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# Disability and Embodiment: Towards an Ethics of Welcoming

A Thesis Presented

by

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#### Abstract of the Thesis

#### Disability and Embodiment: Towards an Ethics of Welcoming

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In this will paper I will examine two ethics of the body and disability. Firstly I will examine Foucault analysis of Biopolitics and examine how Biopolitics formulates an ethics of the body that marginalizes and stigmatizes disabled individuals. I will then examine how Peter Singer's thought is an instance of a biopolitical way dealing with the body and disability. To do this I must first examine his general ethic framework and then I will examine his writing on the ethical situations that arise when one is confronted with problems that relate to disability. I will show how Singer conclusions posit a particular understanding of personhood, and our ethical responsibility towards the other. In contrast to Singer's thought, which I see as an instance of a biopolitical ethics of the body and disability, I will examine Levinas' and Derrida's concept of hospitality as an alternative ethical schema for problems that arise out of questions of disability. In Derrida's and Levinas' thought we can never know the other as other. His or her difference always escapes a complete understanding and eludes our cognitive frameworks. To approach the other in his or her difference, Derrida and Levinas argue that we must adopt a stance of hospitality. Hospitality for Derrida and Levinas, means making a place within one's self to welcome the other's singularity which one cannot not know, and allowing oneself to be affected, disrupted and changed by encountering the other's difference. Derrida writes that the other's difference always places an infinite demand on us to welcome him or her, and that our subjectivity is formed in relation to the demand of the other. Our response to the other is always incomplete and in relation to a singular context. It is my belief that hospitality is a concept that is particularly useful in working with the phenomenon of disability because disability is usually conceptualized in such a way that stigmatizes and marginalizes individuals with disabilities. Further, it is my contention that because the difference of disability stands marked as different that welcoming the difference that disability presents points to a greater understanding of the singularity of all bodies and minds and how our relationship to, and ability to be affected by the others differences is vital to that what makes us human.

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Disability and Embodiment: Towards an Ethics of Welcoming

Two ethics of the body and disability: The ethics of Biopolitics, individuality,
and interest vs. the ethics of hospitality, hetero-affectivity, and alterity.

#### Introduction

It is my aim in this thesis to contrast two radically opposed ethical stances on the body and disability. The first is what I call the biopolitical ethics of disability. This is an ethics that seeks to gain power over the very biological processes of life by deploying modern technology and using statistical data on population, race, disease frequency, disability, and so on. Through the collection of data and the deployment of technologies, biopolitics gains power, which it uses with the aim of constructing categories of normalcy and normative health, which are then employed for political purposes.

The ways in which biopolitics is used politically can be categorized as either constructive or marginalizing. Biopolitics is used constructively when certain populations are encouraged to reproduce and a normative body image is promoted in order to construct a desired population for political purposes such as fighting wars, having a strong workforce, or having a solid consumer base. Biopolitics draws upon political power in a marginalizing way when certain populations; whether racial, ethnic, criminal or disabled, are discouraged from reproducing and forces are deployed against these groups to stigmatize and marginalize them as abnormal because they are seen as a threat to the stability and health of a desired normative

political body. The abnormal, according to this ethic, is a disease, and through medical technology it should be alleviated and covered over.

In the first section of this thesis, I will apply Foucault's analysis of biopolitics to disability. I will then focus on how Peter Singer's work on disability, roughly in the name of interest utilitarianism, stems out of biopolitical ways of dealing with the body and disability, specifying how his writings are an instance of biopolitics. By defining what makes a human being a human as rationality and the ability to make plans for the future, Singer constructs a very self-centered concept of personhood which excludes and devalues people with certain disabilities from ways of experiencing life.

In contrast to what I call the biopolitical ethics of disability, I will place an ethical theory drawn from the work of Levinas, Derrida and Simon Critchley; which I call the ethics of hospitality, hetero-affectivity, and alterity of disability. According to the ethics of alterity shared by these philosophers, to be ethically faithful to the other you cannot impose your own ethical schema on the other but must respond to an ethical demand that comes from the other and not from you. As such, neither does the ethical subject exist prior to the encounter with the other nor does he exist independently of the relationship with the other. He is always hetero-affective. The self is always divided between itself and its responsibility and relationship to the other. It is my contention that it is not rationality and free choice that are essential to our humanity, but rather it is our ability to be affected by, and to welcome, the other's difference.

The concept of Derridian Hospitality and its applicability to an ethics of disability will be a central guiding theme of the section on the ethic of hospitality. Following Levinas, Derrida claims that the face of the other imposes an ethical responsibility on us that cannot be formulated and categorized in terms of our own trajectories. For Derrida, in order to truly be hospitable to the other, we must in welcoming the other, allow ourselves to be changed by the other's difference. This means that to truly welcome the other as other, we must allow our trajectories to be altered by the act of welcoming the other.

I think that an ethic like this is especially important to an ethics of disability because the concept of disability is almost always conceptualized in terms of being abnormal in relation to the trajectories and criteria of normalcy. The way that disability is usually thought of consistently does violence to the disabled person's alterity. An ethics of hospitality is an ethics that is formed in the singleness of encounters. Indeed, in this context the term disability is too overarching and broad because it comprises individuals with such diverse conditions as Down syndrome, Cerebral Palsy, Autism and so on. Even the above categories are too general because according to an ethics of hospitality, in order to welcome the other as other I must welcome him or her in his or her singularity and difference, which will always exceed any attempt at categorization. Because the difference of disability stands as marked and abnormal, it highlights the fact that any uniform construction of what bodies and minds are, or should be, is patently false. An ethics of alterity of the body and disability therefore opens the door to a more singular account of what happens in the encounter between all bodies and minds and can thereby lead one to ponder more

deeply the need for a larger ethics of alterity and hospitality. Thus, I will incorporate the writing of Simon Critchley, whose concept of hetero-affectivity, meaning the double-sided ethical self that is formed in an encounter with the other, is important to what I will be exploring, as well as is his highlighting of the ethical dimension of deconstruction.

I will be drawing upon material from the disability literature that offers practical examples of enacting an ethics of hospitality of the body and disability, even though it may not be formulated in terms common to the philosophers whom I reference for the theoretical part of my thesis. The work of the philosophers Eva Kittay and Martha Nussbaum will be very important for my theory, because their ethics formulated in regard to disability are very close in ethos and spirit to what an ethics of hospitality of disability is aiming at, even though they do not formulate things in a deconstructive or post-structualist manner.

Through pointing out how Foucault's genealogy of the Biopolitical applies to disability, it is my hope to demonstrate that the construction of normalized bodies and minds has had vast effects on disabled individuals. People with certain disabilities have been made to let die when they could have lived happy lives. These lives may not be what a non-disabled person may consider to be happy, but might this judgment be due to a failure in understanding how a child with Down syndrome experiences and enjoys life? Might this also mark a further failure and refusal to welcome the other's difference? Isn't the inhospitality of normalcy and the exclusion of the abnormal something that constantly marginalizes and afflicts disabled people?

Doesn't the construction of normalcy and its security shield all those who strive for a

normalized body and mind from the radicalness and singularity of each encounter with other human beings? Doesn't it thereby block us from being taught by the otherness of the other because we remain enmeshed in the net of our own egoism? I believe that an ethics of hospitality, hetero-affectivity, and alterity of the body and disability can point towards the importance of alterity in all human interaction and help lead us towards awareness of the richness arising from being aware of the difference of the other, as well as towards a more ethical way of conceptualizing disability.

#### I. Singer, Biopolitics, and Disability

#### A. Biopolitics

Biopolitics, which Foucault says began in the late 18<sup>th</sup> century, seeks to establish a level of control upon the body as a living organism. It does this by keeping records on illnesses, mortality rates, longevity, birthrates, and so on. It records these data to intervene in these processes and to gain power over them. 1 With biopower, the state seeks to gain control over the processes of life itself and to make life something that can be manipulated. This is fundamentally different from the old power of the sovereign who had the power to let live and make die. Biopower, according to Foucault, "makes live and lets die." <sup>2</sup> Biopower gains control of the processes of life so it can establish control over them. It uses practices that can save lives by sparing people from what in earlier times might have been certain death.

<sup>&</sup>lt;sup>1</sup> Michel Foucault, Society Must Be Defended: Lectures at the College De France 1975-1976, trans. by David Macey (New York: Picador, 2003), 243.

<sup>&</sup>lt;sup>2</sup> Ibid., 241

However, biopower chooses when to intervene; it sometimes chooses not to and lets people die. An example of this occurred in the nineties when the South African government chose to focus on the prevention of AIDS rather than on treatment because the former was more cost effective.

In Biopolitics, life and death become the objects of calculation. Biopolitics seeks to gain control over diseases and the processes of life so that it can manage them. One of the reasons biopower does this is to create subjects who feel secure and insulated from the harmful effects of disease. Biopower seeks to enact a vigorous social body and healthy individual bodies. It seeks to prevent and intervene in cases of physical disabilities. <sup>3</sup> It has fought wars on persecuted people for the health of the social body. It is focused not just on the physical body but on securing the social body from any perceived threat. It strives to have control over the processes and accidents of life to the extent that it can ensure the health of the social body. <sup>4</sup>

Disability has always been a target of biopower. Ever since biopower became enacted, people with disabilities were seen as persons who could be let to die or prevented from reproducing. Through statistics, biopower produced a normative body and intelligence. People who failed to meet these norms were seen as abnormal and undesirable and were marginalized and sometimes prevented from reproducing. It is my contention that disability remains a target for biopower and that the targeting of disabled people by biopolitics has its defenders. I think that Peter Singer takes such a stance against disability, but in order to show why this is the case, I will first go through a detailed rendering of Singer's views on ethics, how this relates to

<sup>&</sup>lt;sup>3</sup> ibid., 254

<sup>&</sup>lt;sup>4</sup> ibid.

disability, and why Singer's philosophy is an example of a biopolitical exclusion and targeting of disabled people.

#### **B. Peter Singer:**

#### Introduction

For this part of the paper I will examine two aspects of Peter Singer's thought. The first aspect of his philosophy that I will examine is the general thesis of *Rethinking Life and Death* and a major theme in *Practical Ethics:* new advances in medical technology have made it impossible to hold the traditional sanctity of life ethic. This ethic holds that human life is intrinsically valuable in all cases and that under no circumstances should a medical professional provide any treatment that intentionally leads to death or refrain from giving a treatment that will prolong a person's life. The traditional ethic has been enshrined in the Hippocratic oath as "Above all do no harm." According to Singer, medical technology has provided us with ethical challenges that undermine the traditional medical ethic.

To illustrate how the traditional medical ethic has been called into question in recent years, Peter Singer documents several medical and legal examples that show that this traditional ethic no longer applies. With the advance of medical technology, Peter Singer argues, we have the power to sustain the lives of people who would previously have expired. Asking if it is always ethical to do this, Peter Singer argues for a quality of life ethic based on an interest utilitarianism that sees the two primary guiding values in the ethics of life and death as minimization of suffering and respect for a person's plans for the future. Infants of course do not have plans for the future

and because of this Singer proposes that it is ethically permissible for an infant's parents to decide if the infant should live or die in some pointed cases.

This brings me to the second aspect of Peter Singer's thought that I will examine; Singer's view on the medical ethic and disability. He formulates an ethics in which the value of life is based on a person's rationalistic choice and knowledge of himself as existing over time and the resultant capacity to have hopes and plans for the future. In his view, a person who has this consciousness of himself should be able to decide if he lives or dies. Because infants do not posses this capacity, Singer sees it as ethically in the realm of the parents' choice to determine whether they allow a baby to live with such diverse ailments as being born without a brain, Spina bifida, and Down syndrome. He contends that this ethic is based on three main points: the amount of suffering that the infant may experience in his or her life may outweigh the potential pleasures he or she may experience (so it could be argued that his or her life is not worth living), the cost spent sustaining the infant's life could be utilized in other ways that might save others lives (which might be a better way of using scarce recourses if the infant's life might be very short and painful due to his or her disability), and the infant has neither a concept of existing over time nor plans for the future (he or she cannot decide to live or die and has no rationalistic stake in the question).

Because of these factors, Singer sees it as an ethical option for the parents of severely disabled infants to decide for the infant if he or she lives or dies. I will examine hypothetical applications of Singer's view on disability and ask if his ethics are appropriate in all cases. Do changes in consciousness and technology necessitate

the shift in ethics on disability he calls for or is he privileging a certain mode of consciousness over another unjustly?

#### A changing Ethic?

Peter Singer argues that the traditional ethic of the inherent sanctity of human life that has persisted for over two thousand years has been undermined by advances in medical technology that give us increasing capacity to sustain life in one form or another, but also confront us with new ethical decisions.<sup>5</sup> We are now able to sustain people who have little hope of recovering consciousness and who are in a persistent vegetative state or even are brain dead indefinitely. A woman who is brain dead can now be kept alive so that she can give birth and we can keep alive a baby born without a brain who will never gain consciousness. Before these advances in medical technology, no one had to ask if it was ethical to sustain lives such as those described in the foregoing examples, because they would have expired naturally. <sup>6</sup> Indeed the traditional definition of death; "the permanent cessation of the flow of vital bodily fluids" was once absolutely uncontroversial. 7 With changes in technology, this definition had to be abandoned and we are now faced with unprecedented ethical decisions.

Peter Singer argues that there were a series of medical and legal cases that undermined the traditional medical ethic. I would like to briefly outline some of the examples Singer cites, as he argues that they signal a change in public consciousness

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<sup>&</sup>lt;sup>5</sup> Peter Singer, *Rethinking Life and Death* (New York: Saint Martin's Press, 1994), 1. <sup>6</sup> ibid., 19

<sup>&</sup>lt;sup>7</sup> Ibid., 20

about issues of life and death: he was informed by these examples in developing a new ethics concerning issues of life and death.

The first major shift was the abandonment of the traditional definition of death, the legal definition of which was replaced by brain death. The definition of death was changed in response to Dr. Christiaan Barnard, who in 1968 preformed the first heart transplant on his patient Louis Washkanaky, who had terminal heart failure. Although Louis Washkansky died 18 days later, his heart transplant opened the door to heart transplants becoming a common practice. 8 Unlike kidney transplants, which had been done for years at the time, heart transplants have to be donated by living patients because if the heart stops beating it loses oxygen and begins to decay. 9

The first heart transplant raised a new ethical issue. It was now possible to save hundreds of people via heart transplants, but this could only be done when the donors had beating hearts. There were many patients at that time in hospitals that had no brain activity at all and would never regain consciousness, yet they breathed and their hearts still beat. They would be candidates to donate their hearts to patients who needed heart transplants to live and did have conscious brain activity. However, under the then current definition of death, the patients whose brains were dead but whose hearts still beat were alive; taking a beating heart out of such a patient would be murder.

In response to the new ethical and medical dilemmas raised by advances in medical technology, the Harvard Brain Death Committee was formed in 1968. 10 It

 <sup>8</sup> Ibid.,22
 9 Ibid.,23

proposed two main reasons why the legal definition of death should be changed from the traditional definition to brain death. They are quoted as follows:

- Improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only a partial success so that the result is an individual whose heart continues to beat, but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients.
- 2. Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation. <sup>11</sup>

Singer points out that the Harvard committee did not argue that the patients in an irreversible coma were really dead and that the definition of death needed to be changed because dead people were being kept on respirators. The case put forth by the Harvard committee was instead that patients in irreversible comas caused a great burden to themselves, their families, the hospitals, and other potential patients who could be using the beds that they were occupying. <sup>12</sup>This is very striking because it points out that a major part of the rationale for changing the definition of death from the cessation of vital fluids to brain death was not the actual state of the irreversibly comatose patients, but rather the burden that these patients placed on others. They were being defined as dead not because of their actual state, but in part at least because redefining them as dead eased burdens on other people. We must ask what it means when someone could be thought of as dead because the definition of death was changed so that they wouldn't be a weight on other people.

ibia.

<sup>&</sup>lt;sup>11</sup> ibid., 25

<sup>12</sup> ibid.

According to the Harvard Brain Death Committee's report; "responsible medical opinion is ready to adopt new criteria for pronouncing death to have occurred in an individual sustaining irreversible coma as a result of permanent brain damage."

<sup>13</sup> Singer points out that brain death, or "total loss of central nervous activity" is not the only kind of brain damage that can lead to irreversible coma. Individuals can remain in a permanent vegetative state, and have no possibility of regaining consciousness, while parts of their brains live on. The Harvard Committee chose to define brain death as the complete loss of central nervous activity, but Singer argues that "the reasons given by the committee for redefining death--- the great burden on the patients, their families, the hospitals and the community, as well as the waste of organs needed for transplantation---- apply in every respect to *all* those who are irreversibly comatose, not only to those whose entire brain is dead."

<sup>14</sup>

Singer believes that one of the reasons the Harvard Brain committee decided to use the total cessation of brain activity as the definition of brain death is that the committee still wanted to formulate their statement in a way that didn't question the sanctity of life ethic. Singer says that most doctors and nurses do not think of brain dead patients as really dead. The fact that total brain death is an accepted criteria of death, and hence organ transplantation, is due in part to the fact that society wasn't ready to authorize taking organs from living patients. Society wasn't ready to abandon the idea of the inherent sanctity of life and come to the conclusion that some lives are more valuable than others. In addition, Singer believes, society wasn't prepared to accept the idea that a living person's organs would be donated, in part at

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<sup>&</sup>lt;sup>13</sup> ibid., 26

<sup>&</sup>lt;sup>14</sup> ibid., 27

least, because of the burden that he or she would be placing on society by remaining alive.

If brain death is the criteria of death, what are we to make of babies who are born with no parts of their brain but their brain stem? Are these babies then born dead? A small number of babies are born with this condition, called an encephaly, and they have no consciousness and no hope of ever achieving consciousness. <sup>15</sup> This circumstance is usually screened for during an ultrasound, whereupon the mother opts for an abortion. Singer cites a report that states that approximately 300 anaecephalic babies are born each year in the United States. <sup>16</sup>These babies usually die shortly after birth, but this is because medical procedures usually are not used to keep them alive. 17

In addition to an encephalic babies, some babies are typical at birth, but subsequently suffer damage that destroys the cerebral cortex. These babies do not fall under the category of brain dead because they do possess some central nervous system activity; but with their cerebral cortex dead, they have absolutely no hope of regaining consciousness. <sup>18</sup> Their bodies are however very much alive.

Since babies who have their cerebral cortex obliterated are not dead according to the brain death criteria, they cannot be used as organ donors. <sup>19</sup>Singer recounts how this placed Dr. Frank Shann in an ethical dilemma when he was employed at the Royal Children's Hospital in Australia. Dr. Shann had an infant patient who needed a heart transplant in order to live, but their was no available donor. In the next room

<sup>&</sup>lt;sup>15</sup> ibid., 38

<sup>&</sup>lt;sup>16</sup> ibid., 39

<sup>&</sup>lt;sup>17</sup> ibid., 40

<sup>&</sup>lt;sup>18</sup> ibid., 39

<sup>&</sup>lt;sup>19</sup> ibid.,42

lay a baby who had had his cerebral cortex destroyed when blood vessels in his head suddenly burst. The neighboring baby had no chance whatsoever of regaining consciousness and was unlikely to live much longer. <sup>20</sup> The law would not allow Dr. Schann to use the baby with the destroyed cerebral cortex as a donor because technically to do so would be murder. <sup>21</sup>

Because of ethical situations like the one described above, Singer was invited to contribute to a panel discussing the possibility of higher brain death as the criteria of legal death which would mean that the definition of death would be changed from no central nervous activity at all to having the brain destroyed to the extent that regaining consciousness becomes impossible. <sup>22</sup> Such a shift would have the practical advantage of allowing doctors to use such patients for desperately needed organ transplants if the supply were very scarce. The patients used as donors would have no hope of ever regaining consciousness or higher brain activity at all. Henry Beecher, the chairman of the Harvard Committee on Brain Death cited one of his reasons for changing the classical definition of death to brain death, is because with brain death everything that makes a person, e.g. "his individual personality, his conscious life, his uniqueness, his capacity for remembering, judging, reasoning acting, enjoying, worrying, and so on" is lost. <sup>23</sup>

If this was the rationale for changing the definition of death to brain death, it applies equally to those who have no higher brain functioning and have totally lost all possibility for consciousness. While on the panel, Singer agreed with the practical

<sup>&</sup>lt;sup>20</sup> ibid., 41

<sup>&</sup>lt;sup>21</sup> ibid., 42

<sup>&</sup>lt;sup>22</sup> ibid., 47

<sup>&</sup>lt;sup>23</sup> ibid., 48

implications of changing the legal definition of death to higher brain death, but he disagreed with it on fact. While Singer agreed that there was no reason to keep people alive who had loss all capacity for consciousness and that doctors should be allowed to use such patients as organ donors, he disagreed that such people were really dead.

Singer explains that the panel was confused because it lumped together questions that are separate. These questions are:

When does a human being die?

When is it permissible to stop trying to keep a human being alive?

When is it permissible to remove organs from a human being for the purpose of transplantation to another human being? <sup>24</sup>

Singer argues that these questions should be kept separate. While it is ethically permissible to remove organs from patients who have no capacity for consciousness while recognizing that they are being removed from living patients and not dead ones, Singer thinks that the panel's insistence on trying to change the definition of death was an anticipatory response to a potential reaction from a public that still holds to the sanctity of life ethic. The majority of the panel believed that the public was not ready to accept removing organs from living infants, even those without the capacity for consciousness.

#### Singer on Disability

At this point Singer's argument changes. The assertions above demonstrate that through changes in medical technology we have been faced with situations where

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<sup>&</sup>lt;sup>24</sup> ibid., 55

patients whose bodies are alive are able to be sustained even through they have permanently lost the capacity for conscious thought. Although medical technology has made saving lives through organ transplantation possible, in many cases these organs have to be transplanted from bodies that still maintain vital functions. Singer asserts that one has to make a distinction between the value of bare life and conscious life. Putting forth a quality of life argument, which is clear-cut in cases with people who have lost all capacity for consciousness and hence cannot have a life of quality whatsoever, Singer argues for the ethical permissibility of allowing to die certain kinds of disabled infants who do have conscious thought.

Singer's general ethical framework can be described as "best consequence" utilitarianism. Best consequence utilitarianism is different from classical utilitarianism as represented by Bentham and John Stuart Mill. Classical utilitarianism focuses on increasing pleasure and minimizing pain as the criterion for ethical decisions. Classical utilitarianism is not hedonism, because it is not primarily concerned with maximizing the pleasure and minimizing the pain of the particular person making an ethical decision, but rather the pleasure and pain of all those affected by a given action.

However, this view did have some downfalls. From the position of classical utilitarianism, one can argue that if killing someone in a painless way will increase the pleasure of others (for a reason such as financial gain or decreased tyranny) then executing that person would be ethically justified. This would be the case because the person killed wouldn't experience any pain upon being slain in a painless way and other people would be able to experience more pleasure with him gone. The loss of

one person's life is of no concern in itself for classical utilitarianism because once a person has died he doesn't experience anything at all.

However, Singer's "best consequence" utilitarianism is more complicated than classical utilitarianism. According to his view, in order to make ethical decisions one must make choices that respect most thoroughly the interests of all involved parties. This is not a simple egoism. An ethics that only takes into account one's own interests would, according to Singer, be preethical. Interest ethics can only be formulated when a person recognizes that his own interest "cannot count more than the interests of anyone else." <sup>25</sup> Of course people's interests do inevitably come into conflict. In response to this, Peter Singer defines an ethical decision as an action that to the highest degree possible respects the interests of those involved. By doing this, it is hoped that the best consequences will occur for all those affected by an ethical choice. <sup>26</sup>

The reduction of pain and pleasure can be thought of as an interest. According to this line of thought, everyone has an interest in experiencing as much pleasure and the least amount of pain as possible. However, additional interests motivate people's plans for the future. If someone wants to get married, have children, write a book, go to college, and travel, then she has an interest in doing these things. "Best consequence" utilitarianism would argue that these interests have to be taken into account when making ethical decisions. Singer would argue that a person should respect other people's interests and try not to do violence to them. To

<sup>&</sup>lt;sup>25</sup> Peter Singer, *Practical Ethics* 2<sup>nd</sup> *Edition* (Cambridge: Cambridge University Press,

<sup>&</sup>lt;sup>26</sup> Ibid..13

prevent someone from going to college or writing a book would be to do violence to his or her interests.

A person can do violence to another person's interest by forcibly stopping her from pursuing her interests or by taking her life. In "best consequences" utilitarianism the fact that a person is no longer alive to experience being deprived of an interest wouldn't mean that you didn't deprive her of an interest by killing her. By taking away her life, you deprive her of an interest. She had plans and interests in those plans, worked towards those plans, and had hope concerning those plans. If you take away her life, you deprive her of the interests she had in life.

Of course interests can conflict. In such cases the ethical decision would be to do that which is in the greatest interest of all those involved. If you put a convicted murderer in jail rather than executing them, you respect the interests of the families of the victim, society's interest in safety, and the interest of the murderer by not giving him the death penalty. The murderer may have the interest to go on killing people, but to allow him to do this would not be in the greater interest of society. Still his interest in life must be respected, according to best consequence utilitarianism.

Apart from the interests of experiencing pleasure and avoiding pain, Singer thinks that only self-conscious human beings can have an interest in the future.

According to Singer, you can only have an interest in the future of your life if you are conscious of yourself as existing over time and are able to formulate plans for the future. If you cannot formulate a hope or a goal for the future, you do not have an interest in your life beyond experiencing pleasure and avoiding pain.

We must bear in mind who, according to this definition, does not have interests beyond the increase of pleasure and the avoidance of pain. Infants, according to this definition, do not have interests other than the avoidance of pain and the experiencing of pleasure. For this reason, Singer comes to some very controversial conclusions concerning the status of disabled children. He believes that, since an infant has neither consciousness of his or her self existing over time nor wants nor plans for the future, a newly born infant has no rights distinct from the rights of animals. The infant, in a word, has no stake in his or her life. Other people like his or her parents may or may not have an investment in the infant's life; if the parent does, this should be respected. If this is not the case, and the parents have an interest in not letting the infant live, then what should be taken into account is what action will lead to the greatest overall increase in pleasure and minimization of pain.

We have an obligation, Singer believes, to inflict the least amount of pain possible on animals and this should be afforded to infants as well. We use animals for our needs and we don't generally have ethical dilemmas about this because animals don't have consciousness of themselves as existing over time and don't have plans for the future. Animals do experience pain, and Singer thinks we should minimize this, but he sees nothing wrong in utilizing animals for the interests of society, because they don't have interests of their own. Singer argues that this is also the case with infants. If the parents of an infant decide that bringing up the infant would negatively impact their own interests and cause them burdens, Singer sees it as ethically permissible to allow that baby to die if we judge that the baby's life will bring more

pain into the world for the infant and for those around him or her than the pleasure the infant will afford and experience.

Singer doesn't see any substantial ethical difference between the status of a fetus and a newborn baby. Just like a fetus, a newborn infant doesn't fear death because the newborn infant doesn't know what death is. Just like a fetus, the newborn infant's plans for the future won't be curtailed, because the newborn infant has no plans for the future. Just as it is seen as ethically permissible to abort a fetus, Peter Singer sees it as ethically permissible, if there are no other parents willing to adopt the newborn infant, to allow him or her to die if he or she is a burden to his or her parents' interests.<sup>27</sup>

Singer thinks that this may be particularly understandable in cases of disability because a disabled infant may be subjected to more pain in his or her life than the pleasure he or she may experience. This is fully in line with classical utilitarianism. To illustrate this, Singer brings up the case of Spina bifida, which literally means, divided spine. In the most serious cases of Spina bifida, the baby has "part of its spine split and the spinal cord exposed." <sup>28</sup> Spina bifida can have effects like permanent paralysis, intellectual disability, and severe pain. This is not always the case, but it can still have many ill effects of greater or lesser intensity. What is the most ethical decision to make when a baby is faced with sufferings such as the ones described above and the parents don't want to let the baby live?

Singer writes:

<sup>&</sup>lt;sup>27</sup> Peter Singer, *Rethinking Life and Death* (New York: Saint Martin's Press, 1994),

<sup>&</sup>lt;sup>28</sup> ibid., 115

When the life of an infant will be so miserable as not to be worth living, from the internal perspective of the being who will lead that life, both the "prior existence" and the "total" version of utilitarianism entail that, if there are no "extrinsic" reasons for keeping the infant alive—like the feelings of the parents—it is better that the child should be helped to die without further suffering. <sup>29</sup>

Another reason that Singer thinks that it is ethically permissible for a parent to choose to let a disabled infant die is because parents of a child with a disability may not have fulfilled the typical expectations that one has when one has a child. It is also true that there are very few people looking to adopt a child with a disability. If adoption is not an option and the parents realize that they will take on burdens that they do not want by keeping the child who will have to suffer significantly in life, Singer thinks that it is ethically permissible "Both for the sake of 'our children' then, and for our own sake, we may not want a child to start on life's uncertain voyage if the prospects are clouded."<sup>30</sup>

In the case of Down syndrome, Singer writes,

To have a child with Down syndrome is to have a very different experience from having a normal child. It can still be a warm and loving experience, but we must have lowered expectations of our child's abilities. We cannot expect a child with Down syndrome to play the guitar, to develop an appreciation of science fiction, to learn a foreign language, to chat with us about the latest Woody Allen movie, or to be a respectable athlete, basketballer, or tennis player. Even when an adult, a person with Down syndrome may not be able to live independently; and for someone with Down syndrome to have children of their own is unusual and can give rise to problems. For some parents, none of this matters. They find bringing up a child with Down syndrome a rewarding experience in a thousand different ways. But for other parents, it is devastating. <sup>31</sup>

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<sup>&</sup>lt;sup>29</sup>Peter Singer, *Practical Ethics 2<sup>nd</sup> Edition* (Cambridge: Cambridge University Press, 1993). 184.

<sup>&</sup>lt;sup>30</sup> Peter Singer, *Rethinking Life and Death* (New York: Saint Martin's Press, 1994), 213.

<sup>&</sup>lt;sup>31</sup> Ibid.

Because of the fact that a child with Down Syndrome won't fulfill the expectations one normally expects to have satisfied when one has a child, Singer sees no ethical problem with deciding not to undertake to let a infant with Down syndrome live if you do not want to take up the load that raising that child will have on you and your other children. According to Singer, because the infant has no interests of its own, killing him or her will not stop the infant's interests. In addition, Singer argues, if the child is unwanted, it might be better to "treat it to die" rather than for the infant to undergo the negative effects on its development of being unwanted. <sup>32</sup>

Singer also argues that it may be ethical to euthanize an infant who is not so disabled that his or her life can be expected to entail more pain than pleasure. Remarkably, he bases the justification of this in part on the idea that a disabled infant can be "replaced" by a healthier child if the disabled one is euthanized. In this context, Singer brings up the example of Hemophilic patients who lack a blood-clotting agent that most people have. They are at a very high risk of prolonged external or internal bleeding, have to be very careful, can't play sports and are in the hospital frequently. Nonetheless they can live very fulfilled and happy lives. Singer asks if it is ethical to euthanize a baby with hemophilia when one can expect that its life will be worth living.<sup>33</sup>

Singer says that this can be done ethically if it is done so that a future baby without this disability can be born. In the case of a couple that wants to have two kids, a hemophilic baby will replace a non-hemophilic baby. While it might be the

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<sup>&</sup>lt;sup>32</sup> ibid., 212

<sup>&</sup>lt;sup>33</sup> Peter Singer, *Practical Ethics 2<sup>nd</sup> Edition* (Cambridge: Cambridge University Press, 1993),185.

case that a hemophilic child may have more pleasure than pain in his or her life,
Singer maintains that the non-disabled child who would be born if the disabled child
dies would have a happier life and experience more pleasure specifically because he
or she wouldn't have a disability. To let the disabled die can be ethical, Singer
contends, if it is done for an anticipated "replacement" that wouldn't be born
otherwise.

#### C. Singer and Biopolitics

I will now examine how Peter Singer's ethics fit in with an ethics of biopolitics. Biopolitics was first developed in the late 18<sup>th</sup> century with the advent of statistical data. Through collection of this data, the state sought to control the biological processes of bodies so that it could make live and let die. It is really true that in the last 60 years biopolitics gained powers that it never had before. This process started off with very primitive respirators in the mid 20<sup>th</sup> century. By the 1960's, heart transplants became possible and then widely practiced. It is this event that Singer marks as the first major stumbling block for the traditional life ethic. It is interesting that Singer chose this event as his starting point. It seams to me that this also marks a major and even traumatic shift in the effectiveness of biopolitical power.

If it was always the goal of biopower to "make live", what could be a more dramatic demonstration of this power than receiving the transplant of a beating heart? We also have been able to let people live years longer through the mechanical assistance of a respirator. Indeed biopower can now do frightfully powerful things like enabling a brain dead mother to give birth to a living infant. As both the

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extraordinary and terrifying have become possible, new ethical issues have been raised.

First of all, let me state that I find some of Singer's proposals completely sound. Lacking the part of the brain responsible for consciousness or having a brain so destroyed that consciousness is impossible implies that such an individual would not have any experiential mode of consciousness at all. I am not arguing against using such patients as organ donors, especially if there is a short supply of organs to be donated and a great need for them.

Where I draw back is before the ethical permissibility of euthenising disabled infants. By privileging a certain mode of rationality and the capacity to make plans as the criterion of what it means to be human, Singer argues for the ethical permissibility of killing infants with Down syndrome. While Singer is not advocating a state controlled program of euthenizing disabled infants, he is contending that it is permissible to let the infant die, based in part on the lack of capacities that he is privileging.

Singer's argument is a biopolitical one, even through he is not talking about the health of the biopolitical body and constituting a standard of what is normal, because he is basing it on biopolitical foundations. Normal rationality is assumed by him as an acceptable criteria for the right to live: the standard of normalcy that society holds is unquestioned by Singer. The ethical situations Singer addresses arise out of a marked increase of biopolitical power. Through medical technology, we are able to make live in a dramatic fashion that we have never been able to before. Organ transplants and respirators have substantially increased our ability to save and prolong

lives. Although this is generally a positive phenomenon, there are also negative effects that slide into it. Foucault's famous definition of what biopower does is to make live and let die. In the last 40 years, we have experienced an enormous amplification of our power to make live, but who are we letting die?

It would seem that disability, which has been a target of biopower from the very beginning, the original rationale for this targeting being the idea that the abnormal traits of disability could infect the health of the social body, is still seen as a reason to let someone die due to a tremendous jump in Singer's arguments. He leaps from how the need for human organs and the resultant change in the definition of death marked a challenge to the sanctity of life doctrine to the idea that it is permissible to let babies with Down syndrome die because they won't fulfill the expectations that a parent will usually have in raising a child. He further extends the boundaries of his claim to justify euthenizing a child with hemophilia because in doing so a healthier child who wouldn't be born otherwise can come into being.

Singer obviously doesn't question our society's concepts of normalcy; he uses them as an adequate standard of what people should strive for. Yet society's categories are constructed and have a history that is shorter than one might think. The concept of normal as we use it, meaning as an average characteristic of the population, did not come into use in language until the late 18<sup>th</sup> century, after the development of statistical data and the bell curve. The norm of the bell curve was the average level of a recorded trait such as intelligence and fitness in a recorded population. The set of individuals who were bellow the norm were discouraged from reproducing. This process that resulted from the recording of statistical data had a

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eugenic aim. It was thought, that if only those with normal and above desired traits reproduced that only these traits would be passed on. Racism often entered in to this process because of economic conditions made it more likely that minorities would have subnormal levels. The economic conditions that contributed to this, however, were not taken into account and it was assumed that minorities were inferior to the majority. An appeal to "normalcy" always excludes and stigmatizes those who fail to conform to such standards as abnormal and marks an inability to accommodate and approach the differences of someone who has these disabilities.

While it is true that many of the sufferings a hemophilic child would experience in life would come from his or her disability, it still more true that most of this travail comes from how society approaches this disability. A child with hemophilia would have to face some pain and travail in his or her bodily existence, but a greater suffering I believe comes from the social marginalization the child would face from other in response to the difference of his or her body. That a child has to face the latter sufferings is not a sign of a fault in the child, but rather a sign of a fault in society. The idea that a living child can be replaced by a projected healthier child who may or may not come into being is a sure sign of atrocious privileging of the normal and failure to step out of one's preconceived ideas of what a child should be.

I think that Kant's maxim that "A Man can never be a means to an end" still has relevance today. Indeed, whenever this idea is abandoned, whether in Hegelism, Leninism or utilitarianism of Singer's type, it is always a sign of moral degeneracy and of seeking to appropriate the other in the name of some agenda. In regard to the

replaceabilty of human beings, Levinas remarks strikingly "The substitution of men for one another, the primal disrespect, makes possible exploitation itself." By introducing the idea that one infant without a disability can be substituted for a disabled infant, Singer pointedly reveals that in his view a privileged life and body is more valuable than a disabled one. He would most likely argue against the charge of making a person a means to an end by saying that anyone who brings this accusation against him fails to recognize that it is self-consciousness that makes a human a person and therefore the infant is not a person. He would also most likely point out examples of a person who has become brain dead and ask if it is immoral to use that person as an organ donor.

It must be recognized, however, that someone who has lost all capacity for consciousness and a child with Down syndrome are completely different. The child with Down syndrome will have consciousness and will engage with others in joy and sadness. To deem that a child is replaceable and someone who can be let to die because he or she is different is to never accept him or her in his or her difference, but to instead allow preconceived ideals to be more important than an infant's life. It is true that the child, by its very being, throws our ideas of preconceived normalcy into question and accuses us because of this. What Singer does not attempt to recognize, is that when one fails to acknowledge the disabled infant's mode of being as worth letting live, and thus lets it die, this marks a vast moral failure on the part of society whereby we miss an opportunity to grow in ways that we never thought possible.

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<sup>&</sup>lt;sup>34</sup> Emmanuel Levinas, *Totality and Infinity*, trans. Alphonso Lingus (Pittsburgh: Duquesne University Press,1980), 298.

There is a nihilistic trend in Singer's thought that I must address. Singer would certainly dispute any claim that his thought is nihilistic: he would claim that unlike classical utilitarianism he does not believe that life's meaning can be reduced to having the most pleasure and avoiding pain and that he values human interests. However, the idea that human interest is of the highest value appears to be arbitrary. For Singer, human interest has a value because it is an interest as long as it does not interfere with other people's rationalistic interests and does not cause pain for others. The fact the rationality and interest have been privileged to such a point that Singer contends that a baby with Down syndrome can be let to die because the baby's life would interfere with parental individualistic interests shows that there is no appeal to the value of the interest outside of the interest itself.

I would define nihilism as a self-enclosure of the individual causing the individual to not be affected by the other. Choice becomes a value in itself without letting itself be affected by the difference of the other which implicitly calls into question individual interests. It is my claim that Singer's thought is nihilistic because it privileges an autonomous rationalistic idea of personhood wherein choices are arbitrary.

Against this idea of autonomy that privileges rationality, I would point to recognizing what Simon Critchley calls a "hetero-affectivity that precedes any simple claim to autonomy" as a way out of nihilism. <sup>35</sup> In this way of thinking, meaning is found in the concrete presence of the other in his or her difference, which we cannot reduce to our own categories and view according to our interests. It is not our

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<sup>&</sup>lt;sup>35</sup> Simon Critchley, *Infinitely Demanding* (New York: Verso Press, 2007), 119.

rationality and our individualistic plans and goals that give us meaning and make us human, but rather it is our ability to be affected by the other. In speaking about Levinas, Critchley writes,

Ethical subjectivity is the experience of being affected by an other in a way that precedes consciousness and which places in question our spontaneity and sovereignty. Our autonomous majesty is deposed and decapitated, our autonomous self-binding is unbound. Our posturing subject-position deposed. In this sense that Levinas claims that hetronomous ethical experience of the relation to the neighbor is anarchical, the other posits me under their demand despite myself and before any act of will." <sup>36</sup>

#### II. Hospitality

#### A. Towards an Ethics of Hospitality for the Body and Disability

I propose an ethics of hospitality for the body and disability as an antidote to theories like Peter Singer's and other philosophies that continue to frame disability as something abnormal and as a disease in comparison to a strived for normalization. Hospitality is a concept that originated in the western philosophical canon in the writings of Emmanuel Levinas that was later taken up by Jacques Derrida.

Why do I invoke this concept as a remedy for biopolitical philosophies that marginalize and stigmatize disability? As we saw, one of the main effects of biopolitics is the creation of a standard of normalcy that is striven for by large segments of the population and which exercises powerful effects. Of course the corollary to this is that individuals who fail to meet this standard are marked as abnormal and stigmatized because they fail to fulfill the standards of normalcy. This would be an example of what Levinas calls totalizing thought which occurs whenever

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<sup>&</sup>lt;sup>36</sup> Ibid.,122

one tries to impose one's own categories on the other or tries to schematize the other in term of one's own trajectories. According to Levinas, such imposition does violence to the otherness of the other.

This is the case, in Levinas' view, because the face of the other cannot be categorized and precisely escapes being thematized by one's own trajectories.

According to Levinas, the other will always remain other and will always elude any attempt at normalization. According to Levinas and Derrida, the only way to approach the other is to welcome him or her. This means listening to what the other's difference has to teach one and letting oneself be changed by the encounter with the other. An ethics of hospitality is an ethics focused on the other; its criteria cannot be preformulated. An ethics of hospitality can only be formulated in the welcoming encounter itself. The only way you can be ethically faithful to the other's difference is by welcoming the other's difference and by letting one's self be changed and one's own criterion be challenged by this difference.

Levinas states this in Totality and Infinity as:

The face brings a notion of truth which, in contradistinction to contemporary ontology, is not the disclosure of an impersonal Neuter, but expression: the existent breaks though all the enveloping and generalities of Being to spread out in its "form" and the totality of its "content," finally abolishing the distinction between form and content. This is not achieved by some sort of modification of the knowledge that thematizes, but precisely by "thematization" turning into conversation. The condition for theoretical truth and error is the word of the other, his expression, which every lie already presupposes. But the first content of expression is the expression itself. To approach the Other in conversation is to welcome his expression, in which at each instant he overflows the idea a thought would carry away from it. It is therefore to *receive* from the Other beyond the capacity of the I, which means exactly: to have the idea of infinity. But this also means: to be taught. The relation with the Other, or Conversation, is a non-allergic relation, an ethical relation; but in so much as it is welcomed this conversation is a teaching. Teaching is not reducible to maieutics; it comes from the exterior and brings

me more than I contain. In its non-violent transitivity the very epiphany of the face is produced.<sup>37</sup>

In Levinas' view, totalization occurs when you impose upon some object, your own or some inherited schema, in order to view it in a categorical way. While this is useful in many ways, Levinas' point is that this does not work with a phenomenon like the face or the conversation of the other which will always surpass and exceed any attempt to impose your schema on it. By imposing a schema on the face and the conversation of the other, you are only seeing what you impose on the other rather than what the other is revealing. To receive from the other while respecting his or her difference, is to let yourself be taught and expanded by the other. The other's subjectivity can only be solicited by a subject when the subject welcomes the other in his or her difference. This challenges the subject's autonomy in that the subject has to go beyond itself and its trajectories in order to approach the other as other.

This has application to disability because disability is usually conceptualized negatively in reference to categories of what it is normal for a body or mind to be like. These categories in fact obscure the singularity and non-representable aspects of the disabled person's particular and non-totalizable face, mind, life, experience and mode of being. In the act of putting a disabled person in a category, and further in viewing the category of disability as inferior to normalcy, the individuality of the particular person who happens to have a disability is not welcomed but obscured and excluded.

<sup>&</sup>lt;sup>37</sup> Emmanuel Levinas, *Totality and Infinity*, trans. Alphonso Lingus (Pittsburgh: Duquesne University Press,1980), 51.

Singer saw the key to personhood as rationality, a limited definition of rationality wherein infants are excluded from possessing rationality and hence the status of personhood. Additionally, Singer defended the euthanizing of disabled infants because they would cause burdens on their parents whose normal expectations of parenthood wouldn't be fullifilled. However, the concept of normality is a very recently constructed term with a clear agenda behind it. The enforcement of normality has lead to the persecution of non-whites, homosexuals, women, and other minority groups.

By stating that an intellectually disabled infant should not live because parents may not garner experiences that are normally expected from child raising when rearing a disabled child, one is saying that one is unwilling to step out of one's perspectives and prejudices in order to value such a child for who he or she is; that he or she shouldn't live because one is not willing to welcome that which one hasn't been prepared to understand. In this regard, Singer's perspectives and arguments clearly favor a very self-centered and rationalistic perspective of what a human being is. For him, a human being is someone who has a self-conception over time. A human being is a being who makes plans and pursues projects. If an infant is born whose disabilities may interfere with the parent's projects, the parents can, in Singer's view, end that life because the infant hasn't become a human being yet. Through a terminating act of pity, the parents would be sparing the baby future suffering.

This pity, except in the most extreme cases of pain to the infant, is a false argument that spares one the burden of welcoming this infant, or being there to care for it and to be enriched by encountering the infant's different way of manifesting. It

is a fault also of utilitarianism for failing to recognize that tremendous growth and possibilities can arise out of things that might at first be thought of as unpleasant.

Sometimes when one has suffered through something that others are not used to, one is able to articulate a point of view that elucidates injustices within our society that are being covered over.

What if the essential thing about being human is not possessing self-consciousness but being affected and moved by the other? What if our ability to welcome the other in fact made possible the development of self-consciousness? Rationality itself develops because we are born into a world of relation. An infant is able to acquire an idea about his or her self because he or she is welcomed, cared for and loved by his or her mother and father. Isn't it the case that every stage of a child's development occurs when he or she is enriched and affected by experiences and encounters in social situations that expand that child's horizons beyond what he or she knew before?

Why is childhood often so uncomfortable and yet so seminal to our development? Could it be because in childhood our horizons are constantly expanding in different directions and in ways that make us move beyond where we are in any given time? Aren't we enriched because of this? How much of this enhancement is due to growth in response to being exposed to the difference of the other? Might it be the case when we become stagnant and refuse to look beyond our interpretive horizons that we have closed ourselves off from a vital aspect of human relations and a source of tremendous expansion?

There is no real going beyond oneself if one only welcomes those who one expects or is only hospitable to those who conform to a certain expected standard. Any imposition of a preformed standard on the other is the opposite of hospitality. Hospitality, for Derrida, applies especially to the stranger and the foreigner, the one who is not expected. According to Derrida, "to be hospitable is to let oneself be overtaken, *to be ready to not be ready.*" How different is this attitude than striving after what is normal? Hospitality expects that its expectations will be in error. The other will surprise us. How can this not be so? If I try to constrict the other into a norm, I will surely miss him or her. Derrida says further, "If I welcome only what I welcome, what I am ready to welcome, and I recognize in advance because I expect the coming of the hote as invited, there is no hospitality. "<sup>39</sup> This is perhaps the key to the heart of hospitality: the other makes a demand upon me and if I am only able to receive what I expect, I have been amiss in welcoming.

This opening to the other is precisely what Singer says we do not have to do.

When a disabled infant enters into the world, he says we do not have to welcome it,
but we can cut its course short. In an ethics of hospitality, it is our responsibility to
work to ease the barriers that society has imposed that make it difficult for that infant
to feel welcomed. If society makes it complicated to do this, we must take up the task
of alleviating these barriers and make welcoming apparatuses because the infinite
responsibility to welcome the other defies any individual schema.

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<sup>&</sup>lt;sup>38</sup> Jacques Derrida, "Hostipitality" in *Acts of Religion* ed. Gil Anidjar (New York: Routledge Press, 2002), 361.

<sup>&</sup>lt;sup>39</sup> Ibid., 362

According to an ethics of hospitality, my primary responsibility is not to myself, but to the other, to the other as different. Biopolitics ignores the vast diversity of the forms that the human body and mind can assume while trying to create a set form, a mark of normalcy. What does not, and even cannot, fit into this form stands out as abnormal, something to be overcome or let wither, something to be marginalized rather than to be welcomed. Thus, biopolitical ways of thinking ignore the richness that is gifted by the difference of the other.

Derrida's work on hospitality offers us an ethics of welcoming, an ethics of going beyond the place of one's comfort, and making a place in oneself for the other whom one cannot place within one's own cognitive frameworks. In Derrida's view, if you do not question your standpoints and if you have not been moved by the other, you have not welcomed him or her.

#### Derrida writes:

If in hospitality, one must say *yes*, welcome the coming, say the "welcome"; one must say *yes*, there where one does not wait, *yes*, there where one does not expect, nor await oneself to, the other, to let oneself be swept by the coming of the wholly other, the absolutely unforeseeable stranger, the uninvited visitor, the unexpected visitation beyond welcoming apparatuses. If I welcome only what I welcome, what I am ready to welcome, and that I recognize in advance because I expect the coming of the hote as invited, there is no hospitality. <sup>40</sup>

Derrida would not agree with Singer's argument for the permissibility of a family letting a baby with Down syndrome die. Recall that Singer argued that one of the reasons that this would be ethical was that the disabled infant would interfere with the parents' plans and that the parents would not get out of the experience of parenting what one would normally expect. In an ethics of hospitality, one cannot put

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<sup>&</sup>lt;sup>40</sup> Ibid.,361-362

one's own plans or trajectories above saying yes to the other and giving him or her a place. Derrida thinks that to be hospitable one has to say yes to what one does not expect or wait for. Welcoming the other disrupts plans, opens up new trajectories in ways that cannot be expected, and moves us beyond what we were before into the unknown expansion. This growth is the gift of the other. Raising a child with Down syndrome certainly would, I believe, defy the expectations of what one would expect from raising a child. However, such an experience holds the possibility of opening one up to joy that one could not have foreseen. This is due in large part because in raising his or her child a parent would be welcoming, loving, being loved and learning from a person whose way of seeing the world is different from the parent's.

Derrida privileges welcoming the stranger as a mode of enacting hospitality, because in welcoming the stranger you welcome someone whom you did not expect and you welcome someone whose ways are different than yours. Thus, you have to let yourself be disrupted because the stranger's mode of conceptualizing the world is different than yours. To quote Derrida;

...absolute hospitality requires that I open my home and that I give not only to the foreigner (provided with a family name, with social status of being a foreigner, etc.), but to the absolute, unknown, anonymous other, and that I give place to them, that I let them come, and I let them arrive, and take place in the place I offer them, without asking of them either reciprocity (entering in to a pact) or even their names. The law of absolute hospitality commands a break with hospitality by right, with law or justice as rights. Just hospitality breaks with hospitality by right; not that it condemns or is opposed to it... <sup>41</sup>

At this point I would like to propose some ethical tenants of an ethics of hospitality that will serve as the theoretical guiding points for the rest of this paper.

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<sup>&</sup>lt;sup>41</sup> Jacques Derrida and Anne Dufourmantelle, *Of Hospitality* (Stanford: Stanford University Press, 2000), 25.

These tenants have not only been gleaned from Levinas and Derrida's writing on hospitality, but also from the writings of Simon Critchley, who is deep within the tradition of Levinas and Derrida.

Tenant I: To be ethically towards the other's difference you can never impose your own schema on the other or try to fit him or her into your own trajectories. Rather, you must welcome the other, pay attention to the other, and allow his or her difference to teach you and expand your horizons.

Tenant II: To truly welcome the other you must allow yourself to be changed by the encounter.

Tenant III: The face of the other places an infinite demand on you, because it can never be schematized. Because this demand is infinite, you can never fulfill it, and you are never completely up to its challenge. To quote Critchley, one stands in an "originary inauthenticity" before this demand.

Tenant IV. The bodily form and mind of the other is always singular and nonthematizable without doing violence to the other's alterity. The way to welcome the other's singularity is founded in the welcoming encounter itself.

Tenet V: Our ethical subjectivity, to quote Critchley, is a subjectivity of "hetero-affectivity" where the subjectivity is open to the other, and is born in relation to the demand and difference of the other. Expansion happens through being open to the other's difference.

At this point I would like to respond to a possible objection close readers of Derrida might have. Derrida clearly states in his essay *On Cosmopolitanism* that:

Despite all the tensions or contradictions which distinguish it, and despite all the perversions that can befall it, one cannot speak of cultivating an ethic of hospitality. Hospitality is culture itself and not simply one ethic amongst others. Insofar as it has to do with the *ethos*, that is, the residence, one's home, the familiar place of dwelling, inasmuch as it is a manner of being there, the manner in which we relate to ourselves and to others, to others as our own or as foreigners, *ethics is hospitality*; ethics is so thoroughly coextensive with the experience of hospitality. But for this very reason, and because being at home with oneself (the other with in oneself) supposes a reception or inclusion of the other which one seeks to appropriate, control, and master according to different modalities of violence, there is a history of hospitality, an always possible perversion of *the* law of hospitality (which can appear unconditional) and the laws that come to limit and condition it in its inscription as law.<sup>42</sup>

This quote highlights a very important feature of Derridian hospitality. According to Derrida, there is a law of absolute and unconditional hospitality, which is the demand that the other places on us to welcome him or her. This is the same infinite demand the face of the other places on us to welcome him or her. Derrida also cites Kant as writing in *Definitive Article in View of Perpetual Peace* that there is a universal maxim of hospitality, or of making a place for everyone on earth, which is the pre-condition for peace. <sup>43</sup> According to Derrida, the universal law of hospitality cannot be fulfilled, it is infinite.

Derrida speaks of laws of hospitality (i.e. cultural or legal codes that attempt to implement hospitality), which are attempts by a society to respond to the universal law of hospitality. Although these laws are always inadequate and always fall short of the absolute demand of hospitality, Derrida sees them as vitally important. Without concrete codes of enacting hospitality, absolute hospitality remains abstract and irrelevant. This is of course the case with disability. If there were no welcoming apparatuses that would enable a disabled person to achieve financial security and

<sup>42</sup> Jacques, Derrida, *Of Cosmopolitanism and Forgiveness* (New York: Routledge Press, 2001), 16-17.

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<sup>&</sup>lt;sup>43</sup> Ibid., 19

function in society as a participant, there would be no welcoming. Even if these apparatuses fall short, they are essential for any hospitality to take place. For Derrida, all culture and all ethics are founded upon attempts to welcome the other, even though they often exclude.

Derrida fully acknowledges that these laws can often fail in ways that does violence to the other and marginalizes him or her and he thinks that a history of hospitality can help highlighting where hospitality has failed and where it has been enacted. I understand why Derrida resists a specific formulation of an ethics of hospitality. For him, we can never fulfill the absolute demand of hospitality. I agree with him. All ethical formulations are limited ways of attempting to respond to the absolute demand of hospitality in some way or another, even through they exclude the other in certain respects.

To be truly ethical, one must be responsive and welcoming to the other. Part of this involves not imposing one's own conception on the other, but being able to learn from him of her. While I embrace this for the most part, I think that ethics like Singer's, or other examples of biopolitical ethics towards the other, exclude the other due to certain epistemological assumptions within the frameworks of such ethics. Biopolitical ethics have a certain concept of personhood wherein interests are the most valuable thing about personhood. Under this viewpoint, people with certain disabilities are denied personhood: there is no ethical responsibility to nurture them as infants if this interferes with an interest of the parent. This is a very self-enclosed view of what a person is. I think that to enact hospitality more faithfully, we need to shift our stance in relation to the other towards an ethos that is more welcoming and

that is more ready to be affected by the other. I contend that it is to this end that we need to develop a concept of personhood that is hetero-affective and whose development is nurtured by the other's difference. We are so often trapped in thinking in terms of inherited norms that we need to think differently in order to be ready to be exposed to, and welcome, differences that are frequently framed as abnormal or diseased. Since the norms concerning disability have been constructed and we remain under their power, in order to be open to someone who is stigmatized by these norms, the norms themselves must be deconstructed. To be ethically faithful to the other one must take one's cue from the encounter with the other and not impose one's own criterion on him or her.

A rigid Derridian ethic of hospitality could also endanger such fluid openness. Therefore, I understand Derrida's concerns. The ethical tenets I proposed based on Derridian hospitality are ethical and epistemological frameworks that orientate one in the direction of hospitality, inclusion and response to the other. It remains true that one can only learn to welcome the other by saying yes to his or her yes, by responding to his or her cue.

My endeavor is to formulate principles that orient one in the direction of turning towards and facing in an attempt to welcome that which one cannot preformulate. My hope is that in thinking like this, one can better see the value in welcoming one who might not be able to speak, or in welcoming one who conceptualizes things in ways that one cannot understand, or in welcoming one whose body seems strange to one. I also anticipate that through this attempt at conceptualizing ethics and subjectivity based on hospitality, that one can more easily

see the possibilities of change and expansion available in each singular welcoming encounter.

# B. Practical Examples of Hospitality and Disability in Nussbaum and Kittay

At this point I would to look briefly at the work of Eva Kittay and Martha Nussbaum. These two philosophers offer analyses that have parallels to an ethics of hospitality of disability, and they both underscore in their work how disability highlights the need for such an ethic.

In *Hiding from Humanity*, Martha C. Nussbaum asserts that, "No group in society has been so painfully stigmatized as people with physical and mental disabilities." She contends that people with physical and mental disabilities are often treated with disgust, and in the case of severe disabilities a person's full humanity is called into question: people with severe disabilities are often confined to institutions and shielded from public view.<sup>44</sup>

Much of the stigmatization of people with disabilities, Martha Nussbaum believes, arises from fictions of normalcy, independence, and perfection. These ideas are very important for the social contract theory, according to which society is made up of independent, autonomous and equally contributing members. To quote John Locke, parties in the social contract are, "free, equal and independent." People with disabilities are seen as excluded from this contract because of their vulnerability and perceived inability to be valuable contributors to society.

<sup>45</sup> Ibid..311

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<sup>&</sup>lt;sup>44</sup>Martha Nussbaum, *Hiding from Humanity* (Princeton:

Princeton University Press, 2004),305-306.

However, it is true that we are all vulnerable, born into the world in a state of complete dependence that we will return to if we live long enough or if an accident or disease affects us. This fragility scares the modern subject considerably. To shield itself from facing this fact, the modern subject is constructed in an opposing dichotomous relationship with the abnormal, which is anything that calls the security of the independent and autonomous person into question. The social contract theory is precarious even for people without disabilities because at any moment one is at risk of becoming impaired, and thus becoming dependent in an asymmetrical way.

### To quote Nussbaum;

Any productive approach to the social situation of people with atypical disabilities must begin, then, by recognizing that we all have many impairments, and that life includes not only "normal" needs but also periods, more or less prolonged, of unusual and asymmetrical dependency, during which the situation of the "normal" approximates to that of a person with an unusual disability in one or more respects. This means that if we are to give even "normals" the social conditions of self-respect we must at the same time think about the self-respect of the lifelong disabled and try to devise ways to recognize and support their full humanity and individuality. Thinking about them is thinking about us. But then, good thought about both requires revising the idea of the citizen as independent bargainer and replacing it with a more complex image of a being both capable and needy, who moves from helplessness to "mutual interdependence," and, unfortunately, often back to helplessness again.<sup>46</sup>

If we are cognizant of the mobility of the condition of need and ability that we may find in any particular moment in life, it will be clear that the situation is always treacherous and that for anyone to truly feel welcomed in the world at all we need to make it hospitable for those whose physical condition might require more assistance or welcoming apparatuses than what the majority usually need. Being aware of the

<sup>&</sup>lt;sup>46</sup> ibid.,312-313

fact that we all move through different states of need and ability brings into view the fact that the normal body is a fiction and that we are all in singular states of both vulnerability and ability.

Nussbaum writes that society has been structured to accommodate the limitations of the majority. We all have things about our bodies and minds that restrict us. Some people have short memories, eyes that need lenses, or knees and backs that suffer pain. These conditions are not usually classified as disabilities because the majority of people suffer from one of these conditions and society has been built and structured in a way that accommodates these conditions. Indeed society is filled with technologies and structures that accommodate the normal human body's natural inability to do certain tasks. Cars are built to enable human beings to travel distances at speeds that it wouldn't be able to naturally and stairs are designed so that the majority of society can climb up them comfortably. Disabilities and handicaps are formed in part at least when someone's condition falls outside of the majority and so no structures are formed to enable such an individual to function as a productive and active member of society, while structures have been implemented to accommodate the majority.<sup>47</sup>

Reading this in light of Derridian Hospitality, it could be said that society functions as it does because certain structures of welcoming have been put in place so that the majority feel welcomed and function in the world. Each technology that enables us to do things more easily can be said to be a structure that accounts for the weakness of the majority, which has been designed so that the majority feel

<sup>47</sup> ibid.. 306

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welcomed. There is no problem in itself with this. The quandary is that this hospitality has not been extended to those whose level of need and ability is not aligned with the majority. Because of this, such individuals become handicapped because society has not been designed with them in mind. Thus, they become marginalized. If welcoming apparatuses were made available for disabled people to function and be welcome in society, disability would not be something that would significantly hinder most disabled people from engaging in and being a part of society.

Eva Kittay is primarily interested in issues relating to cognitive disabilities.

This issue is very personal for her as she is the mother of a daughter with severe mental retardation. She points out that cognitive disabilities serve as a limit case for a philosophy of disability. One of the reasons this is true is because people with cognitive disabilities have been the least welcomed and the most isolated by society. Kittay says that mental retardation, "is the disability that other disabled persons do not want attributed to them." It is because of fear of mental retardation that most parents choose, often with strong pressure from their doctors, to have a selected abortion if signs of it are detected in the fetus. We should remember that Peter Singer saw it as ethically justified if a parent of an infant with mental retardation decides to let the infant die. It must be said that people with mental retardation have been among the least welcomed and the most stigmatized. They are kept outside of the public view, and may be locked in institutions so that the public is spared seeing

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<sup>&</sup>lt;sup>48</sup> Eva Kittay, "Justice as Care and Caring as Just," in *The Subject of Care* ed. by Eva Kittay and Ellen Feder (Lanham, MD: Rowman & Littlefield Publishers, Inc., 2003), 257.

them. We should remember that Peter Singer denied them the specific attributes that distinguish people from other animals.

We must ask what is going on here? Why have people with mental retardation been stigmatized to such a degree? Kittay argues that they throw into question the whole criterion of the contract theory of rights wherein a citizen is a rational subject who is able to verbally enter into an agreement with society as an independent autonomous contributor. As we discussed above, it has been one of the main arguments of advocates for those with physical disabilities that disability is not a biological fact, but that it is socially constructed. According to this view, society constantly makes adjustments that make up for the majority's deficiencies. The reason someone is disabled, according to this view, is because accommodations have been made for the deficiencies of the majority but not for those with atypical needs. According to this argument, once accommodations have been made for people with disabilities and when society's attitude about disability has changed, disability will cease to be a major social hindrance.

Eva Kittay does not disagree that in the case for many physical and mental disabilities, the above argument is very important and relevant. However, it does not work in the case of her daughter who to survive at all needs constant care and who can never hope to speak and be an advocate for herself.

#### To quote Kittay:

Many individuals with mental retardation, especially when it is severe or profound or compounded by other disabilities, have been unaffected by the important strides made by other people with disabilities. Advocates of disability rights have insisted that independence and productivity that are essential to being considered equal citizens in a liberal society are no less attainable for the disabled than for the nondisabled. They have argued that

their impairments are only disabling in an environment that is hostile to their differences and that has been constructed to exclude them. <sup>49</sup>

The level of care that people with profound disabilities like Eva Kittay's daughter's need will always be asymmetrical. They cannot enter into the social contract because they cannot be an equal contributor to society because they cannot work and are dependent on constant care. It is people like this that Singer suggested might have lives that are not worth living whose parents can be justified in letting them die because the burden they place on society and their parents will always be asymmetrical.

According to Levinas and Derrida, the responsibility we have towards the other is infinite and always asymmetrical. If I welcome the other with expectations of receiving something in return, I have not been faithful to the demand of hospitality because I am not welcoming the other for his or her own sake, but I am expecting something out of it in return. Additionally, saying that people with mental retardation do not count as full citizens and people who meet the standard of personhood is interpreting the disabled person's experiences according to the trajectories and frameworks of the majority and marginalizing him or her because of this. Because this is often done, the difference and singularity of the person with a cognitive disability and what this difference has to teach us is missed and covered over.

Being hospitable to the other means welcoming that in the other which falls outside one's own horizon of experience and allowing one's perspective to be disrupted and expanded by the encounter with the other. Eva Kittay offers us an outstanding description in *The Subject of Care* of how welcoming her daughter has

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<sup>&</sup>lt;sup>49</sup> Ibid., 258

been a source of growth, expansion, learning and joy, which I would like to quote because I believe it provides an exemplary illustration of how an ethics of hospitality has many things to offer a philosophy of disability.

Sesha, as always, is delighted to see me. Anxious to give me one of her distinctive kisses she tries to grab my hair to pull me to her mouth. Yet at the same time my kisses tickle her and make her giggle too hard to concentrate on dropping the jam-covered toast before going after my hair. I can the sticky toast, the hair-pulling and the raspberry-covered mouth. In this charming dance, Sesha and I experience some of our most joyful moments—laughing, ducking, grabbing, kissing. (Kittay 2000b)<sup>50</sup>

Drawing from the description of this experience Kittay analyzes how much her daughter has taught her and how it sheds light on what personhood is.

To quote Kittay on her interactions with her daughter:

They are "small" pleasures, to be sure, but pleasures that provide so much of life's meaning and worth that they permit the deep sorrows of Sesha's limitations to recede into a distant place in the mind; they are small joys, but are so profound that they even make me question that very sorrow. It is a pleasure both Sesha and I would have been denied if we could not share our lives together.

Because we as a family have been able to keep Sesha in our home and community, those who have made contact with her and have learned to see her we who love her do have gained new perspectives on what it means to be a person. Seeing Sesha in her interactions with those who care for—and about—her reveals that being a person has little to do with rationality and everything to do with *relationships*—to our world and those in it. <sup>51</sup>

The above description and the analysis of what follows from it provide a powerful antidote to the concept of personhood that Singer and those who advocate for the social contract view of society put forth. Kittay is arguing for a view of personhood centered on relationship where contact and being affected by the other touches us, enriches us and teaches us profound things about life as beings that are

<sup>&</sup>lt;sup>50</sup> ibid., 265

<sup>&</sup>lt;sup>51</sup> ibid., 266

affected and disrupted by contact with the other. Because those who were able to welcome Kittay's daughter did not try to fit her within their trajectories and objectify her, they saw what she had to show and they were able to receive what she had to give. Through this encounter, they were able to be touched, expanded and instructed in ways that they would not have been if they had not welcomed her difference.

To be welcomed, Kittay's daughter needs a network of caregivers. Care giving professions have been among the most undervalued. Kittay suggests that we as a society need to reevaluate the importance of care giving and give more financial and moral support to these professions. Kittay also thinks that we should revaluate the philosophical importance of care. I will briefly sketch out Kittay's arguments on care on and draw parallels between it and Derridan hospitality.

Kittay states that because care giving is at heart other-directed it is not evaluated highly by our liberal society that sees citizens as rational self-interested actors. She believes that this is especially true with caregivers of severely and profoundly mentally retarded people because the dependency of these people is so great. In order for society to provide care for the severely mentally retarded, society needs to support the caregivers. This means paying them well and providing them with training that would enable them to become the best caregivers they can be.<sup>52</sup>

Kittay argues that because the severely and profoundly mentally retarded require high levels of care not only have they been left out of the social contract but their parents have as well. Care giving is not something that is supported in this society and both paid caregivers and family caregivers are looked down upon. In

<sup>&</sup>lt;sup>52</sup> ibid., 261

order for a severely mentally retarded person to be welcomed, his or her caregivers have to be welcomed and supported, and vise versa. In order for a hospitable environment to exist for a person with severe mental retardation, both his or her parents and outside caregivers have to have the financial support needed to provide sufficient care. Having a child with a severe need without having the capacity to care for him or her is devastating and makes the parents of the child and his or her caregivers feel unwelcome in society because society does not accommodate the need of the parents and caregivers of such a child to respond to the helplessness of the child. An "extensive and costly support system" is necessary for the mentally retarded to be welcomed and to come to show the people who love them who they are.<sup>53</sup>

# To quote Kittay:

Care is a multifaceted term. It is a labor, an attitude, and a virtue. As labor, it is work of maintaining ourselves and others when we are in a condition of need. It is most noticed in its absence, most needed when it can be least reciprocated. As an attitude, care denotes a positive, affective bond and investment in another's well-being. The labor can be done without the appropriate attitude. Yet without the attitude of care, the open responsiveness to another that is so essential to understanding what another requires is not possible. That is, the labor unaccompanied by the attitude of care cannot be good care. <sup>54</sup>

Kittay's analysis has parallels to Derridian Hospitality in a number of ways.

First of all it illustrates that one welcomes a person with severe mental retardation only when one is open to what he or she has to show one without seeking to categorize him or her into one's own trajectories. When this is done, the experience can be very moving and one learns from it. In Derridian Hospitality, one is always changed, taught and disrupted beyond one's own limited horizons by welcoming the

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<sup>&</sup>lt;sup>53</sup> ibid., 266

<sup>&</sup>lt;sup>54</sup> ibid.,259-260

other, being open to what one could not have expected and allowing oneself to be expanded by experiencing the unfamiliar of the other in your encounter with him or her.

I think that Kittay's description of her daughter and how she affects her is an outstanding example of just such an awareness of the other. The above example also illustrates how hospitality is a joyous occasion. This is an aspect of Derrida's writing on hospitality that I have neglected up to this point. Although the responsibility of hospitality is great, it also carries with it great joy.

# To quote Derrida:

If I say to the other, upon announcement of his coming, "Come in" without smiling, without sharing with him some sign of joy, it is not hospitality. If, while saying to the other, "Come in," I show him that I am sad or furious, that I would prefer, in short, that he not come in, then it is assuredly not hospitality. The welcome must be laughing or smiling, happy or joyous. This is part of its essence in a way, even if the smile is interior and discrete, and even if it is mixed with tears which cry of joy.... <sup>55</sup>

I think Kittay's description of her interactions with her daughter brings out this very important aspect of hospitality. In welcoming the other, you are gifted by the other and this is an occasion of joy. Kittay also points out that through this encounter she learned more about what being a person is. Being a human being does not have to do with rationality, but rather with responding and being affected by the other. This is completely in line with Derridan hospitality in which one of the key things about being a human is that in welcoming the other we are always affected, disrupted, and expanded. Our relationship with the other is essentially responsive. It

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<sup>&</sup>lt;sup>55</sup> Jacques Derrida, "Hostipitality" in *Acts of Religion* ed. Gil Anidjar (New York: Routledge Press, 2002), 358-59.

is very important that in encounters with her daughter Sesha, Kittay was taught about what it means to be a human being because this lesson came from someone whom some people would deny personhood to.

From Kittay, we get the notion that in order to respond to the needs of someone with profound mental retardation, resources need to be allotted to his or her family and caregivers to enable them to do this. This is what Derrida would call welcoming apparatuses. In Derrida's view, in order for hospitality to take place and to have a meaning beyond some abstract demand, these apparatuses have to be in place. To be ethical we have to seek to expand these apparatuses. In the case of someone with profound mental retardation, these apparatuses of care, of hospitality, are needed for his or her very existence. If there is deficiency in these apparatuses, it is felt not only by the mentally retarded person, but by his or her parents and caregivers. From a standpoint of Derridian hospitality, these resources are deficient and they need to be expanded so as to be hospitable to a person with mental retardation, his or her family and his or her caregivers. This means concretely that more resources need to be allotted to make providing care more feasible and that caregivers need to be paid more. It also means that care giving and the hospitality it entails needs to be valued more by our society.

The work of Kittay and Nussbaum both embody ethical principles that are a kin to Derridian hospitality, and both these philosophers offer strong critiques of the social contract theory. There are however, important differences to their critiques. In Nussbaum's view most disabilities exist in large part because society has not constructed apparatuses in order for disabled people to function in the world.

Theoretically, Nussbaum argues, if these apparatuses are constructed, then people with disabilities will be able to function and contribute to society. This is important for all of society, because all of us are at risk of becoming disabled at any point in our life. For Nussbaum, the concept of a citizen as an autonomous and independent subject should be replaced by a concept of a citizen as someone who finds his or her self in various degrees of interdependency and vulnerability at different stages of one's life. Nussbaum believes that society should be designed in a way that enables disabled people to be as independent and fulfilled as possible, just as society is designed to enable people without disabilities to be as independent and fulfilled as possible.

Kittay offers a deeper critique of the social contract theory than Nussbaum, because with severely mentally retarded people no accommodation can be made which will enable these people to become independent and contribute as equal bargainers in society. For a severely mentally retarded person to live is to live in need of others in a profound way. Because of the asymmetrical need that these people require, which is a need that cannot be reduced by accommodations, some would deny the severely mental retarded the status of citizenship or even personhood. The severely mentally retarded cannot enter into the social contract. They cannot speak, so they need others to speak for them, and they cannot come to a place where they can care for themselves, so they will always need someone else to care for them. The social contract theory will always marginalize the severally mentally retarded because to admit them as equal citizens would undermine all the principles on which the social contract theory is based.

What Kittay is doing in her critique is saying that the social contract theory needs to be abandoned completely. Although society cannot expect any financial gain from people like Kittay's daughter Sesha, Sesha has given her mother and friends a deeper understanding of relation and what it means to be a human. This example demonstrates that the social contract theory's concept of personhood as an independent, rational and autonomous subject conceptually closes us of from being open to how the difference of someone with severe mental retardation can teach us about our humanity. Kittay argues that we need to develop a concept of personhood based on relation and that we need to shift society's attitudes and practices regarding care.

I think the differences in Kittay's and Nussbaum's critiques of the social contract theory can be explained in large part by the vast degrees of variation in which someone can be disabled. Disability is comprised of many different categories including Autism, Cerebral Palsy, Down syndrome and so on, and each of the individuals with these conditions is affected in different ways. What society's responsibilities are in the case of someone with a mild physical or cognitive disability is very different than what society's responsibilities are in the case of someone with severe cognitive or physical disabilities. In many cases people with disabilities find society inhospitable for them, because they have a desire to participate and work in society, but society won't make the accommodations to make this possible. The ethical thing to do in these cases is to implement the accommodations, which would allow people with disabilities who have a desire to work and participate in society in this manner to do so. In the case of many of the profoundly mentally retarded, many

cannot function without care. The ethical thing to do in these cases is to provide these individuals with the care they need, and to allocate the resources to their caregivers, which the caregivers need to provide care effectively. To welcome and to respond to someone with a disability one has to approach him or her in his or her singularity and individuality. This singularity and individuality includes both individual needs and strengths that cannot be subsumed into the categories of normality.

#### III. Conclusion

Through analyzing the work of Nussbaum and Kittay in the light of the Derridan hospitality my aim was to demonstrate that Derrida's and Levinas' concept of hospitality offers an interpretive schema that offers insights in how to think about disability in an ethical manner that respects the alterity and difference of disabled people. It is my contention that any such ethic must address how disability is marginalized both conceptually and practically. Conceptual violence is done to the alterity of disabled people when disability is viewed as abnormal according to the standards of normalcy, when disabled people are viewed as non-participants in the social contract theory, and when they are denied the status of personhood. The alterity of disabled people is marginalized and done violence to in a practical way when accommodations that would enable a disabled person to engage in society are not implemented, when support structures of care are not given the funds they need, and when a child with Down syndrome is treated to die. The work of Kittay and Nussbaum address both the ways that disabled people are marginalized conceptually

and practically in a penetrating manner and they propose practical solutions that point to a more welcoming and emancipatory ethos.

Levinas' and Derrida's concept of hospitality, along with the writing of Simon Critchley, gives an account of the hetero-affectivity in subjectivity and how respecting the alterity of the other is essential to any ethical thinking that does not do violence to the difference of the other. Subjectivity is hetero-affective because subjectivity is always formed in relation to an other, who cannot be subsumed into the subject's interpretive frameworks. The other instead places an infinite demand on us to welcome him or her. This demand, which we can choose to heed or not, is nonetheless demanded of us. If I choose to respond to this demand I can only do so in a limited and situated way. At no point can I say that I have fulfilled all my responsibilities to welcome the other, I can always welcome the other more. If I choose to welcome the other my trajectories will be disrupted, and I will be moved beyond myself. It is because of this that I am able to learn from the other. One cannot pre-formulate, in an ethics of hospitality, how to ethically respond to the other, because such an ethics is formed in being responsive to singular encounters with singular others. Every person has an unique a body, cognition and life experience that is singular and unrepeatable.

An ethics of hospitality is particularly important to disability, because disability is usually conceptualized in such way that does violence to the alterity of the disabled individual. Examples of interpretive violence done to disabled people in include disability being conceptualized as a disease in comparison with the norm of a healthy body and disability being conceptualized as abnormal because it fails to

conform to standards of normalcy. In each of these cases violence is done to the alterity of the disabled person.

In order to be hospitable to the other, one has to be ready to allow oneself to be disrupted, and one has to be ready to welcome that which one cannot be ready to welcome. Because disability is abnormal when referenced in terms of normalcy, in order to be hospitable to a disabled person one has to allow one's entrapment in, and attachment to, normative ways of thinking of cognition and bodies to disrupted. This can lead one to a greater understanding of the singularity of all bodies and minds. Additionally, welcoming such moments of disruption can help lead us out of the selfenclosure of self-centeredness that haunts us today. Further, an ethics of hospitality can help lead us out of the entrapment of biopolitical norms, in which bodies seek homogenization, and through which the difference of all bodies is covered over. The difference of bodies and minds has an emancipatory power; perhaps we should orientate ourselves in a direction that allows that power to affect us. Instead of letting die, and/or marginalizing those who have disabilities that we cannot understand, perhaps we could be enriched by approaching these individuals with welcome, and thereby allow ourselves to be expanded by their difference.

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<sup>&</sup>lt;sup>1</sup> Emmanuel Levinas, *Totality and Infinity*, trans. Alphonso Lingus (Pittsburgh: Duquesne University Press, 1980), 298.