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Narrative Ethics and Vulnerability

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Introduction

The passage of the Americans with Disabilities Act in 1990 led to the need to define disability and to define the experiences of those with disabilities. Because people with disabilities have been considered to “deviate” from the able-bodied norm and have been systematically oppressed, there came a need to redefine *disability* in response to the cultural and medical narratives that historically associated disability with defectiveness, insufficiency, and imperfection.¹ With the aid of medicine, the goal was to cure the disability and return the body to its original, healthy state. Thus, the body that “has the ‘right’ number of smoothly functional limbs and organs,” does not “drool, spasm, jerk, wheeze, wheel, limp, stutter, piss, or fart uncontrollably either in private or public realms.”² The power to define and regulate impairment, disorder, malfunction, disfigurement, or dysfunction in either the body or the brain, lay in the hands of medical practitioners. From the medical perspective, disability is viewed as something to be overcome and, if it cannot be overcome, then the disabled individual is either recommended to an institution or medical care at home to be kept out of the public eye.³ Furthermore, it is this perceived “deficiency,” particularly in the form of cognitive disability, which has caused certain contemporary philosophers in ethics to argue that people with cognitive disabilities should no longer retain their autonomous *moral status as persons*. Specifically, philosophers such as Peter Singer and Jeff McMahan have argued that people with cognitive disabilities should not be entitled to the same societal protections as those with cognitive ability “within the normal range.”⁴

The aim of this paper is argue against the claim of autonomous moral status and instead to provide an account of interdependent moral status which is based on our relational narrative selfhood. This “traditional” account of moral status based on reason and intellectual capacity has

ignored the “social” or social construction of disability within culture and society. One’s dis-abling condition “exists not as a one-to-one correspondence between impairment and the restriction of activity, but as a result of society’s failure to have universal access for wheelchair users, such as curb cuts, ramps, elevators, and power doors, integrated in the environment.”⁵ Disability is thus a social condition rather than a medical condition. As a result, oppression and prejudice function in society insofar as they “dis-able” someone through discrimination, inaccessible environments and inadequate support. These environmental factors have been completely ignored for considerations of moral status and point to the latent bias of able-ism within the current models of personhood. Thus, cases like “Autism,” Alzheimer’s and other forms of severe cognitive impairment call for a refiguring of moral status based on relations for people with disabilities. A better account, which I develop here, may be established through a *narrative ethics of interdependence*. In order to establish this foundation, I will draw insights from the works of Julia Kristeva and Paul Ricoeur.

The Challenge of Vulnerable Persons for Moral Personhood

The philosophical problematic of moral status concerns two related problems: moral agency and personhood.⁶ The former includes questions of whether individuals with cognitive impairments are able to comprehend their actions, are morally imputable, or may be held responsible for their actions. The latter include questions concerning whether entities with a specific set of attributes qualify as human moral persons. Because the attacks on people with disabilities from philosophers such as Singer and McMahan focus on the latter problem, I shall concentrate on that aspect of the problematic.

The problem of moral personhood focuses on who is counted as a “person.” This question concerns whether an individual will receive dignity, rights, and protection within a given society and has been generally grouped according to three theories: (1) the genetic humanity theory, (2) the sentience theory, and (3) the relationship-based theory.⁷ Moral personhood grants humans, or other beings, moral standing. It is the reason why harming or killing humans is considered a greater offense than killing non-human animals or harming the environment. Like moral agency, moral personhood has been inextricably linked with human reasoning, but it has a much darker past for people with disabilities. Because their personhood was not recognized, certain people with disabilities were victims of unregulated human experimentation. Nazi Germany provides a specific example in this case: many people with disabilities were experimented on or exterminated because they were deemed having lives “not worthy of being lived.” In the United States, the treatment of people with cognitive disabilities at Willowbrook State School provides another example of these abuses.

Willowbrook was home to hundreds of children with profound cognitive impairments, and during 1960s-1970s these children lived in filth, were victims of abuse, and even injected with hepatitis supposedly “in order to find a cure.”⁸ These horrors provide a reminder of the significance of the challenge of moral personhood.

Singer and McMahan have called into question the “equal value and dignity of all human life” for people with cognitive disabilities. Their aim is to reconstruct our concept of “personhood,” with that of human dignity, to provide a graduated form of moral status to humans and nonhuman animals. Although on the surface this seems to be a noble attempt to recognize the dignity of certain species of nonhuman animals, in the end it does not grant equal dignity for persons with cognitive impairments and able-bodied persons alike. Instead, they contend that those who are cognitively impaired should not qualify as “persons” in the same sense as able-bodied individuals.⁹

To make an argument for a graduated form of moral personhood, Singer, in his essay “Speciesism and Moral Status,” compares the various capabilities of animals, like the great ape Koko, who have basic language skills and score between 70-95 on the IQ test with people who have severe or profound cognitive impairments and who may not score as high. His comparison draws from capacities listed with the American Association on Intellectual and Developmental Disabilities: (1) Intellectual Quotient (IQ), (2) the need for supervision, (3) capacity for speech, (4) following simple directions, and (5) social isolation. He uses these factors to compare individuals with cognitive impairments with non-human animals such as apes, border collies, and grey parrots which have these capacities and perform these specific tasks “more efficiently.”¹⁰ Rather than granting personhood to all biological humans, instead, Singer argues, we should “abandon the idea of equal value of all humans, replacing that with a more graduated view in which moral status depends on some aspects of cognitive ability, and that graduated view is applied both to humans and nonhumans.”¹¹ Thus, the implications of questioning, or disqualifying, those with cognitive disability from the status of personhood are frightening for those with cognitive impairments and those with loved ones who may have cognitive impairments.

In response to this “de-valuation” of human life, philosophers who espouse the ability to “empathize” over the “capacity to reason” such as Nel Noddings and Agnieszka Jaworska, have argued that moral agency should be based on social capacities rather than analytical capacities or the ability to carry out a task.¹² They contend that humans are moral agents based on their ability to connect with others and to reciprocate recognition and appreciation, and thus, the ability to care becomes the basis for moral status. This capacity to care can be extended to infants and those with cognitive impairments, but has limited extension to non-human animals.

Such a view might appear to be a suitable response to Singer and McMahan, but difficulties nevertheless remain because certain cognitive impairments can affect an individual's social capacities and ability to empathize. Specifically, children with "autism" may not respond to eye contact, smiles, and may be withdrawn. Among other behavior patterns, children with "autism" may appear to "lack empathy."¹³ Many dependency workers and caregivers of dependent children and elderly parents may not find themselves in relations of reciprocity with those for whom they care. As a result, this emphasis on social capacities rather than analytical capacities turns out to be unable to grant moral personhood to all individuals with cognitive impairments.

At this point, this is a general observation about the difficulty facing any strategy for response. It appears that any response that hopes to use some form of individuated personhood will founder on the same or at least a similar rock. So long as one only considers the attributes of an individual person, one will end up arbitrarily drawing a line that divides some persons from others precisely because they do not "fit." My suggestion is that the main problem of the above views is their reliance on the assumption of *individuated personhood*, measured by individual capabilities. To surmount this problem, I argue that moral personhood should be understood as *relational personhood* and that strong evidence in support of relational identity can be found in psychoanalysis and developmental psychology.

A Relational Understanding of Identity

To develop a relational model of personhood, I would like to begin with a testimony from Eva Kittay, who draws on her own experiences raising her daughter Sesha to argue for the need of a new construction of personhood which accounts for dependence. Kittay's daughter Sesha has cerebral palsy and has profound cognitive impairment. These aspects about Sesha create a fundamental dependence in her relations with others:

While the image of mutuality and interdependence among persons is an important one, life with Sesha, underscores that there are moments when we are not "inter" dependent. We are simply dependent and *cannot* reciprocate. Furthermore, while dependence is often socially constructed – *all* dependence is not. If you have a fever of 105, the dependence you have is not socially constructed. Sesha's dependence is not socially constructed. Neither "labeling" nor environmental impediments create her dependence – although environment modifications are *crucial* for her to have a decent life.¹⁴

In other words, Sesha will always be vulnerable in her relations with others.¹⁵ In response to this vulnerability, Kittay develops an account of

what she calls the *transparent self*, which signifies “a self through whom the needs of another are discerned, a self that, when it looks to gauge its own needs, sees first the needs of another.”¹⁶ This aptly describes, for instance, the self of the dependency worker who may or may not be a primary caregiver. The relation between the dependency worker and the dependent brings to light that our bodies are both interdependent with other bodies and dependent upon other bodies.

Working from Kittay’s account of the transparent self, what I would like to do is to develop further this alternative account of moral personhood by drawing on clinical evidence from the work of Julia Kristeva as well as the hermeneutic articulation of identity that can be found in Paul Ricoeur. Work conducted in both developmental psychology and psychoanalysis suggests that our concept of self and our ability to form attachments depend on the relations we have with others when we are children. Both psychoanalysis and developmental psychology have described how the relation between the child and his or her primary caregiver leads to the development of the *ego*, or the self. In psychoanalysis specifically, this development takes place through the Oedipal Stage. In the works of Sigmund Freud, Jacques Lacan and later Julia Kristeva, the “male child” is understood to be first in union with his “mother.”¹⁷ The child believes that he is one with the mother and that the mother satisfies all of his desires. In the beginning of their relation, the child is unable to tell the difference between himself and his mother. This forms an initial bond, called primary identification, with the mother.¹⁸ Then, the “father” enters the relationship and breaks the relation between the child and the mother by laying down the “law.” The father breaks up this relation by taking the mother’s attention away from the child. The father, metaphorically, tells the child “no” and thus establishes for the child that the “little boy” is separate from the mother. This “no” forms the beginning of the child’s separate identity. According to Kristeva, two possible identifications can be formed in this Oedipal Stage:

a primal one, resulting from a sentimental (*Gefühlsbildung an ein Objekt*), archaic, and ambivalent affection for the maternal object, more frequently produced by the impetus of guilt-producing hostility; and the other, which underlies the introjection into the ego of an object itself already libidinal (*libidinöse Objektbildung*), providing the dynamics of the pure loving relationship.¹⁹

Thus, our early relations with our “mother” and “father” shape the relation of our ego, the development of our identity, and frame our future relations with others.²⁰ Kristeva, however, argues that this relational identity with the mother begins prior to language: it begins with the semiotic communication and bond during the mother’s pregnancy with the child.

To make this argument, Kristeva draws on the experience of her own pregnancy. She describes pregnancy as an “instant of time or of dream without time; inordinately swollen atoms of a bond, a vision, a shiver, a yet formless, unnamable embryo.”²¹ As pregnant, the mother oscillates between union and disunion with her child. Pregnancy and birth question the stability of the subject and object positions because “the other cannot be separated from the self.”²² The relation of the female body in pregnancy, then, blurs the distinction between self and other: just as the mother’s body reacts so does the child’s. This maternal relation, which begins in the womb, begins to shape the child’s healthy development and continues after birth through the practice of loving transference.

Loving transference is the way of moving not only between the language of the symbolic and the murmurings of the semiotic but also provides a way of building around the essential loss of the maternal relationship as the child develops.²³ Maternal love initiates the structure of primary narcissism, but is repressed like the drives of ecstasy and death through language. Sara Beardsworth, in her essay “Love’s Lost Labors” points out the “double indeterminacy” of both the source of love and of the lost object:

This is crucial for [Kristeva’s] presentation of the spontaneity and mystery of love: that love, itself, is source. It is, first, source of the subject, not only constituting the nucleus of the ego in subject formation and making of the subject something intrinsically beyond itself but also allowing for the return of borders dissolved. In this way, love can be the bearer of the trial of going over the loss of self. Second, it is the source of the object insofar as the bearing of the subject beyond itself underlies all objects of desire. Third, it is the source of imaginary formations and of loving metaphor.²⁴

This act of loving metaphor initiates the beginning of a loving discourse. This pure relation of loving transference provides a “bodily dialogue” between the caregiver and the child which begins to shape the *ego* through “utterances” prior to language.

Having developed this model of the loving relation, Kristeva uses it to form the foundation for our larger network of relationships. The child communicates through gesture and sounds and the primary caregiver answers in return. These networks form the healthy (or unhealthy) development of the child’s attachments to his or her peers. Our relations with others develop first in a secure relation with our primary caregivers and this security, (or insecurity), shapes the relations we will have later with others. Thus, our beginning relations with others do not rely upon “recognition” and social abilities like “empathy”; rather they rely upon

bodily dialogue and utterances which begin, according to Kristeva, in the womb and continue to develop throughout our lives.

Relational Identity as Narrative Co-Authorship

While Kristeva has initiated this relational aspect of our personhood in her work on psychoanalysis, Paul Ricoeur develops a complementary account of personal identity. Although Ricoeur chooses hermeneutics instead of psychoanalysis as his philosophical method, I believe that his account of a narrative identity is able to incorporate these insights from Kristeva and understand them as articulating similar phenomena on a different semantic plane. The most important insight from Kristeva's account of our relational ego, is that our development begins prior to language. Paul Ricoeur's account of narrative identity of the self in relation to others is, I believe, able to shed light on our dependency and vulnerability in our relations with others. On his account, we, as individuals, grow, change and develop over time through our encounters with others. How we define and identify ourselves is due partly to the actions we choose and partly to a character sedimented over time.

According to Ricoeur, how we come to find consistency in our identity while remaining dynamic, relational and continually in flux is through our narrative relation with ourselves, with others, and with society. This is a dialectical relation that begins with the recognition of two parts of our identity: what Ricoeur calls "*idem-identity*" and "*ipse-identity*."²⁵ *Idem-identity*, as Ricoeur writes, "unfolds an entire hierarchy of significations... In this hierarchy, permanence in time constitutes the highest orders, which will be opposed to that which differs, in the sense of changing or variable."²⁶ Simply put, *idem-identity* concerns our character or sameness. *Ipsé-identity*, by contrast, is that which *idem-identity* opposes and it concerns our personhood or selfhood. While *idem-identity* seeks to answer the question "What?", it is *ipse-identity* which seeks to answer the question "Who?". Just as in literature the plot mediates between the disconnected events and the story, so our narrative identity is the mediation of *idem-identity* and *ipse-identity* over time as we grow, develop, change and remain in many ways the same. It provides a dynamic unity-in-time to our selfhood.

Idem-identity and *ipse-identity* are interwoven in a dialectic of identity. Although Ricoeur does not write at length how this narrative identity affects our embodiment, he does describe it in the following manner:

Insofar as the body as one's own is a dimension of oneself, the imaginative variations *around* the corporeal condition are variations on the self and its selfhood. Furthermore, in virtue of the mediating function of the body as one's own in the structure of being in the world, the feature of

selfhood belonging to corporeality is extended to that of the world as it is inhabited corporeally.²⁷

As my lived body mediates my being-in-the-world, so that mediation is a narrative mediation of my existential perspective. This narrative, lived embodiment is shared with and affected by others. As Ricoeur writes: “with need and lack, the otherness of the ‘other self’ moves to the forefront. The friend, inasmuch as he is that other self, has the role of providing what one is incapable of procuring for oneself.”²⁸ Even though I myself have the world mediated to me through my narrative embodiment, I am not the sole author of my embodied existence. Instead, I am the co-author and my embodied existence is co-written with other people.

This co-authorship of personhood has been shown in psychological cases of children with profound cognitive impairment and is paramount in our caring relations with family members and loved ones.²⁹ When we consider those who may suffer from dementia, we realize that caring for a loved one with dementia is a form of reminding and reconstructing his or her personhood.³⁰ The practice of reminding in dementia care is a process of aiding the patient in her memory loss of past abilities and experiences. Bruce Jennings, for instance, describes this process as relational: “minding and reminding come through the interaction that is at bottom about the exchange of meaning – the expression, offering, interpretation, and reception of meaning.”³¹ Because our identities are dynamic and relational, they are constructed “tissues of stories,” which involve both our first person experience of them but also include the “important acts, experiences, relationships, and commitments” that are shared with and given to us by others.³² The caring relation experienced with a loved one suffering from dementia, such as a grandmother, involves the caring practice of “holding” onto her identity.

Ricoeur stresses the role of reciprocity in relation to the other. This reciprocity is developed from neither capacity nor response alone, instead it is dialectical. Who I am is constituted by the other. This constitution takes place through solicitude: reciprocity takes place “in the exchange between human beings who esteem themselves.”³³ This exchange involves giving and receiving.³⁴ Within the fragile balance of giving and receiving, friendship lies in the middle of the spectrum. In friendship, according to Ricoeur, giving and receiving are equal and we share an equal vulnerability in interdependence.

Yet, many times our relations with others are unequal. Ricoeur designates one side of the unequal spectrum as *benevolent spontaneity*. In benevolent spontaneity, there is a dissymmetry in the relation “resulting from the primacy of the other in the situation of instruction, through the reverse moment of recognition.”³⁵ Here the self recognizes the authority of the other. This might be an instance of justice but might also be an instance

of care. In the caring relation, this constitutes the parent-child relation or relation of the primary caregiver in a relation of development, instruction, and authority. And in this relation, many times the self is dependent upon the other.

In contrast to benevolent spontaneity, Ricoeur names the other's dependency on the self as *suffering*. When the other is a suffering being, the other is dependent and has had a reduction or destruction in the capacity for acting. Ricoeur describes this relation:

here initiative, precisely in terms of being-able-to-act, seems to belong exclusively to the self who *gives* his sympathy, his compassion, these terms being taken in the strong sense of the wish to share someone else's pain. Confronting this charity, this benevolence, the other appears to be reduced to the sole condition of *receiving*.³⁶

But this suffering is also a *giving* from the other for Ricoeur. Although the self and other are in a position of unequal vulnerability, the other when he or she is suffering reminds us of our own fragility and mortality. The other summons us to be ethical and to recognize value of human life as irreplaceable.

A Narrative Ethics of Interdependent Persons

At this point, I turn to examine how embodiment and impairment refigure this intention. To do so, it should first be noted that I will use the terms "dependent" or "dependency" to replace Ricoeur's "suffering." The term "dependency" more accurately represents the challenges for people with disabilities because they become "dependent on others" and "disabled" by our social environments, such as the lack of resources available or accessibility in buildings or public spaces. "Suffering," by contrast, indicates physical or emotional pain and duress, which does not reflect the social challenges facing people with disabilities. Second, it is necessary that one recall the caring relation and consider the role of narrative in our interdependent relations. Our relations with others constitute the construction of ourselves. As children, we recognize our interdependence with others through our caring relations. As our bodies are relational bodies so others co-author our narratives with us. My series of caring relations finds a unity in the narrative that is my identity. But this unity is not only narrated by me; rather it is narrated *with* and *through* others. Just as I am a narrative unity of idem and ipse over time, so my narrative unity is affected, mediated, and co-authored by other narrative unities. My narrative identity is affected and constructed by other narrative identities. Thus, my narrative identity is both *pre-linguistic* at times and is co-created with others.

And these narratives involve dependent relations with others. This dependent relation with others is part of our "existential vulnerability" and

that our identities are only complete through our commitment to others. Part of the responsibility caregivers hold is to co-author our narratives when we are vulnerable. Kittay describes the powerful story of her daughter Sesha's narrative identity is already interwoven with her own mother and Sesha's dependency caregiver Peggy:

I am Sesha's one mother. In truth, however, her mothering has been distributed across a number of individuals: her father, various caregivers, and Peggy.

Sesha was four when a woman walked into our lives who came and stayed. How and where we acquired the instincts I don't know, but we knew immediately that Peggy was right. She was scarcely interested in us. Her interview was with Sesha. But she wouldn't take the job. Peggy feared the intensity of the involvement she knew was inevitable. We pleaded and increased the salary. She told me later she would never have taken the job if the agency hadn't urged her to do a trial week. At the end of the week, it was already too late to quit. Sesha has worked her way into Peggy's heart.³⁷

Although Sesha is fully dependent in her abilities, her participation in the construction of her parents' and primary caregivers' narrative lives is not. As both receiver of care and giver of care, Sesha has co-authored the narrative life of Peggy and others by adding dimensions to their worlds that they had not anticipated. Peggy describes Sesha's co-authorship as the following:

I had been with Sesha in Central Park and I was working on some walking exercises that the folks at Rusk [Rusk Institute at New York University Medical Center, Sesha's early intervention program] had assigned. I was working terribly hard trying to get Sesha to cooperate and do what I was supposed to get her to do. I sat her down in her stroller and sat down on a park bench. I realized that I was simply exhausted from the effort. I thought, how am I going to do this? How can I possibly do this job, when I looked down at Sesha and saw her little head pushed back against her stroller moving first to one side and then to another. I couldn't figure out what she was doing. Until I traced what her eyes were fixed on. She had spotted a leaf falling, and she was following its descent. I said "Thank you for being my teacher, Sesha. I see now. Not my way. Your way. Slowly" After that, I fully gave myself over to Sesha. That forged the bond.³⁸

As both giving and receiving, Sesha and Peggy share lived experiences together even though Sesha is dependent and Peggy is her dependency worker. Through narration, together they co-author each other's lives. Their interdependent narrative is the gift they share with each other. And this interdependent narrative underscores the fragility of the human condition. Kittay describes this fragility as follows:

As I write this essay, a much older Peggy still cares for a much older Sesha in many of the same ways. But as Peggy and Sesha age, we reach the limits of the laboring aspect of caring... This is a difficult and troubling state of affairs – for us as parents, for Peggy, and, if Sesha understands it, for her. Sesha's possible future without Peggy troubles me profoundly – not simply because we have come to so rely on her, but because I cannot bear the thought that such a central relationship in Sesha's life could be sundered.³⁹

Thus, the fragility of our relations with others affects the narratives we share. Interdependency means shared vulnerability as well as capability, but it also means co-authorship. As *narrating beings* we act ethically and form a communal narrative ethic around the stories we tell.⁴⁰ Likewise our co-authorship with others provides a ground for an understanding of our human dignity as necessarily linked to others and to our communities. An example of a community which practices this narrative ethics is L'Arche, which was begun by Jean Vanier and welcomed those with disabilities who had been rejected in society just after World War II. Today, L'Arche has flourished as a welcoming communal model and has over 130 communities in 33 countries on 6 continents.⁴¹

As a relational, narrative, dynamic agent, I am in interdependent and dependent relations with others. But these relations are not constructed strictly by capabilities; rather they are developed through a dialectic of giving and receiving. My relation to others in friendship forms a bond of equal vulnerability as we co-author each others' lives. Yet, I can also form unequal friendships. I am also possibly in the position of caregiver or dependent. As a caregiver, I care for the dependent other and our relation is of unequal vulnerability. But that is not to say that there is unequal giving. My relation to the dependent other reminds me of my own fragility and vulnerability. I am only myself through the co-authorship of another and my narrative is shared with the one for whom I care. Thus, in the case of "Autism," by having the relation between those caring, their narratives are already interwoven to develop an interdependent gift which reminds of that fragile bond.

Relational Moral Personhood

Kristeva and Ricoeur's proposal of our identities as relational responds to Singer and McMahan's attack on cognitive disability and provides an alternative account of moral personhood for people with disabilities. Although Singer and McMahan have argued that analytical intelligence and certain skill sets serve as the foundation for moral personhood, they are incorrect about what constitutes our personhood over time and thus gives us dignity and moral status. Our dignity, rather, is a relational and interdependent dignity: as humans we exist with and for each other. Furthermore, as narrating and temporal beings, we understand our personhood as inextricably linked with other persons who care for us and for whom we care throughout our lives. Finally, our narrative personhood is not developed or constituted by capacity; instead it recognizes our own vulnerability as persons and our necessary dependence upon the ethical intentions of others. Our moral personhood is a *relational personhood* because our dignity is given to us through our relations with others. A moral identity is not autonomous self-authorship, but rather constituted by relational co-authorship that develops over time. Thus, our moral personhood is not defined by mutual advantage or independent capacity. By contrast, it is defined by the mutual *gift* we give to each other in both our shared vulnerability and to whom we are morally bound. Who counts, then, as a moral person? Those who can and do enter into this sort of interdependent, fragile and ethical existence. Sesha clearly qualifies as a person and co-authors Kittay and Peggy's lives in their shared narrative.

The story of Sesha and Peggy remind us of our own fragility and that we are not the sole authors of our lives. As a relational, narrative, dynamic person, I am in interdependent and dependent relations with others. But these relations are not constructed strictly by capabilities; rather they are developed through a dialectic of giving and receiving. My relation to others in friendship forms a bond of equal vulnerability as we co-author each others' lives. Yet, I am also in the position of caregiver or dependent at various moments throughout my life due to age, impairment or illness. As a caregiver, I care for the dependent other and our relation is of unequal vulnerability. But that is not to say that there is unequal giving. My relation to the dependent other expands and develops my identity through the narrative we share. I am only myself through the co-authorship of another and my narrative is shared with the one for whom I care. Just as Peggy, Sesha's devoted caregiver, gauges her own needs through the needs of her dependent other, so those needs are caught up in interdependent narratives of caregiver and dependent. Therefore, in the cases of disability, my moral status cannot be limited to only reason or social ability. Rather, it is a narrated moral status which in its relation with others reminds us of the fragile bond that makes us vulnerable. It reminds of what makes us human.

¹ See p. 57 in Alexa Shriempf, “(Re)fusing the Amputated Body: An Interactionist Bridge for Feminism and Disability,” *Hypatia* 16, no. 4 (Autumn 2001): 53-79.

² Shriempf, “(Re)fusing the Amputated Body,” 58.

³ Ibid. See Eva Kittay, “At Home with My Daughter” in *Americans with Disabilities: Exploring Implications of the Law for Individuals and Institutions*, eds. Leslie Pickering Francis and Anita Silvers (New York: Routledge, 2000), 64-80, for a full treatment of the victory in *Olmstead v. L.C. and E.W.*

⁴ See Peter Singer, “Speciesism and Moral Status,” in *Cognitive Disability and its Challenge to Moral Philosophy*, eds. Eva Feder Kittay and Licia Carlson (Malden: Wiley-Blackwell, 2010), 331-344, esp. 331. See also Jeff McMahan, *The Ethics of Killing: Problems at the Margins of Life* (New York: Oxford, 2002). For a philosophical response to Singer and McMahan, see Eva Kittay, “At the Margins of Moral Personhood,” *Ethics* 116, no. 1 (Oct. 2005): 100-131. Also see Eva Kittay, “The Personal is Philosophical is Political: A Philosopher and Mother of a Cognitively Disable Person Sends Notes from the Battlefield,” in *Cognitive Disability and Its Challenge to Moral Philosophy*, 393-413.

⁵ Shriempf, “(Re)fusing the Amputated Body,” 59.

⁶ See David Shoemaker, “Responsibility, Agency, and Cognitive Disability,” (201-24), and Martha Nussbaum, “The Capabilities of People with Cognitive Disabilities,” (75-96), in *Cognitive Disability and Its Challenge to Moral Philosophy*, ed. by Eva Feder Kittay and Licia Carlson, (Malden: Wiley-Blackwell, 2010). See also Martha Nussbaum *The Frontiers of Justice: Disability, Nationality, and Species Membership* (Cambridge: Harvard University Press, 2007).

⁷ I have in mind here the categories from Mary Anne Warren, “Moral Status,” in *A Companion to Applied Ethics*, ed. by R.G. Frey and Christopher Heath Wellman (Malden: Blackwell, 2005), 439-50. Warren provides a pluralistic account, which draws elements from all three theories. These three theories are also similar to the three accounts given by Logi Gunnarsson, “The Great Apes and the Severely Disabled: Moral Status and Thick Evaluative Concepts,” *Ethic Theory and Moral Practice* 11

(2008): 305-326. Here Gunnarsson describes them as “rationalism,” “anthropocentrism,” and “animalism.” Warren provides an alternative theory, namely a relationship-based one, which is why I primarily draw from her categorizations. It should be noted that Warren’s relationship-based approach should not be confused with my argument for *relational identity*, since Warren still maintains an understanding of individuated personhood.

⁸ For a further list of the brutalities oppressed on persons with disabilities, see Patrick Boleyn-Fitzgerald, “Experimentation on Human Subjects” in *A Companion to Applied Ethics*, eds. R.G. Frey and Christopher Heath Wellman (Malden: Blackwell, 2005), 410-423.

⁹ Singer, “Speciesism and Moral Status,” (331-344), and McMahan, “Cognitive Disability and Cognitive Enhancement,” (345-369), in *Cognitive Disability and Its Challenge to Moral Philosophy*. See also the following works by Singer: (1) *Practical Ethics*, 2nd Ed., (Cambridge: Cambridge University Press, 1993), (2) *Rethinking Life and Death: the Collapse of our Traditional Ethics*, (New York: St. Martin’s Griffin, 1994), (3) *Writings on an Ethical Life*, (New York: Harper Collins, 2000), and (4) *Animal Liberation*, (New York: Harper Collins, orig. 1975).

¹⁰ Singer, “Speciesism and Moral Status,” 335.

¹¹ Singer, “Speciesism and Moral Status,” 338.

¹² See Nel Noddings, *Caring: A Feminine Approach to Ethics and Moral Education*, (Berkeley: University of California Press, 2003). Also, Agnieszka Jaworska, “Caring and Full Moral Standing Redux,” in *Cognitive Disability and Its Challenge to Moral Philosophy*, 369-392. See also Jaworska, “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value,” *Philosophy and Public Affairs* 28 (1999): 105-38.

¹³ See PubMedHealth on Autism:

<http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002494/>.

¹⁴ Kittay, *Love’s Labors: Essays on Women, Equality and Dependency* (New York: Routledge, 1999), 180.

¹⁵ See Kittay (1) “Dependency, Difference and the Global Ethic of Longterm Care” with Bruce Jennings and Angela A. Wasunna, *The Journal of Political Philosophy* 13, no. 4 (2005) : 443-469, (2) “When Caring is Just and Justice is Caring: Justice and Mental Retardation,” in *The Subject of Care: Feminist Perspectives on Dependency*, eds. Eva Feder Kittay and Ellen K.

Feder (New York: Rowman and Littlefield, 2002) and (3) *Love's Labors: Essays on Women, Equality and Dependency*.

¹⁶ Kittay, *Love's Labors*, 51.

¹⁷ Sigmund Freud, *The Ego and the Id*, trans. J. Riviere (New York: W.W. Norton & Company, 1960); Jacques Lacan, *Ecrits: A Selection*, trans. B. Fink (New York: W.W. Norton & Company, 2004), and later developed by Julia Kristeva, *Tales of Love*, trans. Leon S. Roudiez, (New York: Columbia University Press, 1983). I want to specifically mention the presumed "maleness" of the child, which appears in these authors' works. Kristeva, like Freud and Lacan, assumes a male child within the structure of primary narcissism. Kelly Oliver, however, provides a nuanced interpretation of Kristeva's account to include a recognition for sexual difference in *Reading Kristeva: Unraveling the Double Bind* (1993). My reference to Kristeva's account of primary narcissism is strictly to point to the relational understanding of identity that we share with others which is formed in infancy. I believe this relational understanding of identity is significant for re-defining personhood as *relational* rather than strictly *autonomous*.

¹⁸ In *A Secure Base: Parent-Child Attachment and Healthy Human Development* (London: Basic Books, 1988), psychologist and psychoanalyst John Bowlby describes a similar initial interaction between the mother and male child (7-8).

¹⁹ Kristeva, *Tales of Love*, 33. German spelling errors corrected.

²⁰ Freud, Lacan and Kristeva specifically use the terms "mother" and "father" when describing the child's formation of "his" identity. My use of quotations is to indicate their discursive preference rather than a biological difference. Primary Caregiver will be the term I prefer to indicate the person in the roles of parenting or caregiving hereafter because it is more discursively accurate and biologically neutral.

²¹ Kristeva, *Tales of Love*, 234.

²² Kelly Oliver, *Reading Kristeva: Unraveling the Double Bind* (Bloomington: Indiana University Press, 1993), 66.

²³ See Julia Kristeva, *Black Sun: Depression and Melancholia*, trans. Leon S. Roudiez (New York: Columbia University Press, 1989), chapter 1. Also, Sara Beardsworth, "Love's Lost Labors," in *Psychoanalysis, Aesthetics, and Politics in the Work of Julia Kristeva*, eds. Kelly Oliver and S.K. Keltner (New York: State University of New York, 2009), 133.

- ²⁴ Beardsworth, "Love's Lost Labors," 140.
- ²⁵ Paul Ricoeur, *Oneself as Another*, trans. K. Blamey (Chicago: The University of Chicago Press, 1992), 3.
- ²⁶ Ricoeur, *Oneself as Another*, 2.
- ²⁷ Ricoeur, *Oneself as Another*, 150.
- ²⁸ Ricoeur, *Oneself as Another*, 185.
- ²⁹ Kittay (2005) describes Sesha's enjoyment of Beethoven and her excitement about listening to the music. Also, H. Young et al. use multi-sensory storytelling of life transitions for adolescents with profound intellectual disabilities to help the adolescents understand their own bodily changes. These narratives about the adolescents' identities were co-authored with their parents and caregivers. The narratives were told repeatedly as the adolescents reacted and understood and gained knowledge of their own bodily transitions in life, such as puberty. See specifically, Hannah Young, Maggi Fenwick, Loretto Lambe and James Hogg, "Mutli-sensory Storytelling as an aid to Assisting people with Profound Intellectual Disabilities to cope with Sensitive Issues: a Multiple Research Methods Analysis of Engagement and Outcomes," *European Journal of Special Needs Education* 26, no. 2 (May 2011): 127-142.
- ³⁰ See Bruce Jennings, "Agency and Moral Relationship in Dementia," in *Cognitive Disability and its Challenge to Moral Philosophy*, 172.
- ³¹ Jennings, "Agency and Moral Relationship in Dementia," 172.
- ³² See Hilde Lindemann, "Holding One Another (Well, Wrongly, Clumsily) in a time of Dementia," in *Cognitive Disability and its Challenge to Moral Philosophy*, 162.
- ³³ Ricoeur, *Oneself as Another*, 188.
- ³⁴ For Ricoeur, self-esteem is the arc of reflection on the ethical aim: aiming at the good life, with and for others, in just institutions. Solicitude is the second moment on this arc.
- ³⁵ Ricoeur, *Oneself as Another*, 190.
- ³⁶ Ricoeur, *Oneself as Another*, 190.
- ³⁷ Kittay, *Love's Labors*, 156-157.
- ³⁸ Kittay, *Love's Labors*, 157.
- ³⁹ Kittay, *Love's Labors*, 157.
- ⁴⁰ Richard Kearney, *On Stories* (New York: Routledge, 2004).

⁴¹ See Julia Kristeva and Jean Vanier, *Leur Regard Perce nos Ombres* (Librairie Arthème Fayard, 2011) and Richard Kearney, *Anatheism* (New York: Columbia University Press, 2010).