colonial history and temporarily set aside their own normativity before castigating other value systems. Uma Narayan warns that no dialogue can be productive if the colonial history and imbalance of power is ignored, resulting in the Other being rendered ahistorical without any contextual or local knowledge. Similarly, increased autism awareness becomes problematic when divorced from its history, without acknowledging the permanency of its disability, and as “advocates” pay little attention to their own normative standards or position of power.

Just as the West is positioned to the non-West, neurotypical ability can be imagined in an oppositional relation to autism and other cognitive disabilities. Third World feminists have criticized the notion of “global sisterhood” because the sameness
that it represents is too heavily predicated on Western values, such as autonomy. Mahmood and Abu-Lughod share an anthropological position in the dialogue, suggesting that the conversation can be better sustained with contextual knowledge, local awareness to alter our allegiances to thick constructions of identities. Third World feminists are important to autism insofar as they successfully articulate a counter-normative position. This requires participants in the dialogue to be skeptical of their own perspective, realizing that they have been affected by discourses of power. Conversationalists in the dialogue must learn to practice a judgmental hesitation, during which “we may be remade through an encounter with another.” Postcolonial critiques can serve as guides to disability studies insofar as they successfully decenter the debate from the West to situate it within Third World contextual perspectives. Just as Western feminists learn to hesitate before judging other women’s cultures, neurotypical others can suspend their convictions towards disability, momentarily using the Other’s translation as a guide to comprehension. The remainder of this chapter uses three lenses to challenge three assumptions related to disability: the family, the sibling, and local coherence. I believe the experience of disability can offer a counter-normative perspective to the way in which we interpret the world, potentially challenging two important beliefs:

- the assumption that disability is an individual situation rather than a group experience;
- the assumption that the narratives of siblings to disabled people are burdened by the presence of the latter’s impairment;

I will pay particular interest to siblings since this strategy recognizes my own embeddedness in the narrative as a sibling. These assumptions may appear overly
concerned with the location of the family, but I believe that families with disabilities can offer a counter-normative way of being in the world as yet unexpressed. In addition, families with disabilities may decenter the discussion of abjection from shame to significance. In the following two sections, each assumption will confront each proposition separately in the following subdivided sections.

1. The Family: Expanding Disability

The Americans with Disabilities Act uses three criteria to determine if a person can be considered disabled: “(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.”207 The ADA hinges disability upon a mental or physical impairment, but we may equally ask how the impairments in bodies other than our own can equally disable us. The ADA is somewhat complicit in this maneuver insofar as it bases much of its logic on the social model of disability, a foundation which premises disability’s marginalization equally upon the shoulders of prejudice. Further, from section (c) we can extrapolate how disability can become unhinged from the body of the disabled designee and mover to the mind of the nondisabled other in the deployment of societal stigma. We can imagine a person, like a caregiver, who is substantially limited in at least one major life activity due to a dependent’s excessive needs and who also bears the burden of deviance and stigma. The preceding stories of abjection exemplify the unboundedness of shame and the blanketing effect of stigma upon witnesses to the body’s vulnerability. Under this perspective,
disability shifts from an individual’s bodily or mental state to a location of shared deviance.

Eva Feder Kittay explores profound disability’s impact on families, but Kittay pursues the rhetorical tool of contractual relationships to stabilize the family to the point in which one member’s disability is no longer disabling. Kittay’s model of dependency consists of a dependent and a “dependency worker” whereby the dependency worker risks sharing in the dependent’s disfranchisement. In this model, it is as if the dependency worker can consume all of the dependent’s needs to the extent that the latter’s needs no longer burdens any other person. Kittay’s theorizing creates a contractual notion of care that imports rationality and choice into dependency needs. Most importantly, Kittay ignores the many families, less financially secure, who rely only on themselves for fulfilling care needs. Amongst families who are unable to enter into outside contractual relationships, the dependent’s needs cannot be bracketed by the dependency worker. The dilemma of dependency might shift, formulating the question: how does dependency become absorbed without the contractual position of the dependency worker?

While Kittay might envision the dilemma of care as composed of two antagonist forces, often involving “third world” women, it is estimated that 70-80 percent of care for adults with developmental disabilities is provided by families. “The family is rarely defined as the client system in need of resources.” When families assume primary care for dependent adults, they potentially disable themselves. Under the ADA, an impairment is considered a disability if it substantially limits at least one major life activity. Thus, if an adult dependent requires nonstop care, like some autistics, family
members may be forced to discontinue employment. However, in 2001, the Supreme Court was hesitant to consider working as a major life activity, compared to definitive “major” activities such as walking, seeing, hearing, and performing manual tasks.\textsuperscript{212} Ironically, the ADA regards employment as an important value, notably in its emphasis on productivity and self-sufficiency; however, Justice O’Connor seemed to value the ability to brush one’s own teeth more than the ability to be economically self-sufficient.\textsuperscript{213}

The Supreme Court has been criticized for its miserly approach to the ADA in its restrictive interpretation of who qualifies as being disabled.\textsuperscript{214} This criticism can be extended to ignoring families that care for dependents as also disabled. The Equal Employment Opportunity Commission assesses disability by comparing the impaired individual against “the average person in the general population.”\textsuperscript{215} If the average family is considered to be able-bodied and neurotypical then, in comparison, the family with disabilities is comparatively substantially limited. The ADA misinterprets disability when they only see it as an individual concern, failing to distinguish it as potentially affecting entire groups. Just as wealth can be imagined as affecting entire families rather than income earner alone, severe disability can be imagined as amorphous, affecting each member of the family. The dependency worker works to halt the spread of disability, herself working as a sponge to engulf the disability, but this may be a singular and elite manifestation of disability.

Viewing entire families as disabled might enable social services to adapt to groups of clients to develop plans that take account of each member. Further, recognizing that one person’s demands significantly alters the potential of another
member(s), federal and state disability benefits may be assessed more broadly. As O’Connor noted, the ADA defined disability narrowly when it only recognized 43 million Americans as disabled; it was not the purpose of the ADA to encompass the needs of families.\textsuperscript{216} However, when the policy envisions the disabled person as singular, the solutions that they develop may be unsuited to the clientele they seek to serve. If entire families could be considered disabled, vulnerability could shift from an individual problem to a way of being in the world for certain closed groups, like families. This perspective may enable public policy advocates to design ways of making disabled families permeable to outside assistance in a manner that produces positive, rather than negative, side effects.

In response to the amorphous nature of disabilities, some researchers employ a family systems approach in order to capture the complexity of disability in families. Seltzer et al describe how families draw upon the energies of all family members in support of caring for a permanent dependent.\textsuperscript{217} Rivers and Stoneman stress the importance of looking at the entire family in order to better grapple with the consequences of disability.\textsuperscript{218} Perhaps severe disability would not overwhelm entire families if demands for dependency workers were automatically met, but surprisingly, Rivers and Stoneman reported that some families with disabilities exhibited more stress and negativity with increased access to social services.\textsuperscript{219} This suggests that financial security may not be the only reason why some families decide not to employ an outside worker to help defer some of the effects of dependency: Families may sustain more positive feelings in a closed system, which is not that surprising considering that American society highly prizes the autonomy of the home and disdains government
involvement. Families who value self-reliance may additionally associate outside care with personal feelings of failure and inadequacy.\textsuperscript{220}

Another way to interpret family’s distress related to the advent of social services draws upon the previous section’s stories of shame. While the article fails to specify the types of social services that family’s found upsetting, we can imagine the negative consequences of interaction if the family feels betrayed by its disclosures. If outsiders construe autistic children and their families as deviant, abject, or abnormal, the family’s conception of itself as a successful unit may be threatened. Just as autistic subjects are stigmatized, nondisabled caregivers may be incriminated in the former’s refusal to obey standards of normativity. Mothers refer to the stigmatizing glares that they encounter in grocery stores as their autistic children throw wild tantrums in the check-out aisle.\textsuperscript{221} Siblings report the dread of outside company, afraid of the other’s response to shit stained carpets and blood smeared walls, designs made by their autistic brother or sister. Stigma can disassociate itself from the person designated as disabled to encompass the entire family that shares its secrets.

On the other hand, we may question if the dichotomy of secrecy/disclosure always favors disclosure. Instead, we may want to analyze the ways in which secrets build communities and even may strengthen families. My third conversation was rewarding because our shared stories were like exchanging hidden secrets, and yet, we needn’t fear the other’s reactions since our secrets were the same. As Rivers et al reported, families that received little outside support were likely to report favorable associations with autism. This also implicates dependency workers as the assumed favored response to dependency needs. Families of autistic people may be willing to
shoulder the burden of care by themselves, especially when otherwise risks abjection. In
the next section I want to specifically look at siblings since they bear a unique
relationship to autism, questioning if abjection and normalization are rendered differently
from a sibling perspective.

2. Siblings: Locating Counter-Normativity

When disability renders the disabled person unable to speak for herself, parental
or professional perspectives often are substituted for her experience, but both of these
may be overly encumbered by their normative expectations of neurotypical functioning
as a requirement for personhood. On the other hand, siblings of a brother or sister with
autism may potentially be more normalized to disability due to their location of the home
being permeated by disability. Siblings have a unique relationship amidst all types of kin
relationships because it is the longest in duration, is constituted by the same family life
space, and are egalitarian. They are characterized by supportiveness, concern and
mutual affection, although this varies across age, class, and gender. Siblings are
potentially the next generation of caregivers and are thus of pragmatic concern to long-
term dependency needs. The concept of siblings can also be seen as a rhetorical
device to produce new understandings of how subjects become constituted and whose
subjecthood then creates particular notions of agency. For Judith Butler, the “I” is not
situated along different positions, but is constituted by these shuffling positions. For
subject who is “fully embedded [in] organizing principles of material practices and
institutional arrangements, those matrices of power and discourse […] produce” the
subject. The location of the family can be imagined as the first stage of institutional
arrangements whereby individual subjecthood becomes constituted and normalized. How is the subject’s agency and constitution altered by its embeddedness with disability? Pursuing this perspective may enable outsiders to reevaluate disability’s meaning. I imagine the position of sibling as being located between autonomy/interdependence, disability/ability, and justice/care.

Popular culture in some ways recognizes that siblings to disabled people are more apt to view disability in more accepting and/or compassionate ways. In *The Ringer*, Johnny Knoxville falls in love with Lynn, a Special Olympics volunteer, who is especially accepting and kind towards disabled competitors. Lynn volunteers with disabled adults and lunches with an intellectually disabled woman in a manner that is mutual, rather than patronizing. When Knoxville is alone with Lynn in her car, his fidgeting with the car’s visor reveals a Polaroid picture of an adult male with Down syndrome. Lynn reveals that the man “was” her brother, providing no additional information as to why she speaks of him in the past tense. The disclosure, however, divulges much more as her familial relationship now seemingly accounts for her manner, compassion, and understanding. Lynn, in this scene, not only represents how siblings can potentially be acculturated to disability differently, but she also performs her disclosure as a coming out narrative in which disability is encased in secrecy. Much like queer identities in which people are assumed to be straight until the point of disclosure, people may be assumed neurotypical without any relational bonds with disability until proven otherwise. In this way, heterosexuality and levels of ability constitute normativity. *The Ringer* is not alone in its sibling narrative; *Rainman* followed the burgeoning relationship between adult brothers, one autistic, and the special bond that was its result. In both
films, siblings have a special and positive relationship to disability. From this perspective, siblings may form a version of secrecy wherein the secrecy cements a resilient bond, forming a separation between themselves and outsiders.

Social scientists rarely employed such positive assessments to the effects of mental disabilities. Sibling relationships between non-disabled and disabled brothers and sisters were generally ignored until the late 1970s and mid-1980s. Most of the previous research focused on the disabled person, their parents, or their attachment to nondisabled peers. When attention did turn to the position of siblings, it was encumbered by a presumption of negativity. Early studies of siblings of disabled children assumed that their well-being was jeopardized and at risk, stressing the negative consequences of being associated so intimately with disability. In 1979, Fern Trevino warned of the disparate and tragic position of siblings to “retardates”:

The family with limited finances in need of constant supervision for a retardate has little choice but to ask the normal children to share the load. Clearly the more normal children there are in the family, the more potential help is available. Studies and case histories indicate that the lives of some children with a handicapped sibling are wasted or devastated. Normal children may be deprived of their childhood and may assume the role of substitute parents. Margaret Adams cautions counselors to watch for the ‘golden-hearted’ sister, the one who establishes a maternal relationship with the afflicted child, a relationship that the family accepts all too easily.

Despite the allusions to case histories, these earlier assumptions were often based on little if any qualitative data. Instead the experience of disability was so heavily stigmatized that researchers found it unimaginable for it to have a positive effect on families. In the late eighties, when some experts began to criticize Trevino for her lack of empirical data, they nonetheless persisted in her normative standpoint, describing how disabled
children “enslave their physically normal siblings,” extenuating Trevino’s dark hypothesis. Just as Anita Silvers postulated that nondisabled people experience disability as a “state unthinkable to oneself,” the experience of being in close proximity, as a family member, to disability may be just as unimaginable. Assumptions of negativity persist in current culture, as evident in a recent *The New York Times* article entitled *For Siblings of the Autistic, A Burdened Youth*. The author describes siblings’ reactions to autism as “painful,” “embarrassing,” and “frightening” with little emphasis on any potential positive effects.

In spite of the negative presuppositions, current research is becoming more nuanced while acknowledging a positive trend in sibling narratives. More research has been dedicated to the experience of siblings, but analysts continue to note the overall lack of data. They also continue to assume that the experience of disability is negative, even though the data is altogether inconsistent. This tends to result in a self-fulfilling prophesy whereby researchers begin with a hypothesis that disability impacts siblings negatively, then gather data that is both positive and negative, but then use the negative (rather than positive) feedback to bolster their hypotheses. Normative standards as to the negative consequences of disability persist amidst data that, at times, strongly suggests positive effects, proving the resiliency of normativity. Amidst the inconsistency, researchers conclusively admit that the response to disability varies. Different analyses suggest that social support networks, levels of marital stress, severity of disability, and the age or gender of siblings all may account for divergent reactions.

Seltzer et al. attempted to ascertain what distinctions in disabilities caused siblings to variously react negatively or positively to their disabled brother or sister by comparing
two groups: one consisting of siblings to mentally retarded adults and another comprised of siblings to schizophrenic adults. Seltzer et al. attributed the differing response to mental retardation (positive response) and schizophrenia (negative response) to three factors: the age of the disability’s onset, unstable or unpredictable behavior caused by disability, and the societal stigma attached to the disability. Mental retardation, in comparison to schizophrenia, is diagnosed earlier, produces stable outcomes, and is accompanied by less societal stigma. Siblings to autistic people could thus react either way: the onset of the disability is early (positive response), but autism can also be accompanied by erratic behavior and societal stigma leading to a negative response.

The study considered the duration of the disability more decisive to a positive response compared to its manifestations, suggesting that early acculturation to disability accounts for siblings’ positive translation.

The earlier onset of the disability may prove to have a different effect on siblings due to the home becoming a unique subaltern culture of disability, ways incomparable to disabilities that occur later in life when the home does not have the same acculturating force. Whereas dominant Western culture stresses autonomy, independence and competency as ideals, families with cognitive disabilities may center more upon interdependence, vulnerability, and sacrifice. In this way, disability is similar to third world feminisms insofar as the home becomes an alternate culture to the dominant system of values. Distress noted by siblings may be produced by the clashing of two contradictory value systems, rather than spurred by the disability itself. Further, just as postcolonial feminists critique the West for its interpretation of subordination in non-Western societies as being a result of their “backward” cultures, the perspective of ability
assumes that disability becomes responsible for the majority of disabled families' hardships. Postcolonial feminists suggest that Westerners shift their accusatory gaze away from culture and towards dominant paradigms of power that render Third World countries as abject. Similarly, what types of societal paradigms inflict unspoken forms of violence upon disabled families?

The idea of two cultures, one insulated and invisible, the other dominant and powerful, calls upon W.E.B. DuBois’ “double consciousness.” In *The Souls of Black Folk*, DuBois gives voice to the question, “How does it feel to be a problem?” The question aptly applies to families with disabilities, not just the disabled person, as the family is often construed as responsible for autistic children’s behavior. Dubois’s double consciousness relates to the black man always seeing himself through white eyes, similar to siblings of disability. Several siblings referred to their fears of their family’s abjection, rendered by the normalizing gaze. The double consciousness of siblings can shift from their private realm of shared vulnerability to public standards of private, closeted bodies.

Siblings of autistic children may be misunderstood and pathologized when set against a backdrop of nondisabled sibling dyads. Often, a control group consisting of non-autistic dyads (two “normal” siblings or one disabled but non-autistic sibling and nondisabled sibling), are contrasted against the experimental group comprised of autistic dyads (one autistic sibling and a non-autistic sibling). Under these conditions, nondisabled siblings’ relationships become the norm and siblings with disabilities are negatively assessed if they fail to reach the former norm. On the other hand, the control group positioned against autistic dyads often consists of a child with Down syndrome and
their sibling, a poor choice of comparison due to the respective disabilities divisive differences. Down syndrome is often unaccompanied by behavioral problems, unlike autism, and its frequency is random posing little risk to siblings, again unlike autism which has some genetic basis.\textsuperscript{239}

Despite these problems of design, research regarding siblings to autistic children has produced positive results. Fiona Knott et al compared DS dyads to autistic dyads and hypothesized that siblings would react asymmetrically to one another, as opposed to egalitarian, based on “normal” patterns of developmental in which older siblings take a leadership role while younger siblings take on a mimetic role. Their analysis suggests that disabled dyads, the non-disabled sibling assumes the leadership role over the disabled sibling despite age differences. Predictably, DS dyads responded more often and more positively to one another as compared to autistic dyads. However, autistic dyads still spent more time together and responded more positively to one another as compared to non-disabled peers. Autistic children are much more apt to respond to siblings than to peers, leading Knott et al to draw several conclusions. First, siblings might be a primary site of interaction for autistic children in which their playmate is socialized to autistic traits. Secondly, the existence of unequal roles may be more conducive for autistic interaction in which the autistic child comes to rely on another’s initiative. Finally, researchers concluded that nondisabled sibling may be more motivated to engage with autistic siblings rather than outside peers.\textsuperscript{240} Even though the autistic dyads were less engaged with one another in comparison to DS dyads, the relationships that form between the former may be of greater importance due to autistic
children’s poor interaction skills with peers. From this perspective, the importance of siblings to autistic children is heightened.

Knott et al are unique insofar as they observed interactions between siblings; most of the research into sibling relationships is dominated by data collected from surveys and interviews to judge the nondisabled child’s perception of the autistic child. Even though verbal autistic children account for most of the sample sizes, they are less often scrutinized as researchers seem less inclined to debate how nondisabled kin negatively affect the perceptions of autistics. Regardless, survey responses from neurotypical siblings range from negative to positive, but are predominantly more positive than negative. Siblings are likely to report feelings of admiration towards the autistic child as well as less quarreling and conflict relative to nondisabled dyads.241 In Seltzer et al’s analysis of siblings of DS adults, participants would often attribute positives to their development due to their disabled sibling. Siblings of autistics describe being taught certain values by their autistic brother or sister, such as: “patience, maturity, love, and compassion”;242 “responsibility, patience, stamina, self-discipline, and unconditional love”;243 “acceptance, patience, individual worth, but most of all about love”;244 “he brings us together more, because we’re in it as a family.”245 These siblings replicate patterns of learned behavior gained through their special relation to vulnerability. Instead of reporting the experience of wasted lives, siblings respond positively. Even Seltzer et al’s respondents who reported more negative associations with their schizophrenic sibling, their relationships still possessed a level of resiliency that the researchers found surprising considering their circumstances. Thus they advocate a shift in research,
focusing on the enduringness of relationships, rather than disability’s potential negative consequences.  

Researchers note an overall level of resiliency to sibling relationships, especially as siblings’ age, the loss of other parents and the aging of their own children draw siblings together again after young adulthood and the busyness of their lives had temporally shifted their relationships to a less intimate nature. Siblings in which one child is autistic are therefore continuations of a larger pattern, and yet, the level of their intimacy may be also bound with their unique type of normalization into the world. Families with disabilities can be located in a region of counter-normativity insofar as independence is rendered less important compared to the dominant culture. As one member’s disability draws upon the support capabilities of the others, siblings’ may be socialized to the concept of care differently than nondisabled families that allow for more autonomy. For instance, the level of reciprocity “required” to fuel care-providing may be lessened, as siblings report little effect upon the autistic person’s receipt of care. Thus, the importance of care needs might be instilled without relying on mutuality.  

In relation to care practices, siblings and autism also make evident non-transparency, complicating what might be an overly simplified process of care. In autistic dyads, interpreting care needs might become more difficult when the autistic member is non-communicative and unable to express needs. Siblings thus become imperfect interpreters to autism, translators to its alternative and private language. Communication can exist outside of the boundaries of language, however, imperfectly. For instance, I know that an arm extended in my direction with waving fingers forward means “come here” whereas if the palm faces me, with fingers still, the sign says “stay
Over twenty years, we’ve developed a private language, all of my family learning the signs that Matt ingeniously creates to express his desires. Autism, in this way, is replete with secrets that bind families together in a positive manner. These nonverbal cues seem untranslatable to outsiders, however, it isn’t perfectly legible to family members either. I don’t know what it means when my brother drags my arm in a seemingly vague direction: it seems as if he wants something, but exactly what remains unclear. He often wants to take a ride in the car, but I don’t know where to drive, until his screams pierce the ear, hinting to me that I may have made a wrong turn. This foreignness between autistic dyads exemplifies, in an exaggerated fashion, the indeterminacy of needs in relation to an ethic of care. Care ethicists may well revisit the initial stage of care, recognition, while taking difference and non-transparency seriously.

Amidst all of these differences, siblings may be well positioned to advocate counter-normative values. Siblings’ normalization into the world might begin in a home environment in which the autistic member’s vulnerability needs are rendered more visible than typically expected. Thus, siblings may be socialized to expect disproportionate patterns of contribution-potential when one or more members are autistic, perhaps profoundly. Recognition based on contribution, as earlier expressed in relation to Young, could be less important to families with disabilities. While the outside world focuses on progress, the family with disability may be overwhelmed by daily needs of maintenance. With this in mind, the value of progress is decentered, and instead replaced with the immediacy of the present situation. Further, permanent disabilities like autism strike at the core of progress, envisioning individual worth outside of its relationship to advancement. Instead of measuring siblings and families with disabilities to nondisabled
families to discern their overall success, as if non-disability represented the standard of aspiration, what truths can families with disabilities offer to normative values that have ignored the body’s vulnerability?

**Conclusion: A Foucaultian Analysis of Abjection**

In an interview with Michel Foucault, Foucault attempted to provide a purpose to his philosophy, especially in relation to his studies of madhouses, delinquents, and sexuality. According to Foucault,

> All my analyses are against the idea of universal necessities in human existence. They show the arbitrariness of institutions and show which space of freedom we can still enjoy and how many changes can still be made. [...] This idea of man has become normative, self-evident, and is supposed to be universal. [...] What I am afraid of about humanism is that it presents a certain form of our ethics as a universal model for any kind of freedom. I think that there are more secrets, more possible freedoms, and more inventions in our future than we can imagine in humanism.  

I believe that autism and families with disabilities, in some ways, represent a location of freedom. Foucault rejects humanism, even though it seems to further the positive component of human rights, because he fears its normative system of control. Foucault exemplified normative constraints in his theory of sexuality whereby he interpreted individuals of overly policing their sexual desire in order to avoid marginalization and stigma. The creation of identities, hetero/homosexual, worked as normative boundaries to police desire. Desire, if unbound by these constraints, could be reconfigured in multiple ways, furthering the goal of freedom. Judith Butler extended Foucaultian analysis in relation to gender, illustrating how gender, not just sexuality, is constituted by the deployment of power. Foucault and Butler represent a denaturalization to normative standards of being human.
Similarly, I believe these analyses can be extended to disability, autism, and abjection. Returning to my first narrative in which the feminist lecturer illustrated the ways in which vulnerable bodies are made abject by human interaction, abjection occurs when one person sees the other body as exposed, no longer commanded by the mind. She insisted that she pretended not to see in an effort to preserve her father’s dignity. Situations of abjection, arousing our discomfort, are not necessarily natural responses to the body. What is the arbitrariness of the body’s interpretations that propel us into feelings of abjection? More specifically, what can autism tell us about abjection’s arbitrary nature?

Autism can open up spaces of freedom insofar as some autistic people exemplify imperviousness to shame, illustrating the social construction of the body and can thus denaturalize our response. In contrast to the woman and her father, in situations with my brother, the pretense of invisibility is unnecessary. As she correctly stated, the relationship between siblings may lessen the amount of shame related to the body; however, I believe it is due more to my brother’s state of being in the world as autistic. He behaves in a manner that resists socialization, albeit potentially embarrassing, but also freeing. In a way, Matt does perform a “state of nature” outside of socialization, perhaps very much like the Wild Boy of Aveyron. Rather than pathologize his behavior, perhaps we should turn the gaze to socialized norms, asking if the suitably serve our purposes in the world. For instance, is the pretense of invisibility necessary? How does hiding from vulnerability create a more livable world? Further, what relationships does politics have with vulnerability? What is the political response to the pretense of invisibility? Does it share the blinded gaze, unable to see citizens as embodied?
According to Foucault, the “main interest in life and work is to become someone else that you were not in the beginning.” Taking disability seriously can perform this transformation, especially in relation to autism. And yet, this transformation needn’t be so serious. Disability is associated with deviance, dread, and abjection; however, these interpretations may be the result of non-disabled population’s refusal to imagine disability positively. Permanent disability and dependency can extend our prior constructions of what it means to be human, potentially disassociating human worth from productivity. Families with disabilities can discover that the body needn’t be a site of shame and abjection. Rather our association with each other’s bodies as shaming can be unpacked as a construction can be deconstructed.

Rawls expressed being human in the fullest sense in the liberty to choose, as if our authenticity resided in the freedom to make rational decisions. However, my sibling relationship with my brother reveals alternative freedoms disassociated from reason. I look forward to private moments with my brother and the secrecy and closeness that it provides me with. There, with him, I momentarily feel unbound. He follows few rules, feels little shame, and breaks normal rules of association and standards of decency. His way of being in the world reminds me of my own construction, my own policing. Freedom, as I interpret it through him, has very little to do with decision-making. Instead it is the freedom of the present, a refusal of normalization, a location outing the infeasibility of rules.

When nondisabled people read autism, they may well heed the advice of Third World feminists to practice a moment of hesitation before passing judgment: in that space of hesitation, neurotypicals may have the chance to re-approach the world from a new
perspective. Interestingly, when siblings described the values of living with an autistic brother or sister, patience was the most often featured response. Autism does what Third World feminists suggest: it renders the normative position as an Other, forcing the “normal” position to ask after itself. I had to learn patience with my brother. There is no way that I can enquire into his needs except through patient attentiveness; language is no help in hurrying comprehension as I am unclear as to which of my words he can hear and also understand. The unknown instills hesitation. Similarly, coming out as a vulnerable body and using the family as a counter-normative space, can only be worthwhile if the outsider hesitates, suspending judgment. If not, the stories will be read along normative constructions, rendered pitiful, abject. This chapter has not so much provided an answer, but instead a perspective, a lens, a moment suspended. It has attempted to make dependency and its abjection visible. Abandoning humans as autonomous agents as well as mutual carers, this chapter reads being human as a process of construction and deconstruction. From this perspective, concepts of care must expand, not only associating itself with mutual emotions, but with the complexities of dependency. If care ethicists insist on basing the care receiver’s personhood status on mutuality, autistic children and adults risk being constructed as nonhuman. Disability as a counter-normative tool demands that we be prepared to approach the funkiness of life: the mess, the abjection, the bodies. Most importantly, disability demands that being human is conjoined with being bodied.
Chapter 5:
Conclusion: Imagining Neurodiversity

Somewhere in my kitchen is a coffee mug, perhaps of extreme importance to this project as it may well possess the answer to the introduction’s question, posed in regards to the designation between human and non-human status. The mug was a gift from a friend, who had a friend, who had a daughter, who had been struck by a car almost thirty years ago. The collision caused permanent brain damage resulting in Sue’s continued dependence on her parents since the accident. She attends a day program for mentally retarded adults and in the evening returns home to her aging parents. When her father, Frankie, was battling cancer, he found himself telling Sue about some of his daily concerns, his fears. “What is: is,” she replied, striking Frankie in a momentary pause. What is: is, he told himself. The message seemed profound enough to call up his old buddy in Ted in Ohio, thinking that the new advice would help Ted in his daily struggle with emphysema. Ted relayed the wisdom to me and it has since stuck; we tell it to ourselves, reminding ourselves of our limitations. Limitation: the realization of our embodiment – our potential abjection. For Foucault, limitation was seen as potentially emancipatory. Paradoxically, the Enlightenment symbolized a limit-attitude wherein knowledge was expanded by recognizing the mind’s limitation.249

This project shares a Foucaultian limit-attitude in the recognition of the body as a requirement for human status, no more, no less. Others have attempted to limit full personhood status based on cognitive ability, attempting to assign moral status only on those who can be conscious of their moral status. However, I believe policing this divide
is more concerned with rendering our bodies invisible, rather than representative of the mind’s pinnacle. Placing moral status in the pristine consciousness bypasses the “funkiness” of being bodies, but this detour is only a half-truth to our experience. Thought represents a limitless potential in which reason or emotion can be deployed in multiple arrays of perfection. On the other hand, bodies are limited: they will inevitably malfunction. Whereas the mind seems to float across space and time, the body is branded to a location, its possibilities no longer limitless.

It is in this limit-attitude, however, that new spaces of possibilities can be retrieved. When we recognize our human status as a by-product of the body, acknowledging that (for now) we cannot exist outside of our skin, we are forced to maintain a dialogue that is contextualized, historical, and located, as are we. The answer to the question, “can nonverbal low functioning autistic people be awarded full human status, results in another question: are they bodies?” “Yes.” Thus they are human. This train of thought is based on “‘Occam’s razor’ ‘that the simplest explanation is likely to be accurate.’” 250 The concept of Occam’s razor was applied by authors studying sibling responses to autism, and it can similarly be deployed here. What is: is. Cognitively disabled humans cannot be deported from human status. Applying full personhood status on all human bodies complicates justice as we are forced to confront severe disability, a realm offering no easy answers to the problems of care, justice, or our moral responses. However, justice/care cannot bypass these situations or bodies as they are desperately in need of just answers. Applying the standard of all human bodies are human may be simple; paradoxically, it renders justice and care complex.
A possible solution to the complexity of justice is Kamran Nazeer’s concept of “local coherence.” In *Send in the Idiots*, he interviews four of his former autistic classmates. In 1982, they had been in one of the first classrooms designed for autistic children in New York City. Nazeer was curious as to how each had adjusted in the world and subsequently tracked five of them down. Autistic ability to adjust in the world hinged on their ability to construct their own world with local coherence. Nazeer explains local coherence in relation to the autistic practice of echolalia which “is also often described as the *desire for local coherence*. This is the preference that autistic people frequently demonstrate for a limited, though immediate, form of order as protection against complexity or confusion.”

Nazeer establishes a sense of local coherence by insisting on always carrying an alligator clip with which to busy his self when the world becomes too complex. Another autistic man relies on puppets in order to maintain communication. Many autistics describe the way in which they experience the world as over-stimulation for their sensory perception which causes their surroundings to be overwhelming and chaotic. To cope, according to Nazeer, they try to establish a sense of order and understanding. Sometimes, methods of local coherence appear insane: an autistic schoolmate of Nazeer’s rode his bike to work every morning in Chicago *with his eyes closed*. My brother’s world, as well, depends on a routinized order that to outsiders appears chaotic and neurotic: he insists on wearing the same color of shirt and shorts, the same type of sandals, and on taking the same car rides everyday. In this context, local coherence is how individual autistic people deal with their own lives, but I believe we can expand the meaning of the phrase to incorporate a meaning of justice and care.
Local coherence acknowledges that the solutions to complex ethical dilemmas are placed at the local level, contextualized into the local realities of dependency situations. Instead of aligning solutions to thick constructions of selves or a priori theoretical principles, local coherence begins theory in its location. Applying local coherence to families with disabilities acknowledge a systems approach to disability in which its effects are seen as amorphous and shared. Chapters two and three attempted to make sense of the world by fitting localities into global theories, but this project concludes in the belief that such orientations to the world and justice are likely to enact a continuation of marginalization. Looking locally, we may discover new ways of being in the world that interrogate our own systems of normalization. Local coherence is enabled by the practice of hesitation, described in chapter four. Interpreting local contexts requires a momentary suspension of theory and judgment. Integrating the concept of a limit-attitude with local coherence acknowledges the way in which our embodiment in the world renders us as incapable to answer each dilemma. We cannot simultaneously enjoy a view from nowhere while analyzing multiple local contexts; one must be abandoned. The expansion of care, local coherence, and assuming a limit-attitude are all ways in which we can position ourselves to autism, but what is autism’s relation to justice? Just as optimum care situations for dependent autistics require special knowledge, care, and hesitation, so too does justice.

The importance of looking at justice and autism is also situated personally and politically. The same questions that linger in the periphery of my mind should be floating somewhere upon the radar of politics: who will provide the care for my brother as my parents’ age? If it should be me, what social support networks will be within my grasp?
Will I be too shamed by my incompetence and failure as autonomous to seek help? Can the discourse of curing autism acknowledge its inability to offer solutions to the immediacy of care workers? The focus on curing autism may well deter the political consciousness from asking how to care for autistics and their families.

Most importantly, this project’s emphasis on autism has attempted to deconstruct the mythology of autonomy permeating the ADA, political theory, and disability advocacy. Pragmatically, the enforcement of competence marginalizes severe dependents and normalizes society into the belief that worth is a result of productivity. I have also attempted to uncover significant shortcomings within an ethic of care, opposing its reliance on universal needs and demands for reciprocity. The idealization of care also works to disenfranchise those at the margins of mutuality whose manner of association contests benign theories of care. Above all else, I have attempted to construct a way in which to imagine counter-normative values associated with autism. Using autism as a lens to critique neurotypical commitments, I have tried to continue Foucault’s philosophical purpose to divorce our identities momentarily from the normalizing force and to imagine different ways to be free. I believe that disability justice can only be possible when we situate ourselves as bodies and attempt to shirk some of the shame associated that comes along. Taking autism seriously, we might better envision neurodiversity, recognizing that mental capabilities are not measurements of personhood, but instead diverse ways of embodiment.
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Notes


3. Ibid.


12. Ibid.

14. Jennifer Nedelsky


   Seifert is referring to Tinbergens Theory that places autism’s cause in societal stress.

16. Ibid., 14.


20. Ibid.


22. Ibid.

23. Ibid.


30. Ibid., 133.

31. Ibid., 161.


33. Ibid., 44-45.

34. Lovaas, 135-136.

35. Ibid., 150.


37. Ibid.


39. Ibid.

40. Ibid., 239.

41. Ibid., 242.

42. Judy Singer an autistic advocate who diagnosed herself upon adulthood is considered to be the first to have used the term “neurotypical.” Similarly, Rose-Marie Garland Thomson uses the term “normate” to refer to non-disable people, but I follow Singer’s lead and use neurotypical because I think it signals a focus on mental capacity which is lost in terms like able-bodied or normate.

44. Ibid., 10.


46. Ibid.

47. Ibid., 1.

48. Ibid., 7.


52. Ibid., emphasis added.

53. Levy, 205.


56. Ibid., 7.


60. Ibid., 249.


64. Ibid., 101.

65. Ibid., emphasis added.

66. Ibid.


68. Clogston, 47


70. Ibid., 12.


73. Fleischer, 109.


76. Ibid., 6.


78. Rawls, 79.


84. Ibid., 8.

85. Rawls, 29.

86. Anspach, 602.


89. Ibid., 16.

90. Charlton, 3.

91. Rawls, 249.


93. Ibid.


100. Ibid., 439.


103. Young, 347.

104. Nancy Fraser, “Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy,” *Social Text* 25/26. (1990): 65

105. Ibid., 57.


107. Ibid., 2182.


110. Fraser, 71.

111. Ibid., 73.


113. In general, the women’s movement built itself upon women’s reliance on experience to garner insight into their lives and injustice. To read more about the effect of experience on feminism see: Judith Grant, *Fundamental Feminism: Contesting the Core Concepts of Feminist Theory*, (New York: Routledge, 1993).


117. Ibid.

118. Ruddick, 345.
119. Ibid., 346-347.

120. Ibid., 347.

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122. Ibid., 349.

123. Ibid., 348.


126. Ibid., 154

127. Beals, 32.

128. Ibid.


130. Hooyman and Gonyea, 141.


132. Wong.

133. Seltzer et al, 244.

134. Ibid., 326.

135. Ibid., 246.


137. Bettelheim.

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159. Hooyman and Gonyea, 140.

160. Ibid., 126.

161. Ibid., 113.

162. Fineman.

163. Ibid., 2205.

164. Hooyman & Gonyea, 126.

165. Ibid., 140.

166. Ibid., 88, 100.

167. Levy et al., 205.


171. Ibid.
172. Ibid., 118.


175. Ibid., 84.


177. Ibid., 106.


179. Beals, 33.


182. Konidaris, 1030.


184. Iris Marion Young, “Taking the Basic Structure Seriously,” Perspectives on Politics 4-1 (March 2006), 91-97, 95.

185. Ibid.


190. Ibid., 149.


192. Ibid.

193. Ibid., emphasis added.


198. Kelly, 1.

199. The conference attended was the: Multiple Perspectives on Access, Inclusion, and Disability Annual Conference held in Columbus, Ohio from April 17-18, 2006.


202. Ibid., 18.


205. Mahmood.

206. Ibid., 37.

207. ADA, 2:12102: 2, emphasis added.


210. Ibid., 88.

211. Ibid., 109.


213. Ibid.


216. *Toyota Motor*.


219. Ibid., 391.
220. Hooyman and Gonyea, 108.

221. Beals.


223. Ibid.

224. Butler, 42.


227. Ibid., 128.

228. Seligman and Darling, 118.

229. Silvers, 29.


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235. Ibid., 396.
236. Ibid., 402.


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244. Quoted in Seligman, 130.


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250. Glasburg, 151.