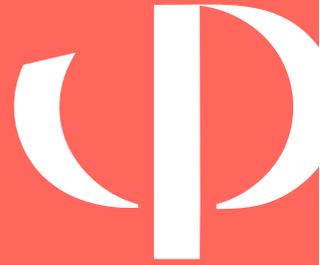


# Philosophy and Medicine



FALL 2016

VOLUME 16 | NUMBER 1

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APA NEWSLETTER ON

# Philosophy and Medicine

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MARY RORTY AND MARK SHELDON, CO-EDITORS

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## FROM THE EDITORS

Mary Rorty

STANFORD UNIVERSITY

Mark Sheldon

NORTHWESTERN UNIVERSITY

Welcome to the fall issue of the *APA Newsletter on Philosophy and Medicine*. This issue contains variety of papers, some of which (but not all) are versions of papers delivered at Divisional meetings in this calendar year.

If sometimes the editors wonder if the newsletter pays as much attention to philosophy as to medicine, this issue in various articles invokes Aristotle, Wittgenstein, Santayana, Foucault, and Kant in connection with various current controversies, all of which are greatly enlivened by their presence. Some papers are continuations of ongoing debates; some foreshadow larger projects currently in the works by our contributors. We have a cluster of articles from a session on Ableism at last spring's Central Division meeting. Ackerman and Scuro draw upon personal encounters with the health care system. Frequent contributor (and blogger) Michael Boylan urges the use of works of fiction in philosophy courses, followed by a thoughtful discussion by Rosalind Ladd of how one novel can help us think about the rights of children. And a haiku!

Enjoy! And keep the newsletter in mind as a place to publish the preliminaries to your next magnum opus, or that occasional piece that doesn't really fit anywhere else. Your editors welcome your comments, criticisms, and contributions—and wish to welcome new committee members, including our new chair, Jennifer Hawkins.

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## SUBMISSION GUIDELINES

The *APA Newsletter on Philosophy and Medicine* is published by the APA Committee on Philosophy and Medicine. We invite submissions of articles and book reviews on any topic related to philosophy and medicine, as well as responses to material that appears in this newsletter.

All papers should follow the APA guidelines for gender-neutral language and use endnotes rather than footnotes. The *APA Newsletters* use *The Chicago Manual of Style*.

Send submissions electronically to the editors: Mary Rorty ([mvr2j@stanford.edu](mailto:mvr2j@stanford.edu)) and Mark Sheldon ([sheldon@northwestern.edu](mailto:sheldon@northwestern.edu))

Submissions for spring issues are due by the preceding September 1. Submissions for fall issues are due by the preceding February 1.

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## ARTICLES

### *Aristotle's De Anima and Modern Biology: Both Irresolute on the Nature of Viruses*

John R. McConnell III

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Just as Hippocrates is considered the Father of Medicine, Aristotle is mentioned as the Father of Ecology. Whereas Hippocrates did study medicine, Aristotle did relatively little investigation into the interrelationships of organisms, both among themselves and between them and their environment, with which the subject of ecology is concerned. The term "ecology" was not actually coined until a millennium and a half later by Henry Thoreau, a contemporary American author. Aristotle, the son of Nicomachus, the famed doctor who served as personal physician to King Amyntas II of Macedonia, probably studied more medicine than ecology.

Other scholars incorrectly describe one of his surviving works, *De Anima*, as psychological in focus. For Aristotle, soul (*psyche*) simply meant life; he was more of a biologist than an ecologist or psychologist. After leaving the Academy when Speusippus, Plato's nephew, was appointed head of the school, Aristotle and his pupils pursued investigations into anatomy, physiology, morphology,<sup>1</sup> and embryology as well as physics and philosophy. In all his disciplines, Aristotle emphasized the collection of empirical data before drawing conclusions, a fundamental principle in scientific research since then. His inductive approach began with the collection, analysis, and grouping of all relevant facts in order to determine their meaning and relationship. Curiously, Aristotle's influence on the biological sciences is emphasized in courses other than biology; in most biology courses, his views are discounted altogether.<sup>2</sup> Yet it was the renowned evolutionist Charles Darwin who regarded Aristotle as the most prominent pioneer in the field of science. Indeed, it is not necessarily his views on biology, but his approach to and reasoning

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in biology, that distinguishes him as a great contributor to the field. Aristotelian reasoning is not to be confused with the scientific method, which employs experimentation to test the validity of hypotheses. Rather, empirical data, for Aristotle, bred familiarity with the subject, thus elucidating, through reason, the underlying principles that governed the soul.

Using Aristotle's *De Anima*<sup>3</sup> as my resource, I will attempt to convey Aristotle's view on the soul—namely, the criteria for classification of living creatures—and juxtapose it with the contemporary view of differentiating living organisms with nonliving objects and chemical reactions. I intend to apply each set of standards to a currently contested scientific issue, the biological status of viruses, and show that both are problematic in the determination of viruses as living.

### ARISTOTLE'S DE ANIMA

Aristotle believed that the soul requires a body, and the soul may be composed of three parts. Aristotle's tripartite soul included the rational soul, the perceptive soul, and the nutritive soul.<sup>4</sup> Plants have only a nutritive soul, while animals also have a perceptive soul. Humans, as beings able to reason, possess all three parts of the soul. Each part expresses what Aristotle called potentialities, characteristics indicative of life. For instance, the rational soul has the potentiality for thought.

Nourishment is the primary potentiality commonly shared by all living creatures. The nutritive faculty includes the absorption, ingestion, digestion, and/or metabolizing of food as well as growth and reproduction. Plants do these and only these, according to Aristotle. The most natural function for living organisms is to survive, if not as themselves, then as offspring like themselves. Because organisms are mortal, i.e., perishable, the only way for them to experience divinity is to propagate the species. For many organisms, nourishment and growth are necessary to advance to a reproductive age. Aristotle was also careful to point out that, in living things, there existed a proportional limit for size and growth.<sup>5</sup> The potentiality for nourishment is the only criterion required to be considered alive in the Aristotelian framework for the soul.

In the perceptive soul, there are three distinguishable potentialities that Aristotle mentioned. Animals and humans have the potentialities for sense-perception, desire, and movement. In addition, the potentiality for sense-perception may be further divided into the five senses: sight, hearing, taste, smell, and touch. The faculty of desire includes needs and wants as well as emotion, if what I believe passion to mean for Aristotle is correct. Aristotle believed that sense-perception and desire were inseparable, "for that which has sense-perception there is both pleasure and pain . . . and where there are these, there is also wanting: for this is a desire for that which is pleasant."<sup>6</sup> Not only do living creatures with the potentiality for sense-perception have an awareness of their environment, but they may also react to external stimuli. On the potentiality for movement, Aristotle suggested that the animal be able to cause the movement itself, rather than affect movement as a result of an outside force. Both desire and intellect may be the intrinsic cause of movement, but Aristotle never mentioned

nourishment as he thought plants lacked the potentiality for movement.<sup>7</sup> With the potentiality for sensation, desire, or movement, an organism may be classified as an animal with a perceptive soul.

The third and final tier of the Aristotelian soul is the rational soul. The rational soul has the potentiality of intellect, the ability to reason. Only humans possess this ability; hence, they are the ones with a complete tripartite soul, according to Aristotle. Whereas the other potentialities require a bodily side to them, intellect does not.

### MODERN BIOLOGY

Modern biology outlines six physical characteristics that all living organisms, including unicellular organisms and individual cells, share.<sup>8</sup> First, life is organized. That is to say that the organism is readily distinguishable from the environment, and its biological systems are governed by order in their interaction with each other and the environment. Second, life requires energy. Living organisms must acquire and assimilate energy to drive their organ systems. Third, living organisms maintain biological homeostasis. Homeostasis, in this sense, is a chemical constancy, i.e., balance, which facilitates internal order. Fourth, living organisms react to environmental change. This requires being able to receive stimuli as well as respond to them. Fifth, living organisms grow, develop, and reproduce. Growth refers to an increase in mass, development corresponds to a maximization of function, and reproduction means an increase in number. The sixth and final characteristic of living organisms is that they adapt, individually and evolutionarily. This is different from reacting to the environment, because adaptation requires a change in the organism itself or in the organism's offspring. For example, bacteria develop resistance to antibiotics over generations by promoting the incorporation of favorable genetic material into the progeny.

### THE NATURE OF VIRUSES

If Aristotle, in his pursuit of empirical data, had access to an electron microscope and was able to view viral replication, he would initially qualify viruses as living organisms with a nutritive soul. His syllogism could be as follows:

- Major premise: All reproductive beings are living.
- Minor premise: Viruses are reproductive beings.
- Conclusion: Viruses are living.

Keep in mind that "nutritive" in the nutritive soul is nominal and that growth and reproduction were qualities, evidenced by empirical investigation Aristotle conducted, that embodied what I believe Aristotle meant the potentiality for nourishment to be: the sustenance of the species, to which growth and reproduction contribute.<sup>9</sup> However, the characteristics of living organisms as portrayed by modern biology would seem to counter the claim that viruses are living organisms. Modern biology, as well as Aristotle, states that life requires energy (Aristotle uses the term nourishment, which I equate with sources of energy). In fact, viruses have no metabolic activity; they do not require nutrients and do not grow. Viruses rely on the machinery of host cells and utilize the host cells' energy for the replication of their genetic material

and thus survive. In essence, they have found a novel and unique strategy for bypassing energy utilization. Instead of parasitically tapping nutrients from a host cell, viruses invade the body of a target cell and incorporate their DNA into the host cell's DNA, thereby using the host cell's biological systems for replication and replacing their protein coats with a more suitable vessel for their progeny. This phenomenon poses another challenge to Aristotle, who stated that the body and soul are inseparable, as two individual souls are arguably inhabiting the same body when viruses infect organisms.

If Aristotle was able to pursue virology further and discover that viruses use a simple marking process to identify the cells they attack, then he could argue that viruses have the potentialities for sense-perception and even desire. All viruses have special molecules on their external surface that can search out and identify cell receptors of potential host cells. The atomic composition of these special molecules dictates which cells the viruses can recognize and infect. The intermolecular interaction between virus and cell determines whether infection of the host will be successful or not. If the host cell is of a very specific type, then markers match, and if environmental conditions are just right, then the virus attaches itself to the cell membrane and infects the cell. As such, viruses possess a sense of touch, albeit of a molecular magnitude. This sense of touch may be seen as a mere chemical reaction, but essentially, every type of sense-perception is a series of chemical reactions. Therefore, Aristotle could attribute viruses as living organisms with a perceptive soul. The line of reasoning could be as follows:

All perceptive beings are living. Perception includes the sense of touch. The sense of touch is the recognition of or between extremes upon contact. Upon contact with the surface of a host cell, a virus recognizes whether the host cell is suitable or not. Therefore, a virus possesses a sense of touch, is a perceptive being, and, ultimately, is living.

On the contrary, there is something to be said about the difference in complexity between a mere chemical reaction and what we normally think of as sense-perception, which usually entails a cascade of chemical reactions and electrical impulses. Plants detect light, pressure, and moisture, yet that did not elicit the potentiality for sense-perception in Aristotle's view. Even certain inorganic compounds undergo more chemical reactions than in viral infections.

Given viruses' unique characteristics—namely, their ability to reproduce without independent metabolic systems and capacity to detect and infect choice host cells—Aristotle's criteria seem insufficiently precise. I suspect that the *prima facie* evidence, i.e., empirical data, would suggest to Aristotle that viruses were living organisms, yet a comprehensive understanding of virology would detract from that conclusion. Perhaps Aristotle would amend his criteria or even recognize another category for viruses in his framework of the soul. With his account of the soul, I contend that the nature of viruses is unresolved regarding their status as living organisms. Alternatively, I turn to the modern day criteria stipulated by the scientific community

to apply to the nature of viruses; again, I reach the same conclusion.

Modern biology requires all six characteristics in order to be classified as biological. Viruses only possess some, therefore creating contention between biologists as to whether viruses are living. To compound the problem, they are surprisingly proficient at the biological abilities they do have. Viruses' ability to adapt is unparalleled. For instance, retroviruses display a very high mutation rate. Probably arising evolutionarily from a lack of natural hosts, retroviruses mutate so fast and to such a high degree so that, while many of the offspring are nonviable, they may secure new progeny with slightly different morphology in preparation for environmental changes or alterations in the hosts' immunity. In addition, viruses' ability to reproduce is highly efficient; thus their survival is virtually guaranteed. By infiltrating host cells and their biological systems, viruses not only satisfy their need for energy but also mutate more selectively and effectively and, via lysogenic replication, position themselves for ready infection of adjacent tissue and organisms. However, it is clear that viruses do not grow, develop, or require energy. In addition, they are more disorganized than organized, relying on chance for infection and subsequent replication. In conclusion, modern biology as well as Aristotle's view of life both remain inconclusive on the nature of viruses, rendering them quasi-organisms, which provokes the question as to whether we indeed have a clear understanding of what life is.

**NOTES**

1. Morphology is a branch of biology concerned with form and structure without regard for function.
2. For example, Aristotle incorrectly classified a seal as a fish.
3. John Ackrill, *A New Aristotle Reader* (Oxford: Clarendon Press, 1987).
4. These parts of the soul are also referred to as the intellectual soul, the sensitive soul, and the vegetative soul, respectively.
5. This restricts fire, which may limitlessly grow given enough fuel, from being considered a living substance.
6. Ackrill, *A New Aristotle Reader*, 170.
7. Plants secrete a hormone in response to ultraviolet light, an essential catalyst for photosynthesis, to direct movement towards the source.
8. Fritjof Capra, *The Web of Life: A New Scientific Understanding of Living Systems* (New York: Anchor Books, 1996).
9. Ackrill, *A New Aristotle Reader*, 171.

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## *Wittgenstein and the Language of Abortion*

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The terms in which abortion discussions take place are often too partisan for much progress to be made. In addition, there is much conceptual confusion in this area. Perhaps some of this is due to the fact that interested parties here

may often be concerned to use language to arrive at pre-determined conclusions.

A major source of difficulty is the idea that our language is a calculus with strict rules. This idea is really a compound of two faulty ideas. The first faulty idea is that we begin with hard and fixed concepts. These are supposed to be discrete and have firm edges—like pebbles—cf. the Latin term *calculus*: “pebble or small stone.” The second faulty idea is that these concepts are then manipulated—think of an abacus or perhaps a modern-day calculator—to yield a definite result.

In abortion debates it is sometimes thought that our concept of *person* is something like a pebble or a small stone, that is, that the concept has fixed boundaries, like a pebble and (it is thought) if we are attentive enough to the boundaries, we will determine the location of the line between what is a person and what is not a person, and from this a solution to problems of abortion will follow.<sup>1</sup> But the concept of a person, like most other ordinary-language concepts, does not have hard edges. Indeed, it is only the exceptional concept, in exceptional circumstances, that has hard edges. Euclidean circles, for example, are—as we say—perfectly round, so that every point along their circumference is exactly the same distance from the center as every other point. But in ordinary language, we are quite willing to speak of circles where such equidistance is not a requirement, and even where visual evidence plainly shows that this condition is not, in fact, met. And people certainly spoke of circles long before the time of Euclid; nor did he forever afterwards change our ordinary concept of a circle. In general, in abstract realms such as geometry, we find concepts with hard edges. We find them in a few other places too—perhaps in kinship systems, number systems, games, bureaucracy, and a few others—but our usual concepts are not hard-edged. By hard-edged, I mean that given any object, the object will either fall under the concept or not. Kinship categories, for example, can be hard, especially among close kin. Of any woman in the world, for example, I can tell you definitively whether she is my sister or not, but in cases of more distant relationships—like that of being a relative at all, hardness does not occur.

In abortion controversies, there is often talk in terms of concepts and words such as *person*, *human*, *alive*, etc. Strangely (to me), some people argue about whether the fetus is alive.<sup>2</sup> In fact, I have been told that the question that is really at the root of the abortion controversy is whether the fetus is alive. Yet, to me, this question seems non-controversial. Of course, it’s alive; so too are most of the cells in the human body. Perhaps people who think that much hinges on whether the fetus is alive are thinking that, if so, then the fetus—unlike other cells—is really a very *small person*. Since the killing of small people is *prima facie* murder, and abortion causes the death of the fetus, it follows that, if the fetus is a very small person, abortion is *prima facie* murder.

Sometimes, it is thought that a great deal hinges on the premise that the fetus is *human*, although here, again, I don’t see that this is of much significance. In abortion discussions, all parties agree that they are talking about

fetuses that are human (rather than, say, canine or feline). But I suspect that the reliance on *human* is perhaps a poor expression of the idea that the fetus is a *human being*. If this suspicion is on the right track, then, again, we would have a valid argument: Since the killing of a human being is *prima facie* murder, and abortion causes the death of a fetus, it follows that, if the fetus is a human being, abortion is *prima facie* murder.

I think that one reason people might want to concentrate (in the first argument above) on the idea that the fetus is *alive* is that this premise is so obviously true. And, likewise, one reason why people might want to rely (in the second argument) on the premise that the fetus is *human* is that this is obviously true. The thought, apparently, is that with the addition of a few more obviously true premises, a valid argument could be constructed that would yield the conclusion that abortion is *prima facie* murder. Yet what seems to be needed in the first argument is the claim that the fetus (even at the early one-cell stage immediately after conception) is a very small person—which is not obvious at all.<sup>3</sup> And what seems to be needed in the second argument is the premise that it is a human being—which, again, is not obvious. (Note the weakness of my claims here. I am not making the very strong claim that the fetus is *obviously* not a person or human being, nor am I even making the weaker claim that the fetus is not a person or human being. My claim here is only that even if the claim about the fetus is true, it is not *obviously* true. In fact, there is controversy here, and part of the reason that there is controversy is that things here are *not* clear and obvious.)

It is often the case that people will cite a premise that is obviously true, or at least more obviously true than the premise that they really need for a valid argument to their desired conclusion. It is not clear whether this is done with the intention of confusing those to whom the argument is directed, or because the arguers themselves are confused, or perhaps for both of these reasons, and/or for some other reason. Perhaps also there is the mistaken thought that arguments are more likely to be valid if they rely on premises that are obviously true. But often, when we actually investigate the validity of such an argument, it turns out that what is needed for validity is not the obviously true premise that had first been offered, but some logically stronger premise that does not seem obviously true at all.

In any case, people with various points of view on abortion, once they get past what I think are useless ideas about the fetus being alive or being human, tend to gravitate to the ideas that the fetus is (or is not) a *human being*, or to the idea that the fetus is (or is not) a *person*.<sup>4</sup> Part of what is important here is that the ordinary application of these concepts commits the speaker to certain attitudes and behavior.

This is one of Wittgenstein’s most important insights about language. Language does not simply provide us with a set of labels that we use to identify things, while leaving us wholly unconstrained with respect to the treatment of the things that we have so identified. If I see the fetus as a human being, for example, then I am committed to regarding it and treating it as a human being. Now, just

what that treatment entails—especially at the limits—can be discussed, but if abortion is going to result in the loss of life on the part of a human being, then there is—at the very least—a significant burden of proof that must be assumed by any defender of “choice.” There are a few recognized situations in which human beings may justifiably be killed—e.g., in self-defense. Defenders of “choice” who also agree that the fetus is a human being must show either (a) that abortion should be considered under one of the recognized categories in which human beings may be killed, or (b) that abortion itself suggests that there is an additional category that should be recognized among those in which human beings may be killed. These considerations are perhaps why one common approach of “pro-choice” supporters is another one altogether: to deny that in abortion it is a human being that is killed.

The use of a concept such as *human being* or *person* both expresses and calls for certain responses on our part.<sup>5</sup> In addition to the constant theme of the *Philosophical Investigations* (PI) that language is tied to—or rather, intertwined with—action and behavior, there is the related and important strand of the PI that stresses that our concepts are tied to our interests. Contrary to those who wish to give priority to an—allegedly—interest-free scientific attitude and scientific language which is supposed to be at the base of language use, where perhaps the use of language in moral contexts is considered to be in need of some derivation from or some relationship to scientific and supposedly interest-free language (which is sometimes thought of as “pure language”—“uncontaminated by human interest”), Wittgensteinians recognize that there is no interest-free scientific language. There is certainly no such language currently in existence, and it would be somewhat paradoxical to claim that nevertheless people could construct such an interest-free language, if that is the way that their interests lead them. (Such a project could probably achieve partial success, as Euclid was successful in using ordinary concepts to devise his Euclidean circles and other geometrical notions.)

But that there is or *must* be some “ideal” or interest-free language seems to be a thought that is *brought to investigation* rather than one that emerges out of investigation. Cf. Wittgenstein’s comments:

We want say that there can’t be any vagueness in logic. The idea now absorbs us, that the ideal “*must*” be found in reality. Meanwhile we do not as yet see *how* it occurs there, nor do we understand the nature of this “*must*.” We think it must be in reality; for we think we already see it there.<sup>6</sup>

Actually, there is a nest of assumptions that are brought to the investigation. For example, there are the assumptions that a concept (such as *game* or *person*) has hard boundaries and is totally detachable from our actions, interests, practices, etc. Our concepts, it might be thought, *must* have essences, and it is these essences that define the hard boundaries for us and upon which our practices are built. Of course, Wittgenstein himself, in his attack on the ideas of essence, hard boundaries, and the calculus conception of language, uses the concept of a *game* and

not that of a *person*. One reason for this might be that the former concept is not as morally significant as the latter (that is, not much hinges on whether or not something is a game, but what hinges on whether or not something is a person may be substantial). But I think another reason that Wittgenstein uses the concept *game* is that it is not a special or technical concept, but rather one that is quite ordinary and is learned at an early age. This is true both of the concept *game* and of the concept *person*.

One assumption I have mentioned—but questioned—is that the concept *person* has hard edges. Another is that the concept is detached (or can be detached) from behavior and practice. Both the “pro-life” and the “pro-choice” sides in abortion controversies recognize a close tie between the concept *person* and behavior. Each side is generally eager to establish a certain answer to the question whether or not the fetus is a person. They tend not to agree on the *answer* to the question, of course, but there is often agreement that this is indeed a relevant question, and that much hinges upon it.

Yet Jane English has already given us reason to think that there is no definitive answer to this question—not for lack of knowledge, but because—as I have put it—the concept does not have hard edges;<sup>7</sup> further, she argues that even if there were such an answer, it would not be dispositive of abortion debates. As English points out, it’s sometimes justifiable to kill an acknowledged person—for example, in self-defense—and, on the other hand, even non-persons, such as animals, can be wrongfully treated. But English agrees that the self-defense justification—which she herself wishes to use to support abortion rights—requires that one take on a burden of proof (indicating the nature of the harm that one would otherwise suffer—and from which one is defending herself, why abortion is the only way to eliminate the threat of that harm, etc.). Even if she grants for the sake of argument that the fetus is a person, she agrees that the default is that (normally) we have no right to choose to kill people. (Of course, being under attack or having an unwanted pregnancy may not count as a normal situation.)

I think that part of what makes an interest-free or “objective” notion of language appealing to many people—although the supporters of such an idea would probably not put it this way—is that such an account puts individuals in a place where they can deny (or relinquish) any personal responsibility for the outcome of the use of that language. So, for example, in poker—where there *are* hard edges—a flush wins over a straight, for example, and that this is so is no judgment on the part of an individual, but simply part of the rules of the game. In an actual game, this rule may, in fact, work to determine the winner. And it may work in a given case either to one’s advantage or to one’s disadvantage. By relying in this way on the rules of the game, people aim to achieve objectivity and fairness. So, for example, personal judgments and observations about the relative strengths of the hands at the showdown may be psychologically or socially interesting, and may even contribute to the enjoyment of the game, but as far as the outcome of at least that hand of the game is concerned, they are irrelevant; the rules of the game determine the winner.

But it is apparently thought that the qualities of objectivity and fairness can be imported into the moral arena—which is quite different. Again, in geometry, the length of a straight line drawn from the center of a circle to a given point on the circumference is said to be equal to the length of any other straight line drawn from the center to some other point on the circumference. Here too the conclusion is not based on the judgment of an individual—so there is no question of the individual having mismeasured the lines or being responsible for having made some other mistake: if we have a Euclidean circle and the case is as described, then the two lines are of equal length.

The constant dream—it seems to me—of some of those who discuss moral matters is that moral language too will relieve them of having to make any personal judgment. It is thought that in morality, we want to be *objective* and *fair*, and that this requires the withdrawal of all personal interest—where prejudice or self-interest may sway one’s judgment—and a reliance upon something external, like the rules of poker or the postulates of geometry. It sometimes seems to be thought that the only alternative to relying strictly on external points of reference is to allow full rein to input of a personal nature, in which case different individuals will give us different answers and different verdicts. If we allow input of a personal nature, it is feared that some items in that input will be biased or prejudiced, and we won’t be able to tell with certainty which are biased and which are not. But one thing that has gone wrong here is that the idea of being *fair*, although a good one in itself, is not being correctly applied.

If we are to render fair judgments and fair verdicts, we must have access to the resources that must be used in order to produce them. And one of these resources is language—language in its home. But one of the problems here is that judgments are thought to be fair by virtue of being couched in terms that are detached (or detachable) from human behavior and practice. This sort of language—the “detached” kind—is what Wittgenstein might describe as detached from any activity or language-game. And so it is free-floating language—or language on holiday. The only way any progress on moral problems can be made—e.g., the problems associated with abortion—is to pay careful attention to the actual ways in which language is used: the concepts of person, fetus, baby, human being, etc. There is no escape to a better place than these concepts. They are not the problem that we have to get away from. Rather, what we have to do is understand our language better and think better. There are no guarantees that satisfactory answers will be attained in this way, but this is the only way that satisfactory answers can be attained.

**NOTES**

1. See Jane English, “Abortion and the Concept of a Person,” *Canadian Philosophical Journal* 5 (1975): 233–43, where she argues that even if we did have a place to “draw the line,” which we don’t, this still wouldn’t yield a solution to the abortion problem, as even non-persons have some moral status (e.g., cruelty to animals is wrong), and even persons may sometimes be justifiably killed (e.g., in self-defense). My own treatment of abortion here is much indebted to English’s article, which is itself greatly influenced by Wittgenstein.
2. I follow established usage in abortion controversies here and use the terminology of “the fetus” throughout, although, medically

speaking, there must first be a zygote and then an embryo before there can be a fetus. Certainly, for example, a newly fertilized cell is not a fetus, although the pro-life contingent maintains a single view about “the fetus” and holds that this view applies from the moment of conception. But sometimes, just as talk about “the fetus” is extended backward in time to include what is more accurately described as an embryo or zygote, a fetus itself is referred to as an “unborn baby”—as if this were a variety of baby—thus extending the idea of a baby backward in time and avoiding the use of the term “fetus” in the very case in which it is paradigmatic.

3. Besides the non-intuitive nature of the claim that there are people so small and so strangely formed that they lack a brain (and a head to house it), limbs, all internal organs (and a body to house them), and that they consist of only a single cell, there are other difficulties with the idea that these are small one-celled people.

We note in passing that although many of these alleged small people never implant in the uterus, the “pro-life” movement has seemingly abandoned them. There may be female dietary factors, drugs, or other unknowns that research could explore or uncover so that the small people whom “pro-life” claims to have identified could be rescued instead of being expelled with the menstrual discharge. It should be added here that this problem of the non-implanting conceptus is far from rare and is estimated to occur in 10 percent to 30 percent of all conceptions—although, due to the nature of the case, there are no reliable statistics on the actual percentage of those that are unknowingly discharged along with the menstrual discharge.

4. There are, of course, differences between these two concepts. Certainly, theists have supposed that God is not something impersonal but a person—or even that there are three persons in God—but the general religious belief is that God is *not* a human being. From another direction too, there have been thoughts that even some animals (or hypothetical creatures from another planet) might qualify as *persons* but not as *human beings*. Such subtleties, although interesting in their own right, will not be further addressed here as they tend to lead us further and further away from the moral topic of abortion.
5. Cf. Wittgenstein in the *Philosophical Investigations*: “Concepts . . . are the expression of our interest, and direct our interest” (PI §570).
6. PI §101, Wittgenstein’s emphasis; see also PI §107: “The more narrowly we examine actual language, the sharper becomes the conflict between it and our requirement.”
7. The claim that the question has no answer is sometimes interpreted as almost its opposite, that is, that the question does indeed have an answer, only we don’t know what the answer to it is. Part of English’s point, however, is that it is not the case that the question is perfectly in order (so that it is only a lack of *knowledge* on our part that stands in the way of a definitive answer to it), but that the concept in the question does not have hard boundaries—and yet the question itself seems to presuppose this.

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## Moral Relativism and Medical Decisions

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Recognizing that different people have different values, contemporary bioethicists tend to place respect for autonomy at the top of their list of ethical principles, ahead even of beneficence. They want to avoid the ugly paternalism of “doctor knows best” that characterized much of medicine in the first half of the twentieth century. One could even say that bioethics owes its existence to the reaction against such paternalism that began to emerge after the Nuremburg trials of Nazi physicians. But some bioethicists and health policy-makers unintentionally embrace paternalism by applying respect for autonomy

within overly narrow limits defined by their own values. In some instances, the principle of beneficence justifies that; in other cases, however, such behavior wrongfully deprives patients of the freedom to live and die as they choose, without first having to obtain the approval of others.

This will not be surprising to those who have studied the history of moral philosophy. To the ancient Greeks, while many were considered unfit to participate in the good directly, there was a single good for all human beings. Something like that theory endures today, receiving tacit affirmation even from full-throated relativists who claim the good is whatever an individual wants it to be. Whatever our theoretical views, most of us seem to believe that some goods are obviously better than others. In that sense, the ancient moral theories of Aristotle and Plato are superior to any modern relational account of morality because they are not at odds with ordinary beliefs. Yet those theories cannot account for the fact that human flourishing occurs with respect to different goods for different individuals. Nor do such valuational differences break neatly along lines of birth, race, or gender. We know from centuries of experience with liberal societies that individuals who choose goods different from the ones embraced by those around them often find happiness.

Modern relational theories of value explain the moral pluralism revealed by everyday life in liberal societies better than theories that posit a universal good. Even casual observers of such societies soon realize that values exist in relation to individuals, not groups, species, or God. At the same time, resistance to the clear implications of value relationalism reminds us of the natural difficulties involved in seeing through the eyes of another. In view of that, we should not be surprised to find contemporary moral philosophers at once espousing relational accounts of value and rejecting what they view as inferior goods. George Santayana is one such philosopher. While maintaining that values exist in relation to the unique natures of individuals, Santayana nonetheless wrote that some goods are just superior. He disliked liberal democracies because they do not foster what to him were the superior goods.

Careful consideration of Santayana's thought is appropriate here for two reasons. The first is that Santayana developed a relational theory of value supported by persuasive arguments. That theory has important implications for medical decisions and healthcare policy, because it places the individual (as opposed to the species, the culture, or the community) at the center of value relations. This lends considerable support to the principle of respect for autonomy at a time when influential communitarian strains within bioethical discourse seek to substitute for that principle respect for the collective decisions of the community. If Santayana was correct that values exist in relation to individuals, then there ought to be a strong presumption in favor of liberal institutions and policies over communitarian alternatives. This is even more important in the healthcare arena, where lives often hang in the balance when decisions are made.

The other reason for paying close attention to Santayana is just as important. While Santayana devised a brilliant

theory of value that clearly supports respect for autonomy within broad limits, he was unable to consistently affirm the implications of his own theory. Some human choices seemed to him to have no value or even negative value, despite the merits of his theory that renders those choices equally legitimate by looking at them as if through the eyes of the beholder. I call this the fallacy of selective relativism. Affirming value pluralism up to the limits of one's personal taste poses a serious threat to the liberal institutions and policies that undergird the principle of respect for autonomy and thus to the principle itself. The fallacy is even more dangerous because it is only natural. We are prevented by physical limits from seeing the world through another's eyes. If we fail to guard against the fallacy of selective relativism, even the best theoretical work in ethics and political philosophy may not be enough to secure the freedom of individuals to make their own choices, whether their lives hang in the balance or not. Santayana's theoretical achievements in ethical theory and his all-too-human blindness to the values that exist in relation to others should remind bioethicists and health policy-makers of the timeless importance of respect for autonomy and the liberal arrangements that provide the only secure foundation for that principle.

The prevailing wisdom among scholars is that Santayana held a relational theory of value. My first objective is to show that such wisdom is not entirely right. Santayana did develop a relational theory of value, but he also failed to consistently affirm its implications. My second objective is to show what this means for bioethicists and health policy-makers applying the principle of respect for autonomy. It means, I argue, that as a rule they should apply the principle more liberally, deferring to the patient's assessment of better and worse. In particular, I want to address a communitarian critique of liberal political arrangements. Bioethicists such as Ezekiel Emanuel advance this type of critique because they are troubled—and rightly so—by the high cost of ongoing disagreement with respect to medical decisions. They seek to achieve agreement and protect pluralism by respecting the autonomy of groups rather than that of individuals. My argument is that such arrangements would have the effect of trading individual autonomy for the appearance of universal agreement. Pluralism would not be altogether destroyed, but the pluralism that survived would be narrower than what we currently find in liberal societies. On the hypothesis argued for here, namely, that values are relative to individuals, we would pay for the semblance of agreement in terms of lost opportunities for individuals to realize their unique life plans. My conclusion is that today's bioethicists and health policy-makers should be consistent relativists and as such should evaluate medical decisions and healthcare policies against the principle of respect for autonomy applied to individuals. Inasmuch as they affirm value pluralism but seek to force agreement that would not arise on its own, they fall prey to the fallacy of selective relativism.

There is no shortage of evidence that Santayana held a relational theory of value. In *Reason in Society*, he wrote: "each possible life knows its natural paradise, and what some unintelligent outsider might say in dispraise of that ideal will never wound or ruffle the self-justified creature

whose ideal it is, any more than a cat's aversion to water will disturb a fish's plan of life."<sup>1</sup> Again, in the same book: "Things could not be near or far, worse or better, unless a definite life were taken as a standard, a life lodged somewhere in space and time."<sup>2</sup> But then there are statements such as the following: "The will which is behind all ideals and behind most dogmas cannot itself be refuted; but it may be enlightened and led to reconsider its intent, when its satisfaction is seen to be either naturally impossible or inconsistent with better things."<sup>3</sup> "Better," one wonders, according to whom? What explains the apparent contradiction between such statements as these? Several explanations are possible, any one of which, if true, would make Santayana a consistent relativist. After examining the full range of evidence, however, we must conclude that none of those explanations is true.

One possible explanation is that when Santayana seems to be saying that values are not relative to individuals, he is just describing what he called "the life of reason." The life of reason was Santayana's name for the idea that we ought to pursue only mutually inclusive goods, such as education and physical fitness. One should not, according to that ideal, pursue physical fitness and the pleasures of chain-smoking. Using a different good as an example, Santayana wrote the following in *Reason in Common Sense*: "The love of fame . . . would tend to take a place in a man's ideal such as its roots in human nature and its functions in human progress might seem to justify. It would be rationalised in the only sense in which any primary desire can be rationalised, namely, by being combined with all others in a consistent whole."<sup>4</sup> This is just one example of what Santayana called the "gradual mastering of experience by reason"<sup>5</sup> that is the hallmark of the life of reason. In a general sense, the life of reason was "a name for that part of experience which perceives and pursues ideals—all conduct controlled and all sense so interpreted as to perfect the natural happiness."<sup>6</sup> But ideals have to be achievable if they are going to "perfect the natural happiness," which meant to Santayana that goods included in ideals had to be consistent with each other. One might pursue sound health and the pleasures of chain-smoking, but in most cases that would prove to be "naturally impossible." Such behavior would also prove in many cases to be inconsistent with "better things," namely, ideals one can actually achieve because they are composed of goods that are consistent with each other. On this analysis, values are relative to individuals, but some goods are superior, provided one embraces the life of reason ideal. Those who do not embrace that ideal can legitimately prefer inconsistent goods.

One problem with this explanation is that Santayana presented the life of reason in strongly normative terms, making it hard to believe that he viewed pursuing inconsistent goods as a legitimate choice on a par with pursuing consistent goods. If pursuing mutually inclusive goods suggested a "gradual mastering of experience by reason,"<sup>7</sup> those pursuing long and happy lives while riding motorcycles without helmets would fall into the category of irrational amateurs. "A perfectly wise and representative will," Santayana wrote, "would aim only at what, in its attainment, could continue to be aimed at and approved; and this is another way of saying that its aim would secure

the maximum of satisfaction eventually possible."<sup>8</sup> But if a wise person is one who aims at "the maximum of satisfaction eventually possible," then one who does not aim at that is a fool. If Santayana held that all goods are equal in relation to those who value them and that individuals who do not value the life of reason are fools, then he contradicted himself and did not hold a relational theory of value consistently.

But there is another possibility. Perhaps Santayana held that values are relative not to the unique natures of individuals but to universal natures shared by all members of a species. Just as the good in relation to elephants might be to shoot water from your trunk, the good in relation to humans could be to pursue only those goods that are consistent. This would mean that Santayana did not stray very far from the ancient Greeks. To Socrates, what explained the fact that some individuals did not pursue the good appropriate to humans was that they were ignorant. Those who knew the good, he claimed, could not fail to do it. The same analysis was available to Santayana, if he held that all members of the human species share a common nature. In that case, values would be relative to human nature, making some goods inferior for humans as a matter of fact, regardless of the opinion of this or that individual. If this is what Santayana held, then we can acquit him of the charge of inconsistency.

A significant amount of textual evidence supports this possibility. In "Hypostatic Ethics," for example, Santayana wrote in reference to radical hedonism that it "is indeed inhuman; it undermines all conventional ambitions, and is not a possible foundation for political or artistic life. But that is all we can say against it. Our humanity cannot annul the incommensurable sorts of good that may be pursued in the world, though it cannot itself pursue them. The impossibility which people labour under of being satisfied with pure pleasure as a goal is due to their want of imagination, or rather to their being dominated by an imagination which is exclusively human."<sup>9</sup> Here, what seems to prevent us from seeing the value of radical hedonism is that we value those things that are appropriate to humans, and radical hedonism is not one of them. Perhaps other species, such as oysters, can be "satisfied with pure pleasure as a goal," but humans simply cannot find that goal worth pursuing, because they are not oysters.

Yet it is not hard to find textual evidence that cuts in the opposite direction, suggesting that values are relative to the unique natures of individuals, not to universal natures shared by all members of a species. Santayana often gave examples of what he viewed as real variety within human nature. These were not examples of individuals choosing on a whim what they mistakenly believed to be their good only to eventually discover that it was not; on the contrary, they were examples of individuals different in their nature from others choosing what in relation to their version of human nature was a genuine good. Again, in "Hypostatic Ethics," Santayana observed that some humans, namely, mystics, are like oysters in finding "changeless pleasure" to be a worthy goal. That Santayana thought human nature often varied from one individual to the next seems unambiguous in the following passage from *Reason in Common Sense*: "Human nature, in the sense in which

it is the transcendental foundation of all science and morals, is a functional unity in each man; it is no general or abstract essence, the average of all men's characters, nor even the complex of the qualities common to all men. It is the entelechy of the living individual, be he typical or singular."<sup>10</sup>

Whether Santayana was a consistent relativist cannot be determined without first clarifying his view of human nature. Was there, to him, a single human nature shared by all, or did he hold that human nature varies across individuals and perhaps within the same individual over time? I suggest that Santayana held both of these views and that they are actually compatible. The idea of evolution suggests how what Santayana called "flux and constancy" coexist in human nature. Evolution cannot take place unless there is a definite something that evolves. *Homo sapiens* or any other species must retain some of its original characteristics as a condition of evolution taking place, or else what took place instead would not be evolution but incoherent change. Santayana wrote: "Mankind can never, without perishing, surrender its animal nature, its need to eat and drink, its sexual method of reproduction, its vision of nature, its faculty of speech, its arts of music, poetry, and building."<sup>11</sup> Even more generally, humanity cannot surrender its mortality without becoming something that is not human.<sup>12</sup> There is, in other words, a "core" of human nature, yet human nature at the periphery "varies indefinitely in its historic manifestations and fades into what, as a matter of natural history, might no longer be termed human."<sup>13</sup> It is therefore possible, and Santayana seems to have held that human nature is at once a constant and a variable. There is no reason why certain features of human nature cannot remain fixed, while others vary. Santayana wrote: "What the majority of human animals may tend to, or what the past or future variations of a race may be, has nothing to do with determining the ideal of human nature in a living man, or in an ideal society of men bound together by spiritual kinship."<sup>14</sup>

But if Santayana really held that all members of the human species share a common nature, then may we not conclude that he was consistent in his relativism? Perhaps what he had in mind when referring to superior goods was that their superiority was in relation to the "core" features belonging to all examples of human nature, not to those features belonging only to some examples or confined to a single one. But we cannot draw that conclusion, because what all humans share in common excludes all but the most generic features. If the core of who we are consists of finitude, metabolism, and sexual reproduction, then knowledge of human nature tells us nothing about what is good for all humans. We cannot even infer from such knowledge that eating is superior to not eating, much less that we ought to pursue consistent rather than inconsistent goods. Without a fine-grained description of who we are as a species, the only means of identifying what satisfies human nature is by observing human behavior under conditions of substantial freedom from control by others. But if observation of human behavior in the absence of coercion is the only available means of determining what is good for us, then Santayana's claim that consistent goods are superior is at best partially supported. Nor could he readily

defend himself by replying that it is possible to freely and consistently choose what is not your true good. Empirical support for such claims is next to impossible to find, and no other form of support is available. Thus, if Santayana held that consistent goods are superior in relation to the core features of human nature shared by all individuals, then his theory of value is incoherent. The only defensible theory open to him was that values are relative to individuals, yet he also stated that some goods are just superior, no matter what individuals choose.

At this point, the conclusion that Santayana was inconsistent in his relativism seems unavoidable. If he had held that all members of the human species share a common nature comprised of more than a few very general features, then he could have argued consistently that values are relative to that nature, and thus that the life of reason is the ideal for all humans, whether we know it or not. But he had to have held that values are relative to individuals. Although they are both mortal, a mystic finds the idea of changeless pleasure irresistible, while an ambitious executive presumably finds the same ideal devoid of appeal. Given that human nature varies from one individual to the next, a consistent relativist, one could argue, would have stopped here. Only the individual can determine what the good is and only for herself. Yet Santayana asserted instead that the life of reason has "absolute authority" as an ideal.

However, that alone does not prove that Santayana was inconsistent in his relativism. That is because the life of reason is no more than a general framework within which there is plenty of room for divergent values relative to a range of different human natures. The only requirement of the life of reason is that one's ideals must be consistent. "If," Santayana wrote, "[an individual] can know himself by expressing the entelechy of his own nature in the form of a consistent ideal, he is a rational creature after his own kind, even if, like the angels of Saint Thomas, he be the only individual of his species."<sup>15</sup> That being the case, Santayana could have concluded, for example, that a short life of hard manual labor, relentless thrill seeking, and much sensuous enjoyment might be, relative to the individual pursuing it, legitimately better than a long life of safety, moderation, and intellectual activity. After all, the former ideal is no less self-consistent than the latter.

But Santayana did not see it that way, at least not always, and that is where we can convict him of inconsistent relativism. Santayana's withering critiques of liberal democracies provide the most unambiguous examples of him rejecting ideals that clearly are versions of the life of reason. Given his relational theory of value, he ought to have welcomed such ideals as legitimate variations in relation to corresponding differences in the underlying instance of human nature. In *Reason in Society*, Santayana's characterization of working class individuals is blatantly contemptuous. To him, such persons have no ideals of their own that are worth mentioning. "Those grimy workmen,"<sup>16</sup> he suggested, must look to their betters if they wish to improve themselves. He wrote: "We see how they spend their leisure to-day, when a strong aristocratic tradition and the presence of a rich class still profoundly influence popular ideals. Imagine those aristocratic influences

removed, and would any head be lifted above a dead level of infinite dullness and vulgarity? Would mankind be anything but a trivial, sensuous, superstitious, custom-ridden herd? There is no tyranny so hateful as a vulgar and anonymous tyranny. It is all-permeating, all-thwarting; it blasts every budding novelty and sprig of genius with its omnipresent and fierce stupidity.<sup>17</sup> Such contempt for average people is elitist and out of step with Santayana's relational theory of value, which clearly implies an ethics of mutual tolerance and respect for autonomy.

To give Santayana the benefit of the doubt, suppose for the sake of argument that we know the life of reason is always good in relation to certain core features of human nature that we all share. Can it be that Santayana was actually consistent in his relativism and meant to say only that working class individuals do not adhere to the life of reason because they are ignorant of their true good? Earlier in the same work, he does say that many people "neither understand their own interests nor have the constancy to pursue them systematically; and further, that their personal or animal interests may actually clash, in so far as they have not been harmonized by reason."<sup>18</sup> But it cannot be the case that Santayana rejected working class ideals simply because in their ignorance of the life of reason, working class individuals pursue inconsistent goods. For there is nothing inconsistent about wanting to work hard, take pride in earning one's keep, sleep soundly at the end of a long day, and look forward to time off.

We must conclude that it was not that working class ideals are inconsistent that prompted Santayana to deny their relative value but his personal dislike of them. Yet that amounts to saying that all values are equal but some, namely, the ones you happen to like, are more equal than others, a claim that overtly contradicts Santayana's relational theory of value. As if to prove my point, Santayana wrote, again in *Reason in Society*, that a society of working class people "has the mind of a worm and the claws of a dragon. Anyone would be a hero who should quell the monster. A foreign invader or domestic despot would at least have steps to his throne, possible standing-places for art and intelligence; his supercilious indifference would discountenance the popular gods, and allow some courageous hand at last to shatter them. Social democracy at high pressure would leave no room for liberty. The only freeman in it would be one whose whole ideal was to be an average man."<sup>19</sup>

The fact that a moral philosopher of Santayana's stature could affirm at the same time that values are relative to individuals and that some values are superior to others should be a warning to contemporary bioethicists and policy-makers. Even more ominous is that Santayana apparently remained unaware of the inconsistency of his own position to the point where he began to consider the merits of illiberal political arrangements. But Santayana more than made up for that blind spot by devising a relational theory of value that can serve as a moral foundation for liberal political arrangements and public policies. If Santayana was right that values exist in relation to individuals, then respect for autonomy ought to be the guiding principle when making medical decisions and formulating healthcare policy. This would seem to fit nicely

within a political framework designed to protect individual choice against encroachments of state power.

But there are bioethicists who, like Santayana, affirm value pluralism yet resist what they view as the unacceptably high cost of respect for autonomy when making decisions and framing policies about medical treatment. According to Ezekiel Emanuel, a liberal egalitarian political framework engenders persistent lack of resolution with respect to bioethical questions of our time and place. Physicians disagree on how to treat incompetent patients, for example, because society disagrees about the goals of care for such individuals. The source of all this disagreement turns out to be liberal egalitarian political philosophy itself, with its defense of individual autonomy.<sup>20</sup> To get an idea of the high cost of placing individual autonomy at the heart of our political philosophy, we need only consider the many personal, professional, and judicial battles that had to be fought in order to establish a right to refuse life-sustaining treatment. Nor does the end result even make logical sense with respect to incompetent patients. What we are saying is that individuals who, by definition, are not in a position to exercise rights nevertheless have the right to refuse life-sustaining interventions.<sup>21</sup>

Those who embrace liberalism and the principle of respect for individual autonomy defend their view by arguing that what matters most in cases of incompetent patients is not *what is decided*, although that certainly matters, but *who decides*. Courts have tended to defer to patients' family members when there is no living will or advance directive. According to Emanuel, however, this is little more than an evasion of the real issue, which is deciding what ought to be done in such cases.<sup>22</sup> Deference to family members of incompetent patients should be considered out of bounds for at least two reasons. First, liberal political philosophy requires the state to remain neutral with respect to substantive ends of human life. Courts' deference to family members violates the liberal norm of neutrality by supporting familial relationships over alternative ends.<sup>23</sup> In the second place, such deference can lead to what Emanuel calls "illiberal" results. If Karen Quinlan's parents, aided and abetted by the state, are allowed to decide on her behalf that she is to be weaned from the ventilator, then the state is forcing Karen to comply with her parents' wishes. In other words, the state is imposing a substantive conception of the good life—one that revolves around strong family relationships—that is not shared by everyone.<sup>24</sup> If the physician is the surrogate in cases of this type, then the state is imposing the current ethical norms of the medical profession.<sup>25</sup> Recently, one of those norms has been a presumption in favor of continuing aggressive interventions past what some clinicians would say was the point of medical futility, as opposed to withdrawing treatment and allowing the patient to die. This has been the cause of much unnecessary pain and suffering, all because liberal political philosophy fuels irresolution about goals of care by zealously protecting individual autonomy.<sup>26</sup> Such protection prohibits government from being helpful by supporting those substantive visions of the good life on which small communities might be able to agree. A more communitarian political philosophy would allow bioethical decisions to be informed by a common worldview, thus resolving current controversies.

Emanuel, like Santayana, is not overtly opposed to pluralism. On the contrary, he would like to affirm pluralism and still be able to devise political arrangements that allow us to agree on the appropriate ends of human life.<sup>27</sup> Nor does the second part of this vision diverge very far from Santayana, who often displayed deep sympathy with the choices of others when they were unlike his own—and at the same time strongly suggested that his own ideal of human life, the life of reason, applied to everyone. For Emanuel, political arrangements capable of rendering autonomy compatible with agreement in the context of pluralism would have to protect the autonomy of small communities, rather than that of individuals.<sup>28</sup> These communities would form around certain fundamental values shared by all of their members.<sup>29</sup> Agreement on such values would allow the community to decide together, through an extensive process of deliberation, how the ends of human life should be defined.<sup>30</sup> Agreement about the ends of human life would in turn enable agreement about bioethical questions, such as when to withdraw treatment from incompetent patients. Pitched battles surrounding these questions, to say nothing of the agony of patients who are better off dying sooner than later, could then be avoided. Nor, in theory, would we have to resort to the “illiberal” use of state power, as that would be unnecessary due to underlying agreement about right and wrong.

One problem with Emanuel’s proposal is that the assumption on which it rests, namely, that values are relative to groups and not to individuals, will not withstand a closer examination. Empirical observation supports Santayana’s theory that values are relative to individuals. No matter how small or close-knit the group, at least a few members will disagree with the rest and want to live differently. It is not hard to find parents who disapprove of their children’s choices. Even within orthodox religious groups, there are always those who see matters differently and become champions of reform. The notion that disagreement stems from liberal political philosophy is belied by the fact that disagreement also exists under communitarian political arrangements. A well-known example of this is Brook Farm, the communitarian experiment undertaken by American transcendentalists in the nineteenth century. Brook Farm was not long in existence before internal disagreement led to its dissolution.

To be fair, Emanuel does distinguish between “resolvable” and “fundamental” disagreements,<sup>31</sup> observing that members of a community can disagree over interpretations or views and yet remain united by a basic commitment to their political community and a shared underlying viewpoint.<sup>32</sup> He adds that “liberal communitarianism” would leave individuals free to make a wide range of choices concerning vocational, avocational, and family matters.<sup>33</sup> Those who found themselves fundamentally at odds with the community would be free to leave.<sup>34</sup> However, it is possible to disagree about where to draw the line between resolvable and fundamental disagreements. It is also conceivable that seemingly resolvable differences would lead to fundamental disagreements, even when all members of the community share certain core values. The members of Brook Farm came from similar backgrounds and shared the ideals of American transcendentalism,

yet their disagreements were serious enough to dissolve the community. At one time, Catholics were divided over the Greek letter iota. A single iota made all the difference between the doctrine that the Holy Spirit was of *one* substance (spelled without an iota) with the Father and the competing doctrine that the two were of *similar* substances (spelled with an iota). It would be nice if those who rejected the core values of their community could simply leave, but the personal, social, and financial costs of exit could be prohibitive. Moreover, one would then have to locate a community whose fundamental values were in agreement with one’s own, incurring still more costs, including the risk of not finding a suitable community.

As much as liberal political arrangements impair the state’s ability to resolve moral controversies by supporting a particular vision of the good life, they enable individuals to make their own choices to the extent possible. This is a weakness only if it turns out that values are not relative to individuals but are absolute, relative to the entire species or relative to groups. But Santayana’s arguments and observational evidence should lead us to the conclusion that values are, in fact, relative to individuals. Liberal communitarianism then cuts in two directions: it resolves moral conflicts in a definitive way, but it also undermines the freedom of individuals to live by their own lights, without deferring to the community, an outcome that must be considered morally objectionable. In a liberal communitarian world, healthcare policies promote substantive ends and are developed collectively by small communities working from a shared conception of the good life. All members of the community are given an equal opportunity to participate in the public deliberations that shape their policies,<sup>35</sup> although they are free to opt out of the process. Because these communities are formed around underlying agreement about fundamental values, they deliberate for the purpose of sorting out fine points and are unlikely to face irresolvable conflicts.<sup>36</sup> Emanuel stresses that there is plenty of freedom here. Individuals are free to choose a community that shares their values, they are free to participate in the political process, they are free to make all sorts of ordinary decisions related to their personal lives, and they are free to leave their community if they choose. However, if Santayana was right that values are relative to individuals, then we should expect intractable conflicts to arise even within such communities. At that point, either the controversial questions will have to be submitted to a vote, or the dissenters will have to leave. I have already discussed the problem with the exit alternative: one is free to exit at one’s own risk and expense. If the controversial questions are submitted to a vote, those in the minority will be forced to comply with the majority’s opinion. But even if all are in agreement with respect to a particular policy at the outset, we can predict that some will eventually change their minds. This is even more likely to occur in relation to policies dealing with medical treatment near the end of life.

Imagine a community that unanimously adopts a policy denying hospital admissions and all acute medical services to members aged 72 years and up. Those under 72 are to receive “all medically necessary treatments,”<sup>37</sup> while older members are to receive only “extensive home nursing and

social services and devices to assist in daily living.<sup>38</sup> Will a man of 73 for whom a bypass would mean a second chance not want to change his mind? Will a woman of 75 who might be able to extend her life with chemotherapy not want to take her chances, regardless of the policy decision she agreed to years ago? Emmanuel's community health programs would include as many as 25,000 members,<sup>39</sup> making deliberations arduous at best, but that is not the true Achilles heel of his view. What he overlooks is that notwithstanding our social nature, we all view ourselves and our loved ones as precious exceptions. It is one thing to frame a policy for "ourselves" in the abstract and something else altogether to submit to that policy, especially when submission means death. Emanuel does explain that no policy is final. The community is free to revise its work.<sup>40</sup> But will the voices of these elderly individuals be strong enough to shape a new policy consensus? What if the deliberations are complex and prolonged, as would probably be the case? There will be casualties in the interim. Even worse is the distinct possibility that the weak and helpless will not feel empowered to disagree with their community over the very policies that they themselves once approved. They will be forced to silently do what is expected of them, as has so often been the case in history when disadvantaged members of a particular community did not feel empowered to challenge the status quo. Formal political arrangements are not the only factors that influence human behavior. Informal and even unspoken social norms also exert a powerful influence, for better and for worse. As painful and as costly as they can be, ongoing moral controversies would seem to be an acceptable price to pay for avoiding political arrangements that expose all of us to the dual tyrannies of the majority and the status quo.

Failure to affirm the full implications of his well-supported position that values are relative to individuals led Santayana to consider the merits of coercive political arrangements. Left to themselves, if the masses persist in their rejection of the appropriate ideal of the good life, could rule by their betters be anything but benevolent? Such a question can be asked in a cynical way, but it can also be asked from a place of honesty and good intentions. Unfortunately, starting from such a premise invariably leads to a conclusion that would have us reject the very principle—respect for the autonomy of individuals—that allows for human flourishing under conditions of value pluralism stemming from individual differences. A clear implication of Santayana's position is that we must tolerate those who choose to live differently than we do.

But this is easier said than done, even by those who affirm value pluralism. The reason is not far to seek, because no matter how generous the soul who affirms pluralism, there are values that if they were to flourish on a large scale would destroy pluralism itself. Emanuel senses this danger but follows Santayana down the wrong path of admiring political arrangements that are less than voluntary. To Emanuel, liberal communitarianism is the guardian of a salubrious pluralism that is fully compatible with agreement about the ends of human life. But if that pluralism is to be secured, he reasons, it will be necessary to take steps to prevent alternative political arrangements from becoming too popular. Government

should not be allowed to actively persecute alternatives deemed threatening to liberal communitarianism but should actively support liberal communitarian institutions financially and with legal protection, while denying similar support to competitors.<sup>41</sup> The tacit assumption is that liberal communitarian arrangements are, in fact, better for everyone, with the exception, perhaps, of a few misguided dissenters who will eventually fall in line and will suffer no great loss in doing so. It is the same kind of assumption made by Santayana in those passages where he seems to be prescribing the life of reason for all. To those who worry that libertarians might form a movement that would threaten liberal communitarianism, Emanuel offers the comforting thought that we do not have to worry about libertarians because in the area of medical care, there are not that many of them anyway.<sup>42</sup>

Emanuel does attempt to respond to the charge that liberal communitarianism "is not pluralistic, because it aims to impose democratic deliberation on all."<sup>43</sup> Here, his argument is that protecting pluralism cannot mean "permitting all possible conceptions of the good life to be pursued,"<sup>44</sup> and liberal communitarianism is "compatible with many worthy conceptions of the good life."<sup>45</sup> But the appropriate charge is not that liberal communitarianism is not pluralistic, but that its pluralism is of the wrong kind and is therefore overly narrow. Allowing only those conceptions of the good life to flourish that can survive a deliberative process places severe constraints on the autonomy of the individual. But if the good is relative to the individual, then the pluralism one should want to protect is not that of popular conceptions of the good life but the broader pluralism of individual choice. The best way to protect that kind of pluralism is by protecting the autonomy of individuals, and for that you must require the state to remain largely neutral with respect to substantive conceptions of the good life. Individuals and groups must be allowed to agitate for all sorts of alternatives on a playing field that has not been tilted in one direction or another by those holding political office. Nor should we become overly concerned with securing liberal arrangements. Rather than using state power to squeeze out intellectual competition, we must run the risk that one of the agitators will eventually be successful. If liberal arrangements are, in fact, the most desirable or the least objectionable, then they will be capable of withstanding vigorous challenges.

Emanuel's argument, that a state that attempts to remain neutral with respect to alternative conceptions of the good life in fact favors a particular conception and therefore cannot be a liberal state, does not work. The argument is that liberalism requires the state to remain neutral, but remaining neutral actually means promoting autonomy, and not everyone values autonomy.<sup>46</sup> The problem is that in a liberal state, those who do not value autonomy are free to surrender much of their freedom, whereas in a liberal communitarian state, those who would like to exercise their autonomy may not be free to do so. By remaining neutral between different conceptions of the good life, a liberal state ensures that we have the freedom to choose but does not force us to exercise that freedom. Thus, the sort of pluralism that is possible in a liberal context is necessarily more inclusive than that which is possible under liberal

communitarian arrangements. On the assumption that values are relative to individuals, a more inclusive pluralism stands a better chance of expanding the scope of human flourishing than a less inclusive one.

But there are other reasons for preferring liberal communitarian arrangements, according to Emanuel. For one thing, such arrangements enable the citizen to realize "a higher level of freedom."<sup>47</sup> This is the freedom to not only pursue one's own conception of the good life but to "create and pursue the conditions within which this good life is formulated and pursued."<sup>48</sup> These "conditions" are social structures and political institutions. Furthermore, participating in democratic deliberations develops at least two "distinctive human capacities."<sup>49</sup> First, such participation transforms the sense of empathy, commitment, and responsibility for the future, capacities that emerge first within family life and friendships, into "communal responsibility for future generations."<sup>50</sup> Second, participating in democratic deliberations develops the capacity for "wide-ranging" moral reflection.<sup>51</sup> One more developmental effect of deliberating is that it enables the individual to "transcend his contingent, individual existence by becoming part of an enduring community, a people with a past and a posterity."<sup>52</sup> Emanuel writes: "Existence, and whatever is done in it, is ephemeral. The only way to overcome these limitations of capacities and time is through union with other people in a community that develops the full range of human capacities and that continues the traditions and ideals after each individual has died."<sup>53</sup>

No doubt shaping the conditions of one's life and developing one's capacities are goals that many find attractive, and the claim that participating in the life of a community facilitates achievement of such goals is not controversial. What is odd is the further claim that "it is only through . . . deliberations" that one can achieve the aforementioned goals.<sup>54</sup> It is hard to see why participating in a community has to entail making a large number of collective decisions. Surely it is possible to come together in ways that allow us to shape the conditions of our lives and challenge us to grow as moral beings, without the requirement that we defer to each other when deciding how to live or when and how to die. Shaping social structures and political institutions is one way of taking control of the conditions of our lives, but spending money is another, and it is one that typically does not involve deferring to anyone. While some individuals may prefer to control conditions by shaping social structures and political institutions, others prefer to do so by going to the supermarket or the big box retailer. Nor do we have to turn to communal deliberations if the domain of empathy, commitment, and responsibility for the future must be expanded beyond family and friends. Earning a living in one's community, serving in the military, and volunteering also strengthen the aforementioned capacities and involve little deliberation. As far as transcending one's individual existence, ancient religions would seem to be as good or better for that purpose than collective political decision-making.

There is no such thing as a political arrangement or institution that does not come with serious costs. Ongoing

disagreement and even prolonged suffering near the end of life are among the serious costs of liberal arrangements. Respecting the autonomy of incompetent patients does not conduce to clear-cut decisions that we can all feel good about, but that does not mean that the entire enterprise of respecting autonomy should be abandoned in favor of collective decision-making. On the assumption that the good is relative to individuals, deciding bioethical questions through a political process places our highest priorities in the hands of others who may or may not see any value in them. This would be one thing if we could reasonably expect our fellow deliberators to be interested in nothing but the greater good of the community as defined by universal agreement, but that is not a reasonable expectation if individuals are the basic units of value. As Edward Shils observed, "It would be contrary to the nature of man and the nature of society for all the members of society to possess to such a high degree the virtue of civility. Selfishness and parochiality are inexpungible from human life."<sup>55</sup> We see our own interests up close and those of others at a great distance, if at all. Under such conditions, something closer to the liberal arrangements rejected by Emanuel is clearly the lesser of the two evils. *Who decides* is not the key question when attempting to determine the appropriate ends of human life, but it should become the key question when no account of those ends can be found that proves more satisfactory to the individuals involved than the freedom to decide for themselves. Even if the individual is not in a good position to decide what she values, it does not follow that someone else or the entire community is in a better position to do so.

Santayana devised an ethical theory and succumbed to a natural blindness that have serious implications for medical decisions and healthcare policy. Neither the genius of his relational theory of value nor his inconsistency in later elevating his own values over those of others can be safely overlooked by policy-makers or the general public. Because we know from Santayana that values are relative to individuals, policy-makers should continue to uphold the principle of respect for autonomy, and we should all be inclined to support the liberal political arrangements that protect that principle. Santayana made the mistake of affirming the relativity of values to individuals, while at the same time attempting to evade some of the implications of such relativism. To him, the most bothersome implications were aesthetic: it was hard to get over the unpleasant appearance of the choices and behaviors of those who did not care for the life of reason. Emanuel found it impossible to affirm individual autonomy if that meant accepting prolonged suffering for patients and frustration for physicians while ethical controversies raged. Decent human beings ought to be troubled by human suffering in all of its forms, but that is precisely why we must devise policies that respect the limitations of human existence. If moral disagreement is rooted in individual natures, then our primary moral obligation is not to proceed as if disagreement can be eliminated. If we do so, we risk creating a greater amount of human suffering than existed previously. Bioethicists and health policy makers should study Santayana's relational theory of values, but those who are persuaded by Santayana's theory must also be willing to consistently affirm the principle of respect for autonomy

that his theory clearly supports. Even the best ethical theories cannot help us if we evade their implications.

**NOTES**

1. G. Santayana, *Reason in Society* (New York: Charles Scribner's Sons, 1919), 98.
2. *Ibid.*, 137.
3. *Ibid.*, 32.
4. G. Santayana, *Reason in Common Sense* (New York: Charles Scribner's Sons, 1917), 247.
5. *Ibid.*, 32.
6. *Ibid.*, 19.
7. *Ibid.*, 32.
8. *Ibid.*, 237.
9. G. Santayana, "Hypostatic Ethics" in *Winds of Doctrine* (New York: Charles Scribner's Sons, 1913), 148.
10. Santayana, *Reason in Common Sense*, 280.
11. *Ibid.*, 287.
12. *Ibid.*, 289.
13. *Ibid.*
14. *Ibid.*, 280.
15. *Ibid.*
16. Santayana, *Reason in Society*, 127.
17. *Ibid.*, 127.
18. *Ibid.*, 118.
19. *Ibid.*, 128.
20. E. Emanuel, *The Ends of Human Life: Medical Ethics in a Liberal Polity* (Cambridge, MA: Harvard University Press, 1991), 155.
21. *Ibid.*, 53.
22. *Ibid.*, 56.
23. *Ibid.*, 88.
24. *Ibid.*, 89.
25. *Ibid.*, 90.
26. *Ibid.*, 92.
27. *Ibid.*, 156.
28. *Ibid.*, 156–57.
29. *Ibid.*, 167.
30. *Ibid.*, 161.
31. *Ibid.*, 168.
32. *Ibid.*, 168–69.
33. *Ibid.*, 166.
34. *Ibid.*, 169.
35. *Ibid.*, 168.
36. *Ibid.*, 217.
37. *Ibid.*, 212.
38. *Ibid.*
39. *Ibid.*, 184.
40. *Ibid.*, 217.
41. *Ibid.*, 221.
42. *Ibid.*, 219.
43. *Ibid.*, 240.

44. *Ibid.*
45. *Ibid.*, 241.
46. *Ibid.*, 36–37.
47. *Ibid.*, 159.
48. *Ibid.*, 158.
49. *Ibid.*, 159.
50. *Ibid.*
51. *Ibid.*, 160.
52. *Ibid.*
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54. *Ibid.*
55. *Ibid.*, 350.

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## *Everything Has Its Price: The Question Is Where to Draw the Line. A Kantian Approach to Human Gene Editing*

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In the spring of 2015, a path-breaking technology called CRISPR/Cas9 changed the biotechnological landscape when Chinese researchers successfully modified the genetic code of a non-viable human embryo for the first time. The experiment sparked a debate on whether so-called human gene editing is an ethically justified way of enhancing human embryos. Aside from the risks possibly leading to a slippery slope towards "designer babies," the method promises to cure human diseases such as Huntington's, Beta-thalassemia, or sickle cell anaemia.

The new possibilities of editing the germline stress the need to specify what is desirable ethically to determine the tipping point between enhancement and endangerment. With respect to enhancing human embryos, it is not easy to define what we actually want to put into practice. In our everyday life, everything has its price. Cars, for example, pollute the environment, but we would never forbid them on the ground of that price alone. Rather, we would try to reduce their emissions because we consider cars crucially practical. Thinking about editing the human germline, then, we immediately see that there is much more at stake: besides other serious risks, human germline modifications are passed along to all future generations and at the current technological level, modifications cannot be undone. We

can sell our car if we wish, but we cannot get rid of germline modifications, or, at least, not yet.

The Chinese experiment shows the necessity to re-evaluate anthropological approaches to the bioethical debate. For the most part, approaches of philosophical anthropology do not play a key role in bioethics, where concepts like risk-benefit considerations and arguments based on “informed consent” are more common. Philosophical anthropology, however, lets us address the tipping point between enhancement and endangerment from a relational perspective. Such an undertaking has, of course, its own “blind spot”: Anthropology might define a “what,” a content of humanity. The relational perspective, though, has the advantage of making room to rethink the “how,” the modes of humanity without speaking of the human nature.

By considering Kant’s *Lectures on Anthropology from a Pragmatic Point of View* and his later writings on history, we are able to say more about the relational perspective. With Kant, the necessity of balancing the interrelations between nature, technology, and the future become obvious. The key word in this passage is “balancing.” It suggests drawing the tipping point in a relational way, to wit, in the already always entangled self- and world-relation. By doing so, we do not have to say that a certain specific technological means is unethical only because we cannot imagine its justified use from our current level. Thinking back to the times of the Industrial Revolution, trains were regarded as a danger and not even useful. But from our perspective today, we have good reasons to consider trains necessary. Therefore, the tipping point between enhancement and endangerment cannot lie in a fixed and stable line. Such a line is, rather, to be discussed at each step in a relational way, considering the interplay between nature, human beings, technology, and the future.

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## *Revisiting the Voluntary, Nonvoluntary, and Involuntary Euthanasia Distinction*

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Ethicists who consider the morality of euthanasia typically parse types of euthanasia using two distinctions. The first is the difference between active and passive euthanasia. The active/passive distinction receives a great amount of prominence in the literature. For example, the *Philosopher’s Index* finds 88 articles using the search criteria “euthanasia,” “active,” and “passive.”<sup>1</sup> The other distinction is among voluntary, nonvoluntary, and involuntary euthanasia. This distinction, while well established, is less prominent in the literature: a search of the *Philosopher’s Index* yields only 17 articles using the search criteria “euthanasia,” “voluntary,” and “nonvoluntary.”<sup>2</sup> While less prominent in the literature, the voluntary, nonvoluntary, and involuntary distinction is nonetheless useful when thinking about the

morality of different types of actions of euthanasia. This paper argues that while the voluntary, nonvoluntary, and involuntary distinction is a helpful one, it is not as fine-grained as it should be. Taking a cue from Helga Kuhse, it is argued that rather than a *three-fold distinction*, the voluntary, nonvoluntary, and involuntary distinction is better understood as a *six-fold distinction*, containing two subtypes each of voluntary, nonvoluntary, and involuntary euthanasia. Breaking the traditional three-fold distinction into six subtypes illuminates important moral differences. Insofar as some ethicists attempt to draw moral distinctions among these categories—arguing, for example, that some cases of voluntary euthanasia may be morally permissible, whereas no cases of involuntary euthanasia are morally permissible—a more nuanced distinction will forward the debate.

The first part of this essay presents a review of the distinction between voluntary, nonvoluntary, and involuntary euthanasia in recent literature. Most discussions adhere to the traditional three-fold distinction. The second part of the essay presents Kuhse’s contribution to the literature—namely, a six-fold distinction. However, while Kuhse references a six-fold distinction, she doesn’t explicitly spell out the differences among the different types of voluntary, nonvoluntary, and involuntary euthanasia. The six-fold distinction that Kuhse introduces is made explicit, including an elaboration of the circumstances in which each of these different types of euthanasia may be performed. Finally, the third part of the essay discusses the ways in which a utilization of a six-fold distinction advances the debate, by bringing additional nuance to what continues to be a controversial ethical issue.

### **PART ONE: THE DISTINCTION IN CONTEMPORARY LITERATURE**

The distinction among voluntary, nonvoluntary, and involuntary euthanasia is referenced in the literature, although it doesn’t receive the same level of scrutiny in the literature as the distinction between active and passive euthanasia. Byron J. Stoyles and Sorin Costreie present the distinction thus: “Euthanasia is said to be voluntary when the person to be euthanized requests or consents to be euthanized, involuntary when the person can but does not request or consent to be euthanized, and nonvoluntary when the person cannot request or consent to be euthanized.”<sup>3</sup> Their distinction mirrors that presented by Robert Young: non-voluntary euthanasia is “carried out when the subject is incapable of voluntarily agreeing to euthanased,” whereas involuntary euthanasia is “carried out when the subject is competent and has not voluntarily agreed to being euthanased.”<sup>4</sup> Young’s account is similar to Dan Brock’s: “My concern here will be with voluntary euthanasia only—that is, with the case in which a clearly competent patient makes a fully voluntary and persistent request for aid in dying. Involuntary euthanasia, in which a competent patient explicitly refuses or opposes receiving euthanasia, and nonvoluntary euthanasia, in which a patient is incompetent and unable to express his or her wishes, will be considered here only as potential unwanted side-effects of permitting voluntary euthanasia.”<sup>5</sup> Stoyles and Costreie argue that the above distinctions do not

adequately engage questions about the voluntariness of persons performing acts of euthanasia, healthcare providers or proxy decision-makers, and instead focuses almost exclusively on the voluntary consent of the person being killed. This is an odd focus, in their estimation, as it isn't in keeping with an Aristotelean account of voluntary action (action that originates in the agent) or involuntary action (action done under compulsion or owing to ignorance). The failure to focus on the voluntariness of the agent of the act of euthanasia, and instead to focus on the consent of the person being acted upon, has the odd result that it is not the *act of euthanasia* itself that is voluntary or involuntary; rather, it is the *consent to be acted upon* which is voluntary or involuntary. Stoyles and Costreie advocate for both a notion of *voluntary patiency*, and a greater emphasis on the voluntariness of the *healthcare provider* when performing acts of euthanasia.<sup>6</sup>

Another departure from the more common demarcation is presented by Kumar Amarasekara and Mirko Bagaric. These authors argue that the legalization of voluntary euthanasia may lead to the legalization of non-voluntary euthanasia, which they fear will ultimately be abusive. According to Amaresekara and Bagaric, voluntary euthanasia "involves a competent patient making a free and deliberate representation to a doctor to bring about an accelerated termination of her or his life."<sup>7</sup> By contrast, "Where there is a deliberate administration of life-shortening substances with an intention to cause death in order to end pain and suffering, it is non-voluntary euthanasia if the patient is incapable of consent,<sup>8</sup> because, for example, an irreversible coma or persistent vegetative state makes that person unable to communicate. Involuntary euthanasia takes place when death is caused contrary to the person's wish or where a competent person has made no request."<sup>9</sup> It is notable that Ameresekara and Bagric conflate voluntariness and non-voluntariness with active euthanasia—a conflation that doesn't appear elsewhere in the literature. However, with the exception of this conflation, it is clear that their demarcation among the three types turns on whether the patient offered actual consent, is incapable of consent, or there is an absence of consent from someone who is nonetheless capable of consent.

Len Doyal doesn't offer a definition distinguishing voluntary active euthanasia (VAE) and non-voluntary active euthanasia (NVAE), although he does offer examples:

Many reflective practitioners who support the legalization of VAE have reservations about taking the lives of those who have not executed relevant advance directive and who are defenseless to protect themselves through the exercise of their autonomy. . . . In my view, however, this emphasis on autonomy should be reconsidered in debates about euthanasia. The interest and needs of severely incompetent humans who may also be in the grip of intolerable suffering are just as important as those patients who are competent to control the circumstances of their death and wish to do so. Therefore, I believe that NVAE should also be legalized.<sup>10</sup>

Among those whom Doyal cites as "severely incompetent patients" who may be candidates for NVAE are those "suffering from such severe brain damage that they will never be able to engage in self-directed activity or social interaction."<sup>11</sup> Doyal makes two claims. The first is that there is a distinction between voluntary and nonvoluntary euthanasia—the former is performed on patients competent to make the decision to die at the time they are killed, whereas the latter is performed on anyone who is incompetent at the time he or she is killed. The second claim is that if voluntary euthanasia is legalized, so too should be nonvoluntary euthanasia.

The above examples from the literature are all fairly consistent in their portrayals of voluntary, nonvoluntary, and involuntary euthanasia. There are a few instances in the literature in which the distinctions between voluntary, nonvoluntary, and involuntary euthanasia are inconsistent with this consensus. As cited above, for example, there are some cases in which the voluntariness distinction is conflated with the active/passive distinction. Another erroneous characterization is Bertha Manninen's: "These concerns are perhaps reflective of what most people fear may happen if non-voluntary active euthanasia is made legal—that is, it would result in a type of involuntary euthanasia, where people who do not want to be killed, but who cannot express such a desire, are nevertheless killed."<sup>12</sup> Contra Manninen's claim, throughout the literature cases in which people are unable to express consent are characterized as *nonvoluntary* cases, and not *involuntary* cases. Strangely, elsewhere Manninen characterizes involuntary euthanasia *both* as cases in which "people will be euthanized 'for their own good' while actively begging not to be killed" as well as "when they are too incompetent to express their wishes: wishes that would have revealed their desire not to be euthanised."<sup>13</sup> Involuntary acts of euthanasia would thus include cases in which people ask not to be killed, but are killed anyway, as well as cases in which patients are killed in the absence of any consent. However, in keeping with most characterizations of nonvoluntary euthanasia, it is possible that a person who did not previously consent to being killed is killed, despite the fact that *he or she would have preferred not to be killed*. Nonvoluntary cases of euthanasia are those in which there is no consent either way—no assertion nor denial—because the person in question is incapable of consent.

In summary, then, the distinction among voluntary, nonvoluntary, and involuntary euthanasia, while not as prominent as the active/passive distinction, is nonetheless well known and is typically consistent across the literature. While there are a few notable deviations from the consensus about the distinctions, the overwhelming consensus is that voluntary cases are ones in which actual consent has obtained, nonvoluntary cases are ones in which there is no consent nor denial of consent, and involuntary cases are ones in which consent *can* be obtained, but there is no actual consent. However, this three-fold distinction may be too blunt a tool to adequately capture the moral subtlety behind controversial cases of euthanasia.

## PART TWO: AN ELABORATION OF KUHSE'S SIX-FOLD DISTINCTION

A more subtle distinction among voluntary, nonvoluntary, and involuntary euthanasia was made in 1991 by Helga Kuhse. The objective of this article is to credit her with this important insight, and, following her lead, to advocate for a more nuanced distinction than the traditional three-fold distinction.

Kuhse sets up her discussion of voluntary, nonvoluntary, and involuntary euthanasia with the presentation of a case, and a subsequent discussion:

Mary F. was dying from a progressively debilitating disease. She had reached the stage where she was almost totally paralysed and, periodically, needed a respirator to keep her alive. She was suffering considerable distress. Knowing that there was no hope and that that things would get worse, Mary F. wanted to die. She asked her doctor to give her a lethal injection to end her life. After consultation with her family and members of the health-care team, Dr. H. administered the asked-for lethal injection, and Mary F. died.

The case of Mary F. is a clear case of voluntary euthanasia; that is, euthanasia carried out by A at the request of B, for the sake of B. There is a close connection between voluntary euthanasia and assisted suicide, where one person will assist another to end her life—for example, when A obtains the drugs that will allow B suicide.

Euthanasia can be voluntary even if the person is no longer competent to assert her wish to die when her life is ended. You might wish to have your life ended should you ever find yourself in a situation where, whilst suffering from a stressing and incurable condition, illness or accident have robbed you of all your rational facilities, and you are no longer able to decide between life and death. If, such as this, then the person who ends your life in the appropriate circumstances acts upon your request and performs an act of voluntary euthanasia (sic).

Euthanasia is *non-voluntary* when the person whose life is ended cannot choose between life and death herself—for example, because she is hopelessly ill or handicapped newborn infant, or because illness or accident have rendered a formerly competent person permanently incompetent, without that person having previously indicated whether she would nor would not like euthanasia under certain circumstances.

Euthanasia is *involuntary* when it is performed on a person who would have been able to give or withhold consent to her own death, but has not given consent—either because she was not asked, or because she was asked but withheld consent, wanting to go on living. Whilst clear

cases of involuntary euthanasia would be relatively rare (for example, where A shoots B without B's consent to save her from falling into the hands of a sadistic torturer), it has been argued that some widely accepted medical practices (such as the administration of increasingly large doses of pain-killing drugs that will eventually cause the patient's death, or the unconsented-to withholding of life-sustaining treatment) amount to involuntary euthanasia.<sup>14</sup>

Unlike Stoyles and Costreie, Young, Amarasekara and Bagaric, Doyal, and many others, Kushe makes a more subtle distinction among *two types* of voluntary euthanasia, *two types* of nonvoluntary euthanasia, and *two types* of involuntary euthanasia. Below, each of these six different types of euthanasia is spelled out in turn.

In presenting the below distinctions, "P" is used to identify a person, and "C" to identify some medical circumstances (a terminal illness, persistent vegetative state, etc.). The distinctions are initially presented without remarking on the moral normative status of any of these acts of euthanasia. After the presentation of each of the six types, a short discussion will address questions of morality that may be illuminated by employing the below six-fold distinction.

### TWO TYPES OF VOLUNTARY EUTHANASIA

*Voluntary1: P is competent to consent to being killed in circumstance C; C obtains; P requests to be killed, and P is killed.* This is comparable the type of legalized physician assisted suicide in Oregon and Washington State as well as the legalized euthanasia in the Netherlands, in which autonomous persons consent to be killed at the time that they are killed. Some of the complex questions about consent—What if the person changes his/her mind? How do we know if this is what the person would have really wanted?—are not raised in voluntary1 euthanasia, because consent from an autonomous individual occurs at the time that the person is killed. As such, voluntary1 euthanasia is typically understood as the least controversial type of euthanasia.

*Voluntary2: P is competent to consent to being killed in circumstance C prior to C obtaining; P requests that if C obtains, that P be killed; C obtains, and P is killed.* Cases of voluntary2 euthanasia include cases in which a living will or advance directive, agreed to by P, states that life-support should be withdrawn in the case of C. In all cases of voluntary2 euthanasia, P was a previously autonomous individual who was capable of consenting to being killed prior to C. If P loses his/her ability to consent, but a living will or advance directive is in place, then voluntary2 euthanasia proceeds on the assumption that P's prior wishes should dictate what should happen to P. Note that if a living will or advance directive is in place, but P is competent to make choices and is asked directly for those choices, bypassing the written documentation, this would be an instance of voluntary1 euthanasia.

### TWO TYPES OF NONVOLUNTARY EUTHANASIA

*Nonvoluntary1: P was previously able to consent to being killed in circumstance C; P doesn't previously consent to being killed in circumstance C; C obtains, and P is killed.* These types

of cases, in which previously autonomous individuals have not explicitly requested to be killed in C, are often fraught. It is notable that in nonvoluntary<sup>1</sup> cases *it is not the case* that P had previously *denied* consent. However, it is not the case that P had previously consented either. The high-profile cases of Karen Quinlan, Nancy Cruzan, and Terri Schiavo are all examples of nonvoluntary<sup>1</sup> euthanasia. In none of these cases did the women have an advance directive or living will in which they explicitly consented to termination of life support given their medical circumstances. They may have offered consent, and they may not have, had they been in the position to offer consent.

In lieu of actual consent, cases of nonvoluntary<sup>1</sup> euthanasia often rely on the consent of a surrogate decision-maker. In the case of nonvoluntary<sup>1</sup> euthanasia, two possible standards can be employed by surrogates to justify the killing of P in C. The first is a substituted judgment standard. Here, proxy decision-makers who knew P's beliefs and preferences state what P would have consented to, had P been able to consent. The substituted judgment standard attempts to replicate what P's autonomous decision would have been, so that others can act on that decision. The substituted judgment standard can only be used with persons who were previously autonomous. It doesn't make sense to talk about the beliefs and preferences of persons who were not previously able to have those beliefs and preferences. The second standard is a best interest standard. Here, the individual who performs euthanasia on P acts in keeping with what is in the best interest of P. For example, the healthcare team may not know what P's beliefs and preferences are, although it may be safe to believe that P had some beliefs and preferences, given that P was formerly able to consent to being killed. However, in the absence of information about P's beliefs and preferences, decisions may be made solely on the basis of what is in the best interest of P. Some commentators believe that the substituted judgment standard, which appeals to the principle of autonomy, should take precedence over the best interest standard, which appeals to the principles of beneficence and nonmaleficence. For example, Allen E. Buchanan and Dan W. Brock claim "Where sufficient evidence is lacking to exercise substituted judgment, the proxy ought to rely on the best interest standard."<sup>15</sup> In other words, only in the *absence of the ability to make an informed substituted judgment* should proxy decision-maker employ a best interest standard.

*Nonvoluntary<sup>2</sup>: P was not previously able to consent to being killed in circumstance C; C obtains, and P is killed.* In nonvoluntary<sup>2</sup> cases, P was not previously autonomous, such that P was unable to consent to being killed. Infants, such as those killed according to the Groningen Protocol,<sup>16</sup> or persons with cognitive disabilities that affect decision-making capacity, would be candidates for nonvoluntary<sup>2</sup> euthanasia. An important distinction between nonvoluntary<sup>1</sup> and nonvoluntary<sup>2</sup> is that in the former, a substituted judgment may be employed to justify the act of euthanasia. However, in the case of nonvoluntary<sup>2</sup>, it makes no sense to discuss what P *would have wanted*, given that P previously did not have beliefs or preferences about his/her situation in C. As such, only a best interest standard applies in nonvoluntary<sup>2</sup> cases.<sup>17</sup> In nonvoluntary<sup>2</sup> cases healthcare

professionals, parents, or loved ones of P may appeal only to beneficence or nonmaleficence when determining what should be done in C.

## TWO TYPES OF INVOLUNTARY EUTHANASIA

*Involuntary<sup>1</sup>: P is able to consent to being killed in circumstance C; C obtains; P is not asked for consent to be killed, and P is killed.* Kuhse cites some cases of palliative sedation as cases of involuntary<sup>1</sup> euthanasia. One can imagine a case in which a patient is given both life-sustaining therapies and significant palliative drugs for a painful and ultimately terminal disease. The drugs relieve the pain, but they also have significant impact on P's cognitive abilities, rendering P unable to consent or deny consent to any medical intervention. On one hand, the healthcare team could temporarily remove the palliative medications, thereby restoring P's cognitive capacities long enough to allow P to consent to removal of life-sustaining therapies. On the other hand, it may be cruel to remove the pain medication, if, for example, the family members were secure in their substituted judgment that if P were able to consent, then he/she would consent to the removal of the life-sustaining therapy. Removal of the life-sustaining therapy in this case, in the absence of consent that could be procured, would be an action of involuntary<sup>1</sup> euthanasia. It is important to note that what distinguishes this case from a case of nonvoluntary<sup>1</sup> euthanasia is that in the above described case of involuntary<sup>1</sup> euthanasia, there is a possibility of getting consent from P. In a nonvoluntary<sup>1</sup> case, there is no possibility of procuring consent from P.

*Involuntary<sup>2</sup>: P is able to consent to being killed in circumstance C; C obtains; P is asked for consent to be killed, P denies consent to be killed, and P is killed.* Intuitively, many recognize involuntary<sup>2</sup> euthanasia as murder. P was asked for consent, explicitly denied consent, but is killed anyway. Even if the other aspects of the killing were consistent with euthanasia—that P was suffering from a terminal condition, that killing P was done so as to promote a good death for P, that P's death was performed in the least painful way possible—the fact that P explicitly refused consent is sufficient to determine that the action was not morally right. The fact that consent, or the denial of consent, carries so much moral weight here is significant.

## DISCUSSION

Kuhse's six-fold distinction focuses primarily on modalities of consent, or the lack thereof, on the part of P. For those who see a downward level of moral permissiveness—in which voluntary<sup>1</sup> is less problematic than voluntary<sup>2</sup>, which is in turn less problematic than nonvoluntary<sup>1</sup>, etc., and so on through each of the six types, bottoming out at involuntary<sup>2</sup> which is clearly morally wrong—the distinctions between what is and what is not morally acceptable are cashed out in terms of consent. This is why creating a six-fold distinction is more helpful than the traditional three-fold distinction: There may be differences in the moral status within the three-fold categories that are more clearly illuminated when six categories are employed. For example, questions may emerge in voluntary<sup>2</sup> cases (What if P changed his mind? How could P truly make an informed decision about C, if P had never experienced C before?) that don't emerge in voluntary<sup>1</sup> cases.

Similarly, drawing a distinction between the two types of nonvoluntary euthanasia is helpful when making moral determinations. The Groningen Protocol proved to be far more controversial than cases of euthanasia of previously competent persons. That is precisely because well-argued-for substituted judgments often carry more weight than do claims about the best interest of individuals. In light of the distinction between the cases in which a substituted judgment may be available and those in which no substituted judgment is conceivable, it makes sense to draw the nonvoluntary<sub>1</sub> and nonvoluntary<sub>2</sub> distinction, and recognize that the distinction carries significant moral weight.

In focusing primarily on P's consent, or lack thereof, the six-fold distinction does not engage the choices of healthcare providers or proxy decision-makers, except insofar as they are articulating either substituted judgments on behalf of P, or what is in P's best interest. Per Stoyles and Costreie, this is perhaps too narrow a focus. We do not disagree with Stoyles' and Costreie's insight; the voluntariness of the action of the healthcare provider has been a neglected topic in discussions of euthanasia. However, their position doesn't undermine our contention that Kuhse's six-fold distinction is more illustrative of different types of euthanasia than the traditional voluntary, nonvoluntary, involuntary distinction.

Stoyles and Costreie observe that "voluntary euthanasia is considered to be less controversial than involuntary or nonvoluntary euthanasia. In part, we suppose, this is because people are more comfortable ending a person's life when that person requests to be euthanized than when no such request is made by the patient."<sup>18</sup> At the same time, they hold that too great an emphasis on consent from P can obscure the value that *should* guide the choice to perform an action of euthanasia: namely, what is in P's best interest. Consent is of value primarily as a means of determining what it is in P's best interest—because P is most often best able to determine what that is. But consent is merely, in their estimation, one of several means to determine what is in P's best interest. As such, undue focus on consent in euthanasia creates a false distinction between voluntary and nonvoluntary cases of euthanasia.

This position is in contrast, according to Young, with the position of John Keown. Young summarizes Keown's position as one that finds arguments from best interest of P to be problematic, precisely because they allow a slippery slope from voluntary<sub>1</sub> cases of euthanasia all the way down to nonvoluntary<sub>2</sub> cases, and possibly involuntary<sub>1</sub> cases. If autonomous decision-making is only useful as a guide to what is ultimately in P's best interests, then nonvoluntary<sub>2</sub> cases, such as those in the Groningen Protocol, or involuntary<sub>1</sub> cases of palliative sedation, are no less morally challenging than voluntary<sub>1</sub> cases. However, in the absence of a six-fold distinction, the slippery slope that Keown is worried about isn't as clear.

Keown's contention illuminates that a six-fold distinction allows for a more nuanced debate among the different types of voluntary, nonvoluntary, and involuntary euthanasia than the traditional three-fold distinction. We

advocate strongly for the incorporation of Kuhse's six-fold distinction in future discussions of euthanasia, so that the above debates can better home in on true moral claims. The topic of euthanasia is fraught enough without further muddying the waters with vague distinctions that do not adequately capture the subtle ethical distinctions among different acts of euthanasia.

#### NOTES

1. Search performed June 24, 2015.
2. Search performed June 25, 2015.
3. Stoyles and Costreie, "Rethinking Voluntary Euthanasia," 674.
4. Young, "Debating the Morality and Legality of Medically Assisted Dying," 152.
5. Brock, "Voluntary Active Euthanasia," 10–11.
6. Stoyles and Costreie, "Rethinking Voluntary Euthanasia," 687.
7. Amaresekara and Bagaric, "Moving from Voluntary Euthanasia to Non-Voluntary Euthanasia," 402.
8. Giesen, "Dilemma's at Life's End: A Comparative Legal Perspective," 202.
9. *Ibid.*, 402–03.
10. Doyal, "Dignity in Dying Should Include the Legalization of Non-Voluntary Euthanasia," 65.
11. *Ibid.*
12. Manninen, "A Case for Justified Non-Voluntary Active Euthanasia," 649.
13. *Ibid.*, 650.
14. Kuhse, "Euthanasia," 295–96."
15. Buchanan and Brody, *Deciding for Others*, 112.
16. Manninen, "A Case for Justified Non-Voluntary Active Euthanasia."
17. *Ibid.*, 645.
18. Stoyles and Costreie, "Rethinking Voluntary Euthanasia," 678.

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## *Balancing Parental Autonomy and Harm to Others in the Wake of the Modern Anti-Vaccination Movement*

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In 2015, an unvaccinated six-year-old boy in Catalonia, Spain, died from diphtheria, a bacterial infection that affects the nose and throat. It was the first death from the disease Spain had experienced in three decades, and the child's parents expressed horrible guilt, saying they were "'destroyed and felt cheated' by the anti-vaccination movement that convinced them not to immunize their son."<sup>1</sup> In 2014 in California, over 100 people who either had visited or worked in Disneyland contracted measles. According to the Center for Disease Control:

Among the 110 California patients, 49 (45%) were unvaccinated; five (5%) had 1 dose of measles-containing vaccine, seven (6%) had 2 doses, one (1%) had 3 doses, 47 (43%) had unknown or undocumented vaccination status, and one (1%) had immunoglobulin G seropositivity documented, which indicates prior vaccination or measles infection at an undetermined time. Twelve of the unvaccinated patients were infants too young to be vaccinated. Among the 37 remaining vaccine-eligible patients, 28 (67%) were intentionally unvaccinated because of personal beliefs, and one was on an alternative plan for vaccination.<sup>2</sup>

All reputable scientific data supports the conclusion that vaccines are effective at significantly curtailing contagious diseases with minimal adverse consequences. In the United States, the measles had been declared eradicated in 2000 because of routine childhood vaccinations, and has only recently resurged given the decline in community (or herd) immunity brought about by unvaccinated children and adults. Other vaccine preventable illnesses, such as chicken pox and pertussis, have also made a comeback given decreased vaccination rates.

As a response to California's measles outbreak, lawmakers in the state have eradicated religious and so-called "philosophical" or "personal belief" exemptions for parents when it comes to vaccinations for school-aged children (medical exemptions still apply). According to Senate Bill 277, as of July 1, 2016, any child attending either a public or private school or daycare facility will be required to show proof of vaccinations. Children who are not vaccinated will have to be homeschooled. Predictably, the bill has drawn the ire of those who argue that it violates parental autonomy. Republican representative Chad Mayes criticized the bill as "an unjustified intrusion into the rights of parents to raise and nurture their children the way they see fit."<sup>3</sup> In 2015, other U.S. states passed similar laws curtailing exemption loopholes for childhood vaccinations. Vermont was the first state to repeal the "philosophical" exemption. West Virginia requires that all medical exemption requests be certified by a licensed physician. Alabama, Alaska, Delaware,

Washington DC, Iowa, Georgia, and Kansas, amongst many other states, have eradicated "philosophical" exemptions altogether, and make securing religious exemptions much more difficult.

In this paper, I will argue that California's (and any other state's similar attempts) move to curtail religious or philosophical exemption clauses when it comes to common childhood vaccines, such as the MMR (measles/mumps/rubella) vaccine, is justified. Such laws, while significantly restricting parental choice, does not eradicate it altogether, and goes a long way to protecting innocent third parties who should not be subjected to injury because of other people's healthcare choices. To be sure, parental autonomy is an important liberty right that we should strive to protect as much as possible, and the goal of this paper is not to contradict this. Rather, I would like to use the recent anti-vaccination movement as an avenue to explore the balance between respecting individual choice, particularly parental choice, and protecting public welfare.

### **HARM TO OTHERS**

In John Stuart Mill's *On Liberty*, he argues that there is only one circumstance in which the state may rightly limit the liberty of their citizens:

The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. . . . The only part of the conduct of anyone, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.<sup>4</sup>

It is not difficult to see how California's SB 277 can be justified using Mill's harm principle. Excluding, for now, the welfare of the children whose parents have chosen not to vaccinate them (this will be explored below), it is imperative to consider the welfare of persons who *cannot*, for medical reasons, be vaccinated. These individuals are either too young to be vaccinated (infants under 12 months of age, for example, cannot receive the MMR vaccine), or are battling diseases that have rendered them immunocompromised. Moreover, even those who have been vaccinated do not enjoy complete immunity. One dose of the MMR vaccine is approximately 93 percent effective at preventing measles upon exposure—two doses raises this number to 97 percent. Herein lies the benefit of community immunity—if the majority of the people in a society are vaccinated against a disease, it makes it extremely unlikely that the disease will infiltrate that society. However, in order for community immunity to be effective, a good portion of that community—over 90 percent—must be vaccinated. This number has been declining as a result of the modern anti-vaccination movement.

In 1905, the United States Supreme Court ruled in *Jacobson v. Massachusetts* that states are authorized to enact or enforce compulsory vaccination laws. Henning Jacobson refused to subject himself to the smallpox vaccination, despite the order for all adults to receive the vaccination given an

outbreak of smallpox in his town. Jacobson argued that the Fourteenth Amendment to the Constitution gave him the right to refuse vaccinations. The Supreme Court rejected the contention that liberty rights are categorical—in a tacit appeal to the harm principle, they ruled that states have the authority to curtail liberty rights when it is necessary to do so in order to promote the general welfare.<sup>5</sup> In 1922, a similar conclusion was reached in *Zucht v. King*, where the Supreme Court ruled that states had the right to prevent unvaccinated children from attending either public or private schools. The court reaffirmed that “it is within the police power of a state to provide for compulsory vaccination.”<sup>6</sup>

One of the main concerns in eradicating religious exemptions is that doing so violates the Free Exercise Clause of the Constitution. However, when religious practices have interfered with the health interests of others, typically the latter has proven to be the more stringent interest. Consider cases where sick children are not medically treated because their parents, being members of the Christian Science church, opted for faith healing instead. In several of these cases, “the State, in the role of *parens patriae*, will attempt to override the parents’ constitutional rights in an effort to save the child’s life.”<sup>7</sup> Despite the fundamental importance of the right to religious liberty as enshrined in the United States Constitution, courts have not shied away from charging parents, often with involuntary manslaughter or child neglect, if a child under their care dies as a result of prayer or spiritual healing being used *in lieu* of medical care.<sup>8</sup> The state has also exercised *parens patriae* when it comes to the children of Jehovah’s Witnesses whose parents refuse to approve a blood transfusion given the belief that the consumption of foreign blood violates God’s will. Often, doctors or medical staff will seek a court injunction allowing them to treat the child with a blood transfusion regardless of parental consent.<sup>9</sup>

The problem, however, is that these examples do not provide clear guidance when it comes to the vaccination issue. In the abovementioned cases, the children put at risk as a result of their parents’ religious beliefs were experiencing afflictions that posed a *clear and immediate* threat to their health. The same cannot be said of vaccinations. Vaccines are typically administered as a kind of preventative treatment, not a curative one. Even though a society with a low vaccination rate is at a higher *risk* of contracting certain diseases, it is (slightly) possible that no one will *actually* contract the disease, and if they do, they may not suffer irreparable health damages as a result. While it may be permissible to violate personal or religious liberty when the alternative is certain and immediate death or harm of a third party, it is harder to justify violating liberty when the danger is not as immediate or as threatening. The pertinent question, then, is just *how* immediate the threat has to be in order to justify a violation of these liberties, and whether low vaccination numbers constitute a sufficient threat.

The Harvard Law Review Association provides some guidance in this regard. One significant observation they make is that “vaccines have become a victim of their own success. Vaccination has substantially obliterated many diseases in this country to the point where new generations of Americans are totally unaware of them, unlike earlier

Americans who lived through the epidemics.”<sup>10</sup> All it really takes is a child dying from a vaccine preventable illness, like the little boy in Catalonia, or the three infants in 2014 who died from pertussis (whooping cough) in California, to be reminded of the terrible and irreparable damage that can come from a resurgence of once-eradicated diseases. According to the Harvard Law Review Association, if enough people are vaccinated so as not to compromise community immunity, it would be unwarranted to limit religious and parental liberty. While the danger of contracting a disease will always exist even if everyone is fully vaccinated, “so long as herd immunity is preserved, the imprecise nature of these exemptions does not really threaten public health.”<sup>11</sup> However, once voluntarily vaccination drops so low as to weaken the populace’s immunity, and once the diseases start infiltrating the community as a result, the Harm Principle can begin to apply, and certain liberties can begin to be limited in order to protect others from what is now a more immediate threat. The Harvard Law Review Association notes that one of the reasons *Jacobson* was decided in favor of the state was because “vaccination was necessary because there were no other reliable options to preserve public health.”<sup>12</sup> When the state reacts fast to an impending epidemic, it can effectively save many more lives: “The 1918 influenza epidemic . . . is an example. Recent studies have shown that the cities and towns that most quickly enacted quarantines and medical isolations had lower death rates than those that were slow to act.”<sup>13</sup>

It is important to remember that SB 277 does not entail some despotic consequence where a child can be forcibly removed from the home and be vaccinated against her parents’ wishes. What SB 277 effectively accomplishes is limiting the exposure unvaccinated children have to other children by curtailing access to schools and daycares. Parents can still choose to not vaccinate their child, but as a consequence they would have to be homeschooled. While this does substantially increase the burden on parents who choose not to vaccinate, it does not eradicate choice altogether. Given the measles and pertussis epidemic in California, this illustrates that voluntary vaccination measures were insufficient for preserving strong community immunity. SB 277, while being a more coercive measure, still preserves some element of religious liberty and parental autonomy, while preventing harm to vulnerable others.

### “MY CHILD, MY CHOICE”

One study surveyed online chat forums concerning the modern anti-vaccination movement and found that most people in favor of vaccinations emphasized social responsibility and the importance of vaccination for protecting others: “The participants who made these criticisms urged parents with ‘no excuse’ for not immunizing to get their children ‘done’ *for the benefit of society as a whole*, and for particular vulnerable groups: children who could not be vaccinated for medical reasons; children who were too young to be vaccinated; and the unborn children of unvaccinated pregnant women.”<sup>14</sup> While, indeed, the effects on the general population, and these particular vulnerable persons, are vitally important to consider, absent from these concerns is the welfare of the unvaccinated child herself.

While in a certain sense children “belong” to their parents, they are not private property—their interests cannot be cashed out solely through the interests of their parents. Children have interests of their own, which are threatened when a parent chooses to not vaccinate them. Parental autonomy *is* a significant aspect of liberty, and one that should be infringed upon as little as possible. Parents, more often than not, make decisions for their children out of love and care. As Jennifer Rosato puts it, deference to them, and to family in general, when making important medical decisions “directly furthers beneficence . . . family members should be permitted to make health decisions because they are able to further the patient’s best interests.”<sup>15</sup> Nevertheless, parental autonomy is not categorical. Rosato argues that there is nothing *inherent* in familial relationships, including parent-child ones, that always render family members the best, or sole, decider for medical decisions. While she does argue that “parents should retain their status as primary decision-makers for their children,”<sup>16</sup> this is only because doing so typically results in the best consequences for the children. We should defer to parental autonomy “as long as the interests of a patient . . . are adequately protected.”<sup>17</sup>

While parents who subscribe to the anti-vaccination movement are often ill informed about the effectiveness and side-effects of vaccinations, they cannot be described as neglectful in the commonly understood sense of the term. Rather than *ignoring* their child’s well-being, they really believe that not vaccinating their child *is* preserving her well-being. Consider Sally Kohn’s experience when she initially chose not to vaccinate her daughter. Kohn and her partner cannot be described as neglectful; quite the opposite is true: “We were also singularly, obsessively concerned with the health and safety of our baby girl. Suddenly my partner and I were solely in charge of an entire human being, one who seemed somehow more fragile than other babies we’d known, because this one was relying on no one but us for her sustenance and survival.” Their reasons for not trusting vaccines stemmed from a larger mistrust of the government in general: “the same people who worry about hormones in meat and pesticides on vegetables. We’ve been told by our industry-cozy government that these things aren’t toxic, but we suspect that’s not right. We seek out farm-to-table food and even organic baby wipes as a prudent expression of that caution and care. Why trust the government and pharmaceutical industry when it comes to vaccines? That skepticism doesn’t seem selfish, but smart. Until it isn’t.” Ultimately, Kohn and her partner vaccinated their daughter due to them taking her abroad to India, and she now agrees that “being vaccinated is a civic and community responsibility.”<sup>18</sup>

Parents who choose not to vaccinate are often surprised if their child actually contracts the diseases that vaccinations protect against, and feel guilt when they do so. In addition to the example that begun this paper, there is the case of Alijah Williams, who ended up with a severe tetanus infection, so much so that he was put in a medically induced coma so as to given him respite from his suffering. As his parents now admit: “We felt terrible . . . it was very obvious that we had made a mistake. . . . The mistake that we made was that we underestimated the diseases and we totally

over-estimated the adverse reactions.”<sup>19</sup> There is also the case of five-year-old Abigail Peterson, who died in 2001 of chicken pox and pneumonia; she had not been vaccinated against either one. It was later discovered she had been born without a spleen, and her immune system was therefore compromised. Her mother is now a passionate advocate for vaccinations.<sup>20</sup> In his autobiography, Benjamin Franklin reveals that he felt a deep remorse after his four-year-old died of smallpox because he had not inoculated him:

This I mention for the sake of parents who omit that operation, on the supposition that they should never forgive themselves if a child died under it, my example showing that the regret may be the same either way, and that, therefore, the safer should be chosen.<sup>21</sup>

What we have to balance here, therefore, is what to do in situations where extremely well-intentioned parental autonomy conflicts with the child’s best interests. While life-threatening afflictions may warrant violating parental autonomy and treating a child against a parent’s will, it is much harder to justify forcibly vaccinating a child against her parent’s will when the child is not in any immediate medical danger. However, that’s precisely the difficulty when one chooses to not vaccinate their child: we do not *know* whether illness, injury, or death will result, and by the time the child contracts the disease, it may not always be possible to save her. This uncertainty simultaneously makes it more difficult to require compulsory vaccinations, and yet also more difficult to *not* act in some way to prevent what would be a tragedy. What we need to concentrate on, therefore, are ways to increase voluntary vaccination participation among skeptical parents.

### SUGGESTIONS FOR WAYS FORWARD

In this section I will discuss two suggestions for raising voluntary vaccination rates: relying on healthcare professionals and the media to increase educational outreach regarding vaccines, and implementing burdensome policies, such as SB 277, that would require parents to carefully consider how far they are willing to take their anti-vaccination stance.

Drs. C. Mary Healy and Larry Pickering argue that the media, particularly internet news sites, have failed to convey the safety of vaccines to the general public, and oftentimes will devote an equal amount of time to reporting scientifically questionable studies on vaccines in tandem with scientifically legitimate ones.<sup>22</sup> Lewandowsky et al. also note the role that the media plays in agitating vaccine hesitancy by giving the erroneous impression that the effectiveness and safety of vaccines is an issue on which there is substantial division:

On certain hotly contested issues, there is evidence that the media have systematically overextended the “balance” frame . . . this asymmetric choice of “experts” leads to the perception of a debate about issues that were in fact resolved in the relevant scientific literature long ago.<sup>23</sup>

Additionally, Healy and Pickering note that there is difficulty in communicating with parents who lack a medical or scientific background because “definitive studies often use scientific language and terms that are familiar to physicians and scientists but are confusing for parents who are trying to process the information.”<sup>24</sup> They also highlight the power of emotional anecdotal experience: “A 30-second clip of a child allegedly damaged by vaccines exploits every parent’s worst fears and is more compelling than clips that detail the reduced incidence or elimination of infectious diseases of which many parents have never heard, much less seen.”<sup>25</sup>

Healy and Pickering focus on helping healthcare providers talk to vaccine-hesitant parents, including admitting that vaccines *can* cause some adverse reactions, but that this needs to be balanced against the risks associated with contracting the disease.<sup>26</sup> In addition, providers should target other fears that have fueled the anti-vaccination movement. For example, some parents worry about vaccines containing thimerosal and the chemical’s link to autism; providers should not dismiss that worry, but, rather, highlight that the chemical has been removed from vaccines as a precautionary measure, even though multiple studies revealed no causal connection to autism. Another worry that some parents have is that a child’s immune system could become “overwhelmed” as a result of too many vaccines being given at once; medical providers need to emphasize there is no evidence that this “overwhelming” occurs.

In light of their multiple studies concerning vaccine hesitancy amongst parents, E. Allison Hagood and Stacy Mintzer Herlihy emphasize how vital it is to provide appropriate and accessible education about vaccines, noting that this

must be the work not only of pediatricians but also of nurses and other HCPs, pre-natal educators, public health advocates, media representatives and other societal stakeholders . . . every healthcare worker should be prepared to serve as a vaccine educator and advocate. A phone call to a nurse practitioner or a consultation with a lactation specialist can all become opportunities for alleviating parents’ fears and misconceptions regarding vaccines. In our experiences, some parents have responded better to another parent’s experiences and reassurance, while others have appreciated a more academic or scientific explanation of why it is easy to develop fears regarding vaccines when misinformation is presented without statistical context. Receiving consistent and accurate vaccination information from multiple sources would drive home the accurate message that vaccines are safe and save lives.<sup>27</sup>

These educational suggestions, however, need to extend beyond just healthcare providers; as Hagood and Herlihy note, media representatives need to take a more active role in trying to help fix a problem that they have helped create. A widely disseminated media campaign should be implemented that distributes information about vaccines in an accessible manner to the general public, one that invites

discussion and education concerning parental fears. It is also imperative that the media stop portraying vaccination safety and efficacy as a “controversial issue,” and that, when they do,

HCPs, public health advocates and vaccine advocates all need to become more pro-active at addressing the media’s continuing efforts to paint vaccination as problematic or controversial. This involvement must take the form of letters to editors, opinion pieces submitted to popular media, comments on public forums regarding scientific information, and other forms of social and mass media participation.<sup>28</sup>

The effect that the media can have on shaping public opinion cannot be denied. Just as easily as they create fear and anxiety when it comes to healthcare issues (one only needs to remember the sensationalistic media reports over the alleged U.S. “Ebola outbreak” in 2014), they can combat against it. Take, as an example, the United States Agency for International Development’s VISION Project, which utilized the media in Nigeria to increase HIV/AIDS awareness and prevention. A 2006 study illustrated that the increase in condom use for individuals exposed to this media was slight, but nevertheless promising; indeed, the authors recommended that increasing “programmatically efforts be continued, scaled up, and done in conjunction with other interventions.”<sup>29</sup> A 2008 study illustrated a reduction in adult smoking prevalence after exposure to anti-smoking mass media campaigns.<sup>30</sup> A 2002 study found a similar result in reference to youth smoking practices,<sup>31</sup> as did a 2004 study on the reduction of youth smoking due to the “Truth” tobacco counter-marketing campaigns.<sup>32</sup>

Media exposure can also serve to humanize problems that may seem otherwise abstract. In the 1980s in the U.S., 18-year-old Ryan White challenged the stereotypical view of AIDS patients, and had a great impact on AIDS education, before he passed in 1990 from the disease. Four months after he died, the United States Congress passed the Ryan White Care Act, which funds HIV/AIDS treatment for low-income or uninsured patients. White became the “face” of the HIV/AIDS epidemic in America and, aided immensely by media exposure, helped change many views and fears regarding the disease. Thomas Brandt, the spokesman for the National Commission on AIDS, explained White’s influence thusly: “After seeing a person like Ryan White—such a fine and loving and gentle person—it was hard for people to justify discrimination against people who suffer from this terrible disease.” After a paltry show of support of HIV/AIDS patients by President Ronald Regan, Republican predecessor George H. W. Bush planted a tree in White’s honor once he passed and said, “Ryan’s death reaffirms that we as a people must pledge to continue the fight, his fight, against this dreaded disease.”<sup>33</sup> White’s struggle humanized the fight against AIDS in a way that had not been achieved before, mostly because many wrote the disease off as something limited to promiscuous homosexual men who “deserved” what they got. White not only combatted that stereotype, but also spoke out against the view that anyone “deserved” to die from AIDS.

Similarly, using the media to publicize stories of children who have suffered or died from vaccine-preventable illnesses may serve to put a real face on the consequences of the anti-vaccination movement. Although there have always been groups of individuals suspicious about vaccinations, the number of individuals opting-out “was not so severe when parents often saw children who were harmed by the diseases we vaccinate against and understood the risk facing their own children.”<sup>34</sup> That risk needs to be re-emphasized in a way that will pack an emotional punch. The Facebook page *Light for Riley* has been conducive to this goal by sharing the tragic story of Riley Hughes, who died when he was just four weeks old from pertussis. Riley’s parents note that “we seek to educate people about the dangers of whooping cough, and positively promote the need for vaccination.” Linda Anderson’s son, Phoenix, died in 2005 when he was seven months old due to the Strain B version of *Neisseria meningitidis*; while a vaccine exists now for the disease, it did not back then. Anderson writes:

As I read about the measles outbreak spreading across the nation now, I can’t help but think that we’ve simply forgotten. We don’t see these diseases anymore; they don’t seem real. I know that the parents who choose not to vaccinate their children truly believe they are doing what is best for them. They love their children as much as I do. But what I want them to know is that I would give anything—I would trade all the rest of my life to go back in time for the chance to give Phoenix the vaccine that would have saved his life. It is real for my husband and me in a way that I never want anyone else to have to know.<sup>35</sup>

The website *ShotByShot.org* features a collection of stories of individuals who suffered from vaccine-preventable illnesses. Judith Beatty shares her experiences as a six-year-old girl who contracted polio in 1949, was quarantined from her family, had to wear a leg brace for seven years, and still experiences health effects decades later. She ends her story by writing: “If there had been a polio vaccine available in 1949, I would like to think my parents would have had me vaccinated without question. If they had decided not to, I wonder if I would ever be able to forgive them. Do parents who oppose vaccinating their children in these times ever consider that they might one day face that possibility?”<sup>36</sup> Sharing similar stories as part of a widely circulated media campaign may serve to humanize the consequences of the anti-vaccination movement, and help people remember what life looked like before vaccines became readily available, in a similar way as White’s story humanized the HIV/AIDS epidemic.

Admittedly, there are reasons to believe that these proposals may be ineffective against some groups of people. One recent study suggests that “pro-vaccination messages,” designed to counter misinformation and highlight the unfavorable consequences of not vaccinating, may actually backfire. Nyhan et al. tested four commonly used strategies by health agencies to promote vaccines: “(1) correcting misinformation, (2) presenting information on disease risks, (3) using dramatic narratives, or (4) displaying visuals

to make those risks more salient or accessible.”<sup>37</sup> When combatting the misperception that the MMR vaccine is causally linked to autism, the authors found that while information “successfully corrected misperceptions about MMR causing autism . . . the correction also reduced vaccination intent among parents with the least favorable vaccine attitudes.”<sup>38</sup> That is, the anti-vaccination mentality continued even after the subjects accepted the corrected information, and the authors hypothesize that this is because “respondents brought to mind other concerns about vaccines to defend their anti-vaccine attitude.”<sup>39</sup> In an even more curious finding, “dramatic narratives about measles and images of sick children *increased* misperceptions about MMR.”<sup>40</sup> Ultimately, the authors conclude that “no intervention increased intent to vaccinate among parents who are the least favorable toward vaccines.”<sup>41</sup>

However, as the authors repeatedly point out, this study illustrates a lack of effect on individuals who have the *least* favorable attitudes toward vaccines. While these tactics may not do much to change the minds of parents who have become wedded to a particular ideology, there may be many more parents who reside “on the fence” and may be more open to pro-vaccine education. Hagwood and Herlihy note that “education providers . . . [should] be aware of this group of parents who likely will not respond to education efforts”; however, they also go on to emphasize that they remain in the minority.<sup>42</sup> Far from giving up the attempt to disperse factual information about vaccines, Hagwood and Herlihy maintain that vaccine education should focus on other groups of parents who, while perhaps still hesitant, are more open to information.

Vaccine-resistant (VR) parents are those that, while they are currently rejecting vaccination, are willing to consider information regarding the safety and efficacy of vaccines . . . vaccine-hesitant (VH) parents are not as committed to misinformation about vaccinations and tend to come to the health care provider’s office with more of a generalized anxiety about vaccines . . . failing to adequately address VH parents’ concerns may result in their becoming more resistant for future vaccinations.<sup>43</sup>

Whereas VR parents may respond more to the abovementioned personal stories, as “an emotion-based or empathy-based approach may be most effective,” VH parents would benefit by educators “identify[ing] specific concerns first and then providing fact-based education . . . this approach allows the VH parent to put a name to their diffuse vaccine concerns, and gives the educator a direction for the provision of information.”<sup>44</sup> Moreover, we should not just be targeting current skeptics, but also striving to prevent the creation of new ones. Future parents who have grown up in a society that provides broad and accessible vaccine education would perhaps be far less likely to become vaccine skeptics when the time comes to vaccinate their own children. In short, “the more that [current and future] parents hear vaccine-supportive arguments from multiple sources, the more likely that parents will recognize that anti-vaccine beliefs are not grounded in scientific fact.”<sup>45</sup>

Lewandowsky et al. highlight all the various ways in which misinformation is spread among the general population and then outline several cognitive factors that have proven most effective for combating that misinformation. One relevant point they emphasize is that when misinformation is circulated, merely retracting it does little to change people's mind. This explains why so many continue to be influenced by Andrew Wakefield's 1998 study linking autism to the MMR vaccine, despite the fact that it was retracted from *The Lancet* and that its findings have been thoroughly repudiated. According to Lewandowsky et al. "only three factors have been identified that can increase the effectiveness of retractions: (a) warnings at the time of the initial exposure to misinformation, (b) repetition of the retraction, and (c) corrections that tell an alternative story that fills the coherence gap otherwise left by the retraction."<sup>46</sup> These factors can be implemented in any media or medical campaign aimed at combatting vaccine misinformation. For example, the authors suggest that, before mentioning any myth to the public (e.g., that vaccines have been linked to autism), it is best to "provide an explicit warning before mentioning the myth, to ensure that people are cognitively on guard and less likely to be influenced by the misinformation."<sup>47</sup> As Healy and Pickering note above, one obstacle physicians face when communicating with parents is that the latter often lack a scientific background, and therefore cannot typically process information given to them that is not in layman's terms. Lewandowsky et al. confirm this and suggest that "material [be kept] simple and brief. Use clear language and graphs where appropriate. If the myth is simpler and more compelling than your debunking it will be cognitively more attractive, and you will risk overkill backfire effect." While just informing vaccine skeptics that Wakefield's study was repudiated may not be enough to dissuade them, "repeated retractions to reduce the influence of misinformation . . . without reinforcing the myth"<sup>48</sup> has proven to be more effective.

While it is unlikely that these tactics will impact committed vaccine skeptics, they may help reach VR and VH parents. This may sufficiently keep non-compliance low enough so as not to compromise community immunity. However, if these tactics are not sufficiently successful, more aggressive ones that increase the burdens on non-complaint parents should be considered. As I have argued above, SB 277 is defensible under the harm principle, as it seeks to increase the encumbrances on parents who opt not to vaccinate without removing parental choice altogether. States that experience vaccination rates falling below what is needed to secure community immunity, and who have consequently experienced an outbreak of a communicable disease, should consider implementing similar burdensome policies. Hagwood and Herlihy suggest, for example, that "states may need to address loopholes in public health policies such as religious or philosophical exemptions to vaccination for public school attendance. . . . West Virginia showed a vaccination rate of 99.85% for 7th and 12th graders in the first year after it eliminated religious and personal exemptions and only allowed for medical exemptions. To increase and/or sustain vaccination rates nationwide, it might be necessary for more states to follow West Virginia's example."<sup>49</sup> If a combination of increasing

informational outreach and escalating the burdens for non-vaccinating parents fails to increase vaccination rates to the point of securing community immunity, then it may be necessary to consider policies that would allow parents to be held legally responsible in some fashion if they choose, for non-medical reasons, to not vaccinate their child, and if, as a consequence, their child either died or was permanently injured as a result of acquiring a vaccine-preventable illness, or if their decision played a role in any ensuing outbreak.

What kind of "legal responsibility" would be appropriate for these cases is beyond the scope of this paper and is best left up to legal scholars. However, there are some suggestions that can get the conversation started. Moser et al. propose that states consider implementing statutes that would impose the monetary costs of containing and treating a disease outbreak in society to those individuals who have opted out of vaccinating themselves or their children (for non-medical reasons) if they either initiated or contributed to the spread of the disease. A 2005 measles outbreak in Illinois and Indiana was traced back to a single unvaccinated teenage girl and "the cost of containment for public health authorities was \$62,216. The total cost of the outbreak was over two hundred thousand dollars."<sup>50</sup> This cost was largely absorbed by (vaccinated) tax payers. Moser et al. model their suggestion after Arizona's "Stupid Motorist Act" which "allows non-profit and public entities to collect costs expended in rescuing a driver who, ignoring barricades (or otherwise behaving recklessly), drives a vehicle onto a public street or highway that is temporarily covered by floodwaters."<sup>51</sup> Similarly, they argue:

we propose a statute that imposes the costs on those whose choice to not vaccinate causes [disease outbreaks] . . . the statute makes not vaccinating a public nuisance and forc[es] individuals to internalize these costs. It thus fits comfortably within the ideas of personal responsibility embodied in our system: individuals are free (subject to other applicable rules, like school immunization requirements) not to vaccinate themselves or their children. If, however, an individual's choice creates risk, then the individual is required to pay for those risks if they materialize.<sup>52</sup>

Dorit Reiss offers a tort remedy for parents whose children were infected by a communicable disease as a result of being exposed to a non-vaccinated child. This allows for compensation to the injured child or her family, and assures that the consequences and costs of the anti-vaccination movement are not absorbed by them. The primary goal of such a policy is, of course, to function as deterrence from choosing to not vaccinate. However, even if it is unsuccessful in this capacity, it is nevertheless an issue of justice and fairness. Reiss writes: "the injury to the plaintiff is real, and was caused by the problematic choice of another. Without a tort remedy, the plaintiff may face dramatic financial burdens on top of emotional and other burdens that accompany the death of or severe harm to a child . . . if this active decision causes harm to others and the parents do not have to compensate the victims, they

have, in effect, externalized the cost of their decision onto the victim"<sup>53</sup>

While Moser et al.'s and Reiss' suggestions are meant to compensate third-party families whose children are injured as a result of an unvaccinated child, what about the stricken unvaccinated child herself, who is now suffering as a result of her parents' misguided, albeit well-intentioned, decision? In these cases, the parents themselves will absorb the financial costs, but that does not thereby mean that all claims of justice have been met; parents of an unvaccinated child cannot absorb the actual suffering their child now experiences as a result of being afflicted with these preventable diseases. It would perhaps be helpful here to look at existing cases where parents have been held legally responsible for their child's welfare if they did not secure adequate healthcare for her. In 1985's *Commonwealth v. Barnhart*, for example, the parents of Justin Barnhart were charged and convicted of involuntary manslaughter and endangering the welfare of a child after they failed to retain medical care for his cancer, instead relying on prayer and faith healing.<sup>54</sup> Similarly, 1988's *Walker v. Superior Court* resulted in Laurie Walker's conviction of involuntary manslaughter and felony child endangerment after her daughter died of meningitis; Walker too, being a Christian Scientist, opted for prayer and faith healing instead of medical care. In these cases, and in similar ones, the courts ruled that religious freedom has its limits, and one of those limits comes when religious beliefs become at odds with a child's interests and welfare. As the United States Supreme Court ruled in *Prince v. Massachusetts*,

The family itself is not beyond regulation in the public interest, as against a claim of religious liberty. And neither the rights of religion nor the rights of parenthood are beyond limitation. . . . The right to practice religion freely does not include the right to expose the community or the child to communicable disease or the latter to ill-health or death. . . . Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children.<sup>55</sup>

I have argued in this paper that we cannot justify violating parental autonomy by forcibly vaccinating a child against her parents' will solely due to the *possibility* that she may get sick. However, if that possibility materializes, and if the child suffers permanent injury or death as a result of her parents' choices, then the parents leave themselves open to being held accountable for those choices. The extent to which they are held accountable, i.e., what they are charged with and what punishments may result, and whether this would be a criminal or civil suit, is best left up to those with more legal education than I possess.

It should be emphasized that this step, if taken, should be a last resort, and should only be implemented if neither educational outreach, nor increasing the burdens on non-vaccinating parents, nor providing legal means to compensate injured third parties, is successful at increasing voluntary compliance. Prosecuting well-meaning parents who clearly love their children and made a decision that

they, for better or worse, really felt was best for their families is not at all an ideal way to address the anti-vaccination movement. The hope is that it need not come to that. However, if our society experiences an alarming level of resurgence of once eradicated diseases, and if less aggressive tactics fail, then preserving public health, including the health of the children of anti-vaccination advocates, must take primacy.

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## Mandatory Vaccination: A Response to a Libertarian Defense

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*This paper is a response to a paper delivered at the 2016 APA Eastern Division meeting by Jason Brennan of Georgetown University, currently being published in the Journal of Medical Ethics.*

### INTRODUCTION

Jason Brennan's argument is as follows.

First, he endorses the **Clean Hands Principle (CHP)**: There is a (sometimes enforceable) moral obligation to not participate in collectively harmful activities.

By collectively harmful activities, Jason has in mind "an activity in which a group causes harm to another, but in which individual inputs into the group activity are negligible, in the sense that the harm will occur regardless of whether any individual participates or not."<sup>1</sup>

P1. There is a (sometimes enforceable) moral obligation to not participate in collectively harmful activities

Next, he claims that the CHP extends not only to "foreseeable and known harm," but also to cases where participating in the activity would impose an "unacceptable risk" of harm. Jason draws on the work of Sven Hansson to characterize unacceptable risk. Hansson's considered view is as follows:

**Hansson on risk-acceptance:** Exposure of a person to risk is acceptable iff this exposure is part of an equitable social system of risk-taking that is to her advantage.<sup>2</sup>

P2. Collectively harmful activities include both activities that expose others to foreseeable harm and activities that expose others to unacceptable risk

Next, Jason argues that participating in the "activity" of not getting vaccinated is to participate in an activity that, collectively, exposes others to unacceptable risk—and thus, violates the CHP.

P3. To refrain from vaccinating oneself or one's children is to participate in a collectively harmful activity, and the activity in question is harmful in virtue of exposing others to unacceptable risk.

So we get

C1. (From 1-3) Thus, not vaccinating oneself/one's children violates a moral obligation

While he does not expressly state it as such, it's evident that Brennan thinks that the obligation to not expose others to risk is an enforceable one and that the government is the entity that is permitted to enforce the obligation.

P4. The moral obligation of citizens/residents to vaccinate themselves/their children is coercively enforceable by the government

So we get

C2. (From C1,P4) Thus, for each citizen/resident, the government may coercively enforce her obligation to vaccinate herself/her children. The government is permitted in instituting a policy of universal mandatory vaccination.

I'll argue as follows.

First, Jason's argument is incomplete. This is because *universal* mandatory vaccines aren't necessary to prevent the harm he has in mind, and thus we should reject (P3). To avoid this objection, there is an obvious response—but this response renders (P1–3) superfluous.

Second, I object that P1 and P2 are in tension with libertarianism—or at least libertarianism in the sense that makes Brennan's argument an especially powerful and interesting defense of universal mandatory vaccines.

### I. HERD IMMUNITY AND COLLECTIVE ACTIVITIES

We should reject (P3) because of the nature of herd immunity.

At one point in his article, Brennan gives an example in which a group of ten people roll ten ten-sided dice. If the roll comes out to be 21, they will all fire shells at a CDC BSL-4 laboratory wall, thereby causing an outbreak of an extremely harmful disease. He argues that one would be wrong to join in this group's activity on the basis of CHP and the fact that the CHP extends to cases of unacceptable risk.

But there is a significant difference between this case of imposing unacceptable risk on others and the risk imposed by not getting vaccinated. For at least some diseases for which we have discovered vaccines, herd immunity is such that only a significant percentage of the population needs to be vaccinated in order to ensure that there is no risk of an outbreak of the disease. In the case of mumps, for instance, about 74 percent of the population needs to be vaccinated in order for us to enjoy herd immunity.

But this means that if the population stays above the relevant threshold, someone who refuses a vaccine isn't

necessarily participating in an activity that, collectively, imposes unacceptable risk of harm to others. So long as a sufficient number of persons do not participate in the activity, there is not a risk of harm. What are the implications of this for universal mandatory vaccination?

First, if we know that a sufficiently large number of persons are getting vaccinated, then one person going unvaccinated does not amount to participating in a collectively harmful activity—at least, it's not a collectively harmful activity in virtue of imposing unacceptable risk of harm. Second, if more persons wish to go unvaccinated than is safe vis-à-vis remaining above the herd immunity threshold, there are institutional arrangements other than universal mandatory vaccines that could accommodate this desire, thereby allowing those individuals to go unvaccinated without putting others at risk. For instance, the government could set up a lottery system such that a certain number of individuals who don't want to be vaccinated can be exempt. Presumably we would not want the percentage of exempt persons to come close to the percentage necessary for herd immunity. But to return to the example of mumps, the state could allow, say, 2 percent of the populace to go unvaccinated, and that 2 percent would not be acting so as to put us at risk of undermining herd immunity.<sup>3</sup>

Thus, as it stands, (P3) needs to be revised or supplemented. Moreover, I take it that because libertarians cannot appeal to the common good in justifying coercion, as silly as the lottery system might seem, libertarians need to treat it as a serious possibility.

Before moving on, I wish to articulate an obvious response to my objection. By going unvaccinated in public, individuals impose a tiny, albeit unacceptable, risk on particular individuals: namely, unvaccinated children, pregnant women, and persons for whom the vaccine was not fully effective. To go unvaccinated in public is to expose these individuals to unacceptable risk, *independently of how others are behaving*. That is, so long as we stay above the threshold necessary for herd immunity, going unvaccinated imposes no *overdetermined* unacceptable risk of harm, but it does amount to imposing an unacceptable risk of harm.

But if Brennan opts for this response, then his remarks about unacceptable risk of harm from collective behavior and the Clean Hands Principle—premises (P1) and (P2)—are superfluous. Going unvaccinated in public creates an unacceptable risk of harm, but so long as we are above the threshold for herd immunity, this risk of harm has nothing to do with the behavior of others who also refuse vaccines. This obvious response seems to be promising for securing the conclusion that Jason wishes to reach, but it amounts to abandoning the argument Jason provides.

### II. UNACCEPTABLE RISK AND LIBERTARIANISM

In the second part of my comments I'll raise some broad questions about whether conjoining CHP with claims about unacceptable risk have implications that are in tension with right-leaning libertarianism—that is, whether libertarians should be comfortable with endorsing (P1) and (P2), and the claim that obligations identified by (P1) and (P2) are

coercively enforceable. My remarks will focus on two aspects of libertarianism that are typically distinguished.

The first aspect of libertarianism concerns its moral foundations. Traditionally, libertarians conceive of the person as a self-owner, which means persons have very strong natural rights to property, where property includes one's own body.<sup>4</sup> These rights may not be violated for the sake of promoting the common good or some other value. So if the libertarian wants to accept Jason's claim about the wrongness of imposing unacceptable risks, she must claim that each of us has some sort of claim-right against being exposed to unacceptable risk, and others have a correlative obligation to not infringe on this claim-right.

In the examples from Hansson and Brennan, the distinction between acceptable and unacceptable risk seems to turn on whether there is a net benefit to each individual in a (reasonably equitable) society if we allow individuals to expose others to the risk in question. Such considerations appear to involve an appeal to the common good to indicate which risks are acceptable and which ones are unacceptable—and thus something like the common good is determining the contours of our rights and correlative obligations vis-à-vis exposing others to risk. But such an appeal seems to amount to a departure from the moral foundations of libertarianism by grounding the content of some of our rights in considerations of the common good rather than our status as self-owners.

And if such an appeal is compatible with libertarianism in this instance, why shouldn't it extend to determining the contours and content of our other moral rights that libertarians insist on? Why not think we should ground the scope and content of our property rights only to the extent to which protecting those rights would promote the common good? The appeal to the common good to specify the content of our right to not be exposed to certain kinds of risk seems, on the face of it, ill at ease with the moral foundations of libertarianism. Perhaps Jason could say more about how the moral foundations of libertarianism are compatible with CHP when extended to cases of unacceptable risk.

The second way of characterizing libertarianism is in terms of a particular set of institutional arrangements. Libertarianism is most commonly associated with a defense of extensive free market rights, extensive civil liberties, and a minimal state.<sup>5</sup> If we endorse the claim that the CHP should extend to cases of unacceptable risk, however, then it would seem that significant departures from traditional right-libertarian institutional arrangements are in order.

For instance, driving Hummers isn't especially beneficial compared to driving other, more fuel-efficient vehicles.<sup>6</sup> And Hummers pollute significantly more than other cars. Insofar as we accept that extensive pollution puts persons at risk, and driving a Hummer more significantly contributes to that risk than other, more fuel-efficient alternatives, it seems that extending the CHP to unacceptable risk would imply that using Hummers is wrongful. Furthermore, there does not seem to be a principled reason to think that the state would be wrong in this instance to restrict our right

to participate in the activities of buying, selling, and driving Hummers.

But in this case (and in the case of many other activities), the CHP and the claims about unacceptable risk will entail significant departures from traditional right-libertarian institutional arrangements insofar as the state will be coercively enforcing restrictions on our rights to property and free exchange in a far wider variety of contexts than is typically endorsed by libertarians.

Perhaps Jason is comfortable with this implication of CHP and the claims about unacceptable risk, and the accompanying departure from traditional libertarian institutional arrangements. If he is, however, I doubt that other libertarians are, and thus his argument would not be as powerful. Jason correctly notes that if his argument in defense of mandatory vaccination is successful, it is especially powerful because he starts from a background political theory that seems at odds with mandatory vaccination, and then shows that such a position can vindicate mandatory vaccination. If, along the way, the background political theory changes, however, then obviously his argument is no longer as powerful.

Alternatively, maybe Jason would reply by invoking his government failure objection. He might argue that there are merely contingent reasons, such as government incompetence, that would rule out the government enforcing our obligation to not participate in the host of activities that violate CHP due to imposing unacceptable risk on others. But nobody would claim that a government should attempt to enforce our moral obligations even if it is incompetent at doing so. If the majority of the work circumscribing government coercion involves an appeal to alleged government incompetence, then Brennan's view doesn't seem distinctly libertarian insofar as there is nothing in principle wrong with the government restricting free market rights in a host of ways. A sufficiently competent government would be permitted to depart from right-libertarian institutional arrangements.

I have argued that Jason's arguments, as they stand, do not succeed in making a case for universal mandatory vaccines that is compatible with libertarianism. I have suggested that there is an argument that is similar in spirit to the one he provides, and that this argument could arrive at the desired conclusion, but it would render many of Jason's remarks about collective harms superfluous. I have also suggested that Jason's proposed moral principles that are meant to both ground vaccines while remaining consistent with libertarianism are actually in tension with libertarianism, both at the level of moral foundations and at the level of institutional arrangements. I look forward to hearing his response.

#### NOTES

1. Jason Brennan, "A Libertarian Case for Mandatory Vaccination," a paper presented at the 2015 APA Central Division meeting.
2. Sven Hansson, "The Theoria Bibliography: Swedish Theses in Philosophy 2003," *Theoria* 70, no. 2–3 (2003): 305.
3. Brennan objects to the unfairness of a similar proposal in the context of driving—i.e., determining by lot who gets to drive and

who doesn't. See Brennan, *Libertarianism: What Everyone Needs to Know* (New York: Oxford University Press, 2012), 74–75. Insofar as not getting vaccinated is a far less widely desired liberty than a liberty to drive, I don't think the unfairness intuition would apply to the present case.

4. These rights include a Hohfeldian liberty to use and exchange our property, a Hohfeldian claim-right against those who violate our property rights, and a Hohfeldian immunity against others—especially the state—who claim the authority to change our property. See SEP on Libertarianism; Erik Mack, "The Natural Right of Property," *Social Philosophy and Policy* 27, no. 1 (2010): 53–79; Robert Nozick, *Anarchy, State, and Utopia* (New York: Basic Books, 1974).
5. I will not consider left-libertarianism in this paper. I should also note I'm assuming that Brennan's use of libertarianism is distinct from classical liberalism. Various classical liberals also call for extensive protection of free market rights, but they typically do so on the basis of considerations of promoting various goods, such as utility, and the empirical claim that markets are especially efficacious at promoting these goods—i.e., free markets are justified by appealing to some notion of the common good. For this distinction, see, e.g., Samuel Freeman, "Capitalism in the Classical and High Liberal Traditions," *Social Philosophy and Policy* 28, no. 2 (2011): 19–55. More recent neo-classical liberals defend extensive free market rights on the basis of considerations of public reason—see, e.g., John Tomasi, "Social Justice, Free Market Style," *Public Policy Research* 19, no. 1 (2012): 26–33; Gaus 2012.
6. I borrow this example from Brennan, *Libertarianism: What Everyone Needs to Know*.

Many people would say that only this doctor exhibited the right attitude toward me. I say the opposite.

What did he think I would be upset about at that moment—world hunger? And if his question was a clumsy attempt to encourage me to express my feelings, was the emergency room an appropriate place? I had been kept waiting for over two hours. I realized that life-threatening emergencies had priority. But the question about my feelings got me wondering whether I had been kept waiting while other patients were likewise being encouraged to emote.

The operating surgeon, by contrast, gave me precisely what I had come to the hospital for. He fixed my elbow. I was not looking for sympathy and personal involvement from him or from other health professionals. I got plenty from the people who could make it mean something: my family and friends.

Obviously, health professionals should be considerate and unhurried. Why should they also express concern for a patient "as a person," in the sense of showing interest in a patient's emotional and personal life?

Some reasons serve doctors' self-interest. "Personality may be more important than clinical ability when it comes to lawsuits. . . . Having a good bedside manner and long-standing relationship with patients will often protect doctors from lawsuits, regardless of their level of competence"<sup>1</sup> advises a website for doctors. Showing warmth and compassion can help doctors manipulate people in other ways as well. In a 2012 article in *Time Magazine*, Joe Klein approvingly describes how doctors in the Geisinger healthcare system, who get to keep a portion of the money they save on Medicare patients, are taught to establish rapport by getting schooled "in basic procedures like shaking hands with members of the patient's family, looking them in the eye and introducing themselves." Klein praises these procedures as "especially important in a system in which doctors sometimes must try to deny care requested by patients or their families that is deemed unnecessary." Thus, a Geisinger doctor convinced Klein to sign a "Do not resuscitate" order for his father, who, Klein chillingly admits, "probably would want to be resuscitated."<sup>2</sup>

Of course, there are more honorable reasons for doctors to try to establish rapport. Rapport can make patients more likely to divulge medically relevant information, to return for follow-up care, and to accept medical advice that will benefit them. But do inquiries into patients' emotional and personal lives help bring about rapport?

The answer is a resounding sometimes.

For every patient like me, who wants her doctors to confine their concern to strictly medical matters, there are undoubtedly patients who welcome a show of personal caring. Doctors and other health professionals should take cues from each patient about how much personal involvement will be welcome. Doctors should also realize that any show of personal caring is apt to ring hollow in the absence of such basic decencies as sparing patients

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## Postcandelic

John R. McConnell III  
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The wet wax descends  
as the withering wick drowns  
and radiance ends.

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## The Elbow Speaks

Felicia Nimue Ackerman  
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"This is the elbow."

Two people were standing at my bedside in the hospital recovery room. My groggy consciousness registered that they were talking about me. To them I was "The Elbow," as opposed to "The Knee" or "The Hip"—labels for patients who had undergone operations on those body parts.

For the rest of my hospital stay, I remained The Elbow, a broken mechanism in need of repair. The staff patched me up, checked my overall physical functioning, and supplied pain medication—as if repairing an engine, checking its overall functioning, and supplying lubrication. No one asked if I was unhappy or frightened. No one asked about my emotions at all, except the emergency room doctor who, after telling me that my "shattered" elbow would need prompt surgery, added, "You seem upset. What are you upset about?"

long delays in waiting rooms, charging moderate fees, accepting Medicare and Medicaid, and returning telephone calls promptly.

Moreover, doctors can demonstrate sensitivity in ways that no one would find intrusive. Several years ago, I had a mammogram that was prompted by a frightening symptom. When I was called to the radiologist's office, he said, "Everything looks fine, Ms. Ackerman," before I even crossed the threshold. He did not probe into my feelings, but he had the sensitivity to spare me an extra moment of fear.

He ended the consultation with "Have a nice day," and I assured him that I would.<sup>3</sup>

**NOTES**

1. Mark Crane, "Patients Who Won't Sue Their Doctors—Even When They Could," *PositivePhysicians.com*. Accessed July 12, 2016. Available at <http://positivephysicians.com/industrynews/patients-who-wont-sue-their-doctors-even-when-they-could/>
2. Joe Klein, "The Long Goodbye," *Time Magazine*, June 11, 2012, 18–25.
3. Earlier versions of some of this material appeared in my op-ed columns in *The Providence Journal* ("A Few Thoughts from the Elbow," October 30, 2012, and "Are Broken Ribs Worse Than Death?" June 26, 2012) and are used here by permission.

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## Using Fiction to Help Teach Ethics in Medical Ethics Classes

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**ABSTRACT**

It is the contention of this article that using extended narratives, novels, is a very good device for teaching applied ethics—including medical ethics. This is supported by an empirical study for which Boylan was the lead author on how students responded to a class using fiction to reinforce the philosophical models in class (generally called an indirect measure).

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It has been standard fare for philosophers teaching bioethics or any other area in applied ethics (such as environmental ethics, business ethics, gender ethics, etc.) that short, defined cases are useful to the learning process. But few instructors also employ more extended narratives: short stories and novels. This article presents a recommendation for more extended narratives.

First, let's examine the premise behind all of this: we want to teach students skills that will enable them to engage in a real-life situation with all its messy details and be able to take this practical, momentary baggage into account and still be able to keep in mind ethical and professional principles that will allow them to successfully execute decisions that include ethical components.

Now, the standard case study in medical ethics is rather succinct and frames the decision into two or, at most, three alternatives. This exercise follows some texts on the "proper" way to solve these artificially simplified examples. There is nothing wrong with this. It is certainly better than presenting theory by itself for a class in applied ethics. The short cases or thought experiments have only one major caveat: they must have no boundary conditions that are so far divorced from real life that they create a false scenario that will not help the student apply the pedagogy to life in the world.

What I want to suggest here is that professors consider adding a novel to their reading lists for courses in applied ethics. These can come from the subject area itself or outside the subject area so that they speak generally to applied ethics. An example of the first case might be the novel *Turn of Mind* by Alice LaPlante (2012). The novel's protagonist is a retired female orthopedic hand surgeon who has Alzheimer's disease. The story is told in the first person with the voices of those outside in a different type font. The twist is that the retired surgeon may have murdered her best friend and cut off four of her fingers. The ensuing plot helps us think about how we should and can interact with someone with advanced dementia.

An example of the second case is *Broken Harbor* by Tana French (2013). This is a tale about a police investigation into the murder of a husband, wife, and their two young children in Ireland in the middle of the recent housing crisis/great recession. Though this is not about a medical situation as such, it is indirectly because the novel's focus on police ethics and what it means to balance work, life, and ethics is very adroitly told. There is a direct carryover to any field of professional ethics.

Both of these books could easily fit into any applied ethics class. Why do they work? I think it is because with a longer narrative you are exposed to so much more detail concerning lived experience. This makes the novel-reading experience a better surrogate to everyday life than the very concise case or thought experiment.

I am not advocating that we give up cases or thought experiments, but merely that we add to our pedagogical presentation a longer narrative presentation as well.<sup>1</sup>

Further, I'd like to alert readers to my own novels that fit generally into the mode of applied ethics: *The Extinction of Desire* (2007), about the effects of sudden wealth to one's life equilibrium; *Rainbow Curve* (2014), about loyalty and positive duties to others; *To the Promised Land* (2015), about individual and group forgiveness; *Naked Reverse* (2016), about self-knowledge, changing one's life, and learning to love; and *Georgia: A Trilogy—Part One* (2016), about trying to live one's life under the burden of racial prejudice. Some kind words that have been said about my work as philosopher and novelist:

Camus said, "If you want to be a philosopher, write novels." A few philosophers have heeded his advice: William Gass, George Santayana, Rebecca Goldstein, Michael Boylan, and Iris Murdoch.<sup>2</sup>

Like his Existential predecessors Jean Paul Sartre and Albert Camus, Simone de Beauvoir and Iris Murdoch, Michael Boylan has found an effective way of bringing ideas to life.<sup>3</sup>

This is a novel of fictive philosophy that examines perennial philosophical concerning the human condition. Jean-Paul Sartre, the French existentialist philosopher of the 1950s, did it with his classic *Nausea*. Boylan does it with *Rainbow Curve*.<sup>4</sup>

**NOTES**

1. For those who would like to read more on this, see: Michael Boylan, Felicia Nimue Ackerman, Sybol Cook Anderson, Gabriel Palmer-Fernandez, and Edward Spence, "Using Fictive Narrative to Teach Ethics/Philosophy," *Teaching Ethics* 12, no. 1 (fall 2011): 1–34, and three articles by Felicia Nimue Ackerman, Wanda Teays, and Michael Boylan in *Teaching Ethics*, spring 2017 (forthcoming).
2. From Charles Johnson, Winner of the National Book Award in Fiction (and a Ph.D. in philosophy) in *The Way of the Writer* (New York: Scribner, 2016): 241.
3. From Wanda Teays, philosophy professor at Mount St. Mary's University.
4. From Edward Spence, senior research fellow at CAPPE and senior lecturer at Charles Sturt University in Australia.

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## Children's Rights and The Fault in Our Stars

Rosalind Ekman Ladd  
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**"BECAUSE IT IS MY LIFE, MOM. IT BELONGS TO ME."**  
That's the question, isn't it? Does a child's life belong to the child or to the parents?

Do children or adolescents have a right to make decisions for themselves?

John Green captures the minds and hearts of young adult readers with his 2012 book, *The Fault in Our Stars*. He paints a compelling picture of feisty teens and vulnerable families caught in the emotional ups and downs of life-threatening illness.

He gets it right: the skillful use of teens' language, the background facts about terminal illness, cancer treatment and its final end, the complex family dynamics, all wrapped up in engrossing plot lines. He does not talk down to his readers but lets them experience with the characters the sadness and the small triumphs of the daily life of kids with cancer.

The book is, first and foremost, a good read. It is also an important contribution to educating readers about the world of those who are forced to think about the end of life, their own life, at a too-early age. And, within the story, the book explores a deeper theme: the question of young adults' right to self-determination.

The desire to make one's own decisions is part of typical adolescents' psychology, but it takes on special poignancy in the context of teens facing terminal illness. The first response is to protect them. Isn't it the role of parents to make the hard decisions? Shouldn't doctors and parents spare the child from the responsibility of making high-stakes decisions? Who knows how to measure quality versus quantity of life?

But—whose life is it, anyway? "It's my life, Mom."

These questions clearly have special significance for Green's characters, but they are questions for every teen. And this, I think, accounts for the tremendous appeal of the book. Readers are not simply following the story of Hazel and Augustus—it is every teen's story. Not all teens have life-threatening illness, but all teens want autonomy. And sooner or later all must recognize the facts of human mortality, even their own. The teenage years are full of self-questioning: What kind of person am I? What kind of adult do I want to be? What is my role in this complicated world?

The ultimate truth, the book suggests, is that the answers are up to me. My life is not written for me "in the stars." I need to make decisions for myself; I want to make decisions for myself; don't I have a right to make decisions for myself? It is exhilarating and it is scary.

### A LITTLE PHILOSOPHICAL BACKGROUND

What is a right?

What kind of rights are there?

Rights are defined as justified claims, and philosophers distinguish between two kinds of rights. Welfare rights are protection rights, claims to be given something or protected from something. Liberty rights allow a person to do something and obligate others not to interfere. Children's rights to the basic necessities of life are fairly non-controversial, although some societies do not always have the resources to fulfill them. There is much controversy, though, about what liberty rights children should have and at what age.

In the history of childhood in this country, the prevalent attitude was that children should be seen and not heard. In the '60s, however, along with the recognition of civil rights and women's rights, the idea of children's rights emerged. The movement toward recognizing children's rights, including the right to be heard, found expression in the United Nations Convention on the Rights of the Child in 1989, although the rights mentioned there are not well defined and there are no teeth to enforce them.

Interestingly, liberty rights and protection rights stand in inverse relationship to one another. The more liberty rights children have, the more risk of harm they will experience if they make bad decisions; but the more protection rights that are exercised on their behalf, the less freedom they have to act as they wish.

Assuming that parents will typically tend toward protection rights for their children and teens will typically

be anxious to exercise liberty rights, the setup for parent-child conflict is dramatically complete. Right from the first page, readers are drawn into such a conflict: teen readers can identify with Hazel, who does not want to go to the support group her mother thinks will be good for her. This conflict is rather mild; Hazel gives in after some protest, but it sets the stage for the later high-stakes emotional conflict between Augustus and his parents.

### AUTONOMY

Making decisions for oneself is a way of establishing identity, and creating a personal identity is one of the really important developmental tasks of adolescence. Although parents remain legal guardians and decision-makers for their children until the age of 18, growth toward autonomy is and should be a gradual process. Parents need to decide when and how to “let go,” and children and teens need to learn to make decisions on their own.

The arguments to justify limiting children’s and adolescents’ liberty are familiar: they lack experience in life situations; they are impulsive and act on emotion; they do not always see or appreciate consequences; they choose for the short term instead of the long term; they change their minds. In short, they are not competent to make good decisions. The reasoning is this: to have a right to autonomy, one must have competence; children and adolescents lack competence; therefore, they do not have a right to autonomy.

These are generalizations, of course, and the law solves the problem by establishing a chronological dividing line between minors and adults, and a person becomes legally qualified to drive, drink alcohol, marry, etc., upon reaching a certain age. With moral rights, such as the right to autonomy, the problem cannot be solved as easily. Many theorists recognize childhood and adolescence as a time of increasing competence and thus recommend a model of emerging autonomy, granting some liberty rights along the way toward full self-determination.

Green handles the issue of emerging autonomy with great understanding. Augustus is 17, very aware of how close he is to legal adulthood. His parents seem to recognize this as well, for although they do not want him to make the trip to Holland, they do not, perhaps cannot, stop him. Hazel, at the younger age of 15, is still obedient to her parents’ wishes, but Green offers clues about her developing competency and her increasing autonomy. She shows competence when she asks to consult the physician (113), which is something an adult might suggest. Hazel’s physician plays a pivotal role in advocating for Hazel’s autonomy. In giving the OK for Hazel to make the trip, she says, “it would increase some risks. . . . But it’s your life” (117), and she convinces the mother to agree, saying, “she needs to live her life” (127). By the end of the book, Hazel is saying “Mom, I don’t need you like I used to” (255).

When Hazel’s physician and mother finally agree to let her go, the reader understands that calculating risks for a teen with life-threatening illness is different from calculating risks for a typical teen. With uncertainty about what the future will bring, or if there will be a future for

them, it makes sense to allow for a greater degree of risk. Parents of children with life-threatening illness cannot simply follow the widely accepted rule of thumb that says one should choose for children in ways that preserve an open future for them.<sup>2</sup> A *carpe diem* attitude seems more appropriate.

Developmental psychologists and other scientists are interested in children like Hazel and Augustus, measuring the effects of their experience of illness on their level of maturity and competence. The anthropologist Myra Bluebond-Langner studied children on a cancer treatment hospital ward. The study was done at a time when cancer and its prognosis were not talked about openly with child patients, yet she found that the children were aware of their condition, including the possibility of death, and talked about it among themselves in the privacy of the bathroom. However, they did not admit their knowledge to parents in order to protect the parents (144). In the years when cancer treatments were not very successful and a child with cancer did not survive long, doctors and parents did not think it necessary or wise to share knowledge with the children. As treatments became more successful and prolonged, children had to be told what was happening to them, partly to enlist the child’s cooperation and partly in acknowledgment of the child’s right to know. Green’s book reflects the kind of open communication which is now the norm.

This kind of communication is reflected in a new initiative at the National Institutes of Health which is designed to give teenagers with fatal cancer a voice in end-of-life decisions: “including them in the discussions acknowledges a terrible fact that patient and family members struggle to keep from each other: the likelihood of death. . . . Then people can be together as opposed to alone.”<sup>3</sup>

In a much-quoted 1982 study, social scientists presented children in different age groups with hypothetical cases and asked them to make choices between medical treatments. What they found was that almost all the children, even the youngest, made the same decisions that physicians and parents would have made. The only exception was a group of young adolescents who rejected a treatment which has the side effect of changing body image, reflecting the concern, indeed, sometimes obsessive concern, adolescents have about how they look. The study shows that even young children are competent to understand consequences, risks, and benefits. The authors conclude that their findings do not support the denial of the right of self-determination to adolescents in healthcare situations on the basis of incapacity.<sup>4</sup>

Allowing teens to make decisions with potentially devastating consequences is certainly controversial, but the law is sometimes on the side of the teen. An increasing number of states recognize the legal status of mature minor, which allows children or teens the right of self-determination when physicians judge that they are competent. In some cases, the question ends up in court, and, surprisingly, there is precedence in the courts to allow teens to refuse even life-saving treatment when they can demonstrate understanding and firm commitment to,

e.g., Jehovah's Witness beliefs which prohibit the use of life-saving blood transfusions.<sup>5</sup> The reader cannot miss Augustus's loud claim to self-determination, but it is not until the end of the book that Green reveals that the decision Augustus makes is a decision not simply to make the Holland trip, but the significant decision to forego continuing treatment.

Adolescent decision-making presents challenges in many interesting ways, for even competent adolescents often hold values that adults do not hold. Thus they make choices that adults would not make. Someone might try to explain it by saying that adolescents who are risk-takers are miscalculating the dangers and are, thus, not really competent. On the other hand, one could say they do understand the consequences, but they value certain experiences more than they value personal safety. Adolescents have what we may call age-specific values.<sup>6</sup>

Adults, too, have age-specific values. As adults, we might criticize adolescents for their risky behaviors, but many adults are also risk-takers and they are free to act on their values. Actually, we are subject to age-specific values at all stages of life. For example, as 80-year-olds, we might criticize the values of our earlier 30-year-old selves for choosing career over family. It is appropriate in some sense for adolescents to be risk-takers, and, it can be argued, we should respect their values despite their age. The content of a choice does not, in itself, constitute evidence of incompetence.

Once again Green gets it right. He shows that adolescents have their own values and at times it is appropriate for adults to respect them. When Hazel's mother initially vetoes plans for the Holland trip, she is choosing the safer option, but she comes to recognize and respect the high value Hazel puts on being able to make the trip. When the reader learns about Augustus's relapse and the futility of further treatment, Green is quietly leading the reader to understand that his decision to forgo treatment is not an unreasonable one. We come to respect Augustus's values.

There are other decisions that Hazel and Augustus make that reflect their parents' increasing willingness to let them live according to their own values. In the opening pages of the book, Augustus's parents require him to entertain Hazel in the living room, not in his basement bedroom. By the end of the book, the two teens are left alone in the bedroom. They are also left alone in Holland to confront Mr. Van Houten, to enjoy a decidedly adult dinner with champagne, and ultimately to share physical intimacy. It is in part a tribute to their developing competence and in part an embracing of a *carpe diem* attitude.

Adolescents make various kinds of momentous decisions for themselves, and Green incorporates one of the big ones into his narrative: Augustus and Hazel decide to go to bed together. Their encounter is complicated by the apparatus of their illness: Hazel's shirt gets entangled with her oxygen tube, and Augustus has to prepare her for the sight and feel of his amputated leg. Green handles the scene with sensitivity, brevity, and dialogue that is in keeping with their irreverent approach to their disabilities.

## CHILDREN'S RIGHT TO AUTONOMY: THE ROLE OF LITERATURE

What does the young reader take away from this book? How does this book help form adolescents' views on their right to autonomy? How does the dramatic impact of Hazel and Augustus's story empower adolescent readers?

The transfer from literary character to real reader is easy: "If Hazel and Augustus can exercise self-determination in decisions with such dire potential consequences, then maybe I, an ordinary adolescent, have that right too and I should make my voice heard." The book offers a role model for exercising autonomy, and the very title suggests that one's life is one's own. "The fault, dear Brutus, is not in our stars, But in ourselves . . ." (111).

The characters of Hazel and Augustus are drawn with great insight and sensitivity. Hazel is a girl with cancer, but she is not defined by her cancer. She has the same wants, challenges, and emotions as any 15-year-old. Augustus has the same interests and values of many typical teens. Thus it is easy to look beyond the cancer to the universal themes of adolescence. This is the appeal of the book: teens with cancer are different in many ways, but are also the same. They are not strange specimens to be examined, but real living and feeling teen-aged human beings. They have a life to live, and it is their own lives. That is what rights are all about.

### NOTES

1. John Green, *The Fault in Our Stars* (New York: Dutton Books [Penguin Group], 2012), 139.
2. Joel Feinberg, "The Child's Right to an Open Future," In *Whose Child? Children's Rights, Parental Authority, and State Power*, ed. William Aiken and Hugh LaFollette (Totowa, NJ: Littlefield, Adams, 1980).
3. *New York Times*, March 29, 2015, p. 1.
4. Lois Weithorn and Susan B. Campbell, "The Competency of Children and Adolescents to Make Informed Treatment Decisions," *Child Development* 53, no. 4 (1982): 1589.
5. Rosamond Rhodes, "Death or Damnation: An Adolescent's Refusal of Life-Saving Treatment" *Hastings Center Report* 38, no. 1 (2008).
6. Rosalind Ekman Ladd and Edwin N. Forman, "Adolescent Decision-Making: Giving Weight to Age-Specific Values." *Theoretical Medicine and Bioethics* 16, no. 4 (1995): 333-45.
7. Shakespeare, *Julius Caesar*, Act 1, Scene 2.

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## Disability and Well-Being: Appreciating the Complications

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Being disabled is widely thought to be a bad thing for the one who is disabled. In fact, this view is so widely held that we may call it the *Standard View* of the relationship between disability and well-being.<sup>1</sup> The purpose of this essay, which draws upon our more comprehensive treatment of this topic,<sup>2</sup> is to highlight some reasons why the Standard View about disability and well-being is false, and why (with certain exceptions) it is difficult to make true generalizations about disability's impact on well-being.

Two terminological clarifications. First, we are not committing ourselves to any particular definition or model of disability. Instead, we use the term "disability" to pick out conditions that are commonly given that label.<sup>3</sup> Paradigmatic examples include Down syndrome, cerebral palsy, achondroplasia, spina bifida, autism, blindness, deafness, paraplegia, and quadriplegia. With this terminological strategy, it is an interesting open question what the relationship between disability and well-being is since there is no valuation built into the definition. Second, whereas psychologists typically use the term "well-being" to refer to a purely psychological phenomenon, we are using that term, as philosophers standardly do, to refer to how well or poorly a person is doing or faring, or how well or poorly one's life is going for her. Well-being in this sense is conceptually related to a range of other notions: benefit and harm, what is good or bad for an individual, self-interest, prudential value, one's best interests, one's good, flourishing, and the good life. Well-being, as it is being used here, is a *normative* (as opposed to descriptive or empirical) notion, and there is room for normative debate about what exactly well-being and the good life consist in. For our purposes, we will assume that such things as happiness, rewarding relationships, achievement, and knowledge are among the "goods of life." We remain neutral, however, on whether there is some deeper unifying explanation as to why these things are good for us.

### 1. THREE FACTS ABOUT DISABILITY

To set the stage for our critique of the Standard View, let us consider three facts about disability: (1) the variation across disability categories, (2) the variation within disability categories, and (3) the high impact nature of disabilities.

The first fact is that there is great variation across the different types of conditions that we label "disabilities." Some disabilities have a direct impact on how a person

experiences the world (e.g., through the absence or diminution of a sensory capacity or through its impact on cognition), whereas others have a more indirect impact. Some disabilities can be without any cost or inconvenience in the right kind of environment, whereas others involve features (such as chronic pain and early death) that seem costly independently of one's environment. Some disabilities are "visible" in the sense that their presence is often easily apparent to external observers; others are "invisible" and might be difficult or even impossible for an observer to detect without the disabled person identifying themselves as such. Different disabilities have a tendency to evoke different forms of response from others (including pity, amusement, surprise, disgust, admiration, compassion, envy, etc.). Particular disabilities differ in terms of the size and characteristics of the population that has that condition and the extent to which those individuals constitute a community. In short, there is a host of differences among the different kinds of disability.

Turning to the second fact, there is also great variation within most disability categories. Even when two individuals are said to have the same disability, there can be all sorts of variation in the nature of their conditions and in their experience of that disability. Imagine two deaf individuals. One has been fully deaf from birth, was raised in a household and community where ASL was the primary first language, knows how to successfully navigate her environment, enjoys a range of pleasurable pastimes (that are sometimes enmeshed in Deaf deaf culture), and is secure in her identity as a Deaf deaf person. The other person lost his hearing abilities late in life due to a work-related accident, is surrounded by people who are unsure how best to communicate with him and often deal with this by limiting their interactions with him, has trouble navigating his environment, regrets no longer getting to listen to music, and thinks of his condition as a very serious malady. Here we have instances of the same disability that differ along several significant dimensions.

Finally, there is what we will call the "high impact" nature of disabilities. High impact traits are traits that have a significant causal impact on how an individual's life unfolds. To illustrate this idea, it helps to consider the contrasting notion of a "low impact" trait. Take hitchhiker's thumb, the ability to bend the top portion of one's thumb back at an angle approaching ninety degrees. It is safe to say that, for most people who have this ability, it has played no major role in the direction that their lives have taken. Had they lacked this ability, their lives would have unfolded in more or less the same way. In contrast, the conditions that we come to label "disabilities" are almost always on the high-impact end of the spectrum. Blindness, paraplegia, achondroplasia, Down syndrome, cerebral palsy—these conditions tend to have a colossal impact on the direction that one's life takes. They can have a significant influence on a person's day-to-day activities, her choice of employment, the nature of her interactions with family, friends, and strangers, her goals and aspirations, and even her sense of identity and the phenomenology of her everyday life.

## 2. EXPLAINING DISABILITY'S VARIED IMPACT ON WELL-BEING

The three facts about disability help to explain why simple generalizations about disability and a person's overall well-being cannot be made. We can begin with high-impact traits. Consider this case:

Imagine a set of identical triplets, sisters with paraplegia who use wheelchairs and who live in different cities. The sisters have a great deal in common. They are of a similar temperament, have had similar life-experiences, and share common values. Furthermore, each lives in an accessible building and enjoys accessible public transportation. Despite these similarities, the sisters' lives diverge radically. The first sister attends a social gathering for people with paraplegia where she meets and eventually marries a woman who becomes the love of her life and her best friend. They live happily into their old age. The second sister attends a similar social meeting and falls head over heels for a woman who turns out to be physically and emotionally abusive. This leads to years of suffering, an eventual divorce, and deep regrets. The third sister is traveling to the same type of social gathering, but her taxi gets hit by a bus and she dies instantly.<sup>4</sup>

As this case illustrates, even if a group of disabled individuals were to have very similar disabilities, social environments, temperaments, values, and so forth, we can easily imagine ways in which their disabilities, in combination with the intricate contingencies of life, can take their lives in very different directions, resulting in very different patterns of well-being. (Notice that we would not expect a low-impact trait like hitchhiker's thumb to have that sort of effect.) But the intricate contingencies of life are only one type of difference in people's lives. People vary in their temperaments, likes and dislikes, values, beliefs, jobs, projects, etc., and live in a range of different kinds of physical and social environments. When you combine a high-impact trait like a disability with variations in individuals' life-circumstances, this leads to further variations in life-circumstances and, often enough, variations in well-being. This point applies even if we focus our attention on individuals with more or less the same high-impact trait.<sup>5</sup>

Of course, more often than not, disabled people do not have the same high-impact trait. Our first fact about disability—the variation that exists across disability categories—reveals that "disability" encompasses a wide range of different types of high-impact traits. Since a single type of high-impact trait can yield great differences in well-being in different circumstances, it should come as no surprise that the presence of different high-impact traits will have an even greater tendency to produce divergence in well-being. Our second fact about disability highlights important differences in how a single type of disability can manifest itself in the lives of different individuals. If such individuals possess the same high-impact trait (a point that

might be debated), there is clearly a rich diversity of ways that the trait can be realized in a life.

These considerations help to explain why we cannot make simple generalizations about the relationship about well-being and disability in general. Furthermore, the high-impact nature of disabilities and the variation that exists within disability categories helps to explain why we often cannot even generalize about what role a particular disability has on the well-being of those with that condition.

## 3. INTRINSIC, INSTRUMENTAL, AND COMPARATIVE VALUE

To this point, we have been referring somewhat vaguely to individuals' overall well-being. Let us now get more precise. The Standard View states that, in the vast majority of cases, having a disability is *bad* for those who are disabled—or, in other words, having a disability negatively impacts the well-being of those who are disabled. This view is open to three noteworthy interpretations. First, the Standard View might be interpreted as saying that disabilities tend to be *intrinsically* bad for a person—that is, *bad in and of itself*, apart from its causal consequences. Second, the claim might be that having a disability tends to be *instrumentally* bad for a person. Something is instrumentally bad for a person when it leads to things intrinsically bad for her and/or prevents the occurrence of things intrinsically good for her.<sup>6</sup> Third, the Standard View might be understood as saying that having a disability tends to be *comparatively* bad for a person—that is, it renders a person worse off than they would have been in the absence of that disability. The comparison in "comparatively bad" is between one's actual level of well-being and one's well-being level in a counterfactual scenario. With this trifold distinction in view, we are now in a position to specify our suggestion that we cannot make simple generalizations about the impact of disability on well-being.

What we cannot do is make true simple generalizations about the *instrumental* or *comparative* goodness, badness, or neutrality of disability.<sup>7</sup> The high-impact nature of disabilities pertains to their causal influence on a person's life. Instrumental and comparative value are the modes of prudential value that are intimately bound up with causation. Because disabilities are high-impact traits and people's lives vary along countless dimensions, we cannot make simple generalizations about the causal impact of disabilities on people's lives and well-being. Given the diversity of disabilities and the fact that most of them are compatible with achieving many of the goods of life, we also cannot make simple generalizations that disability tends to be instrumentally or comparatively good, bad, or neutral for a person.<sup>8</sup> We should therefore reject the Standard View on the instrumental and comparative interpretations.

Intrinsic prudential value is a different story. The high-impact nature of disabilities has less relevance to the question of whether disabilities are intrinsically bad, good, or neutral for people. For here we are concerned not with a disability's causal consequences, but with how the disability itself—apart from its effects—impacts well-being. While it is not possible to provide a full defense here, our view is

that, despite the wide variation across and within disability categories, most disabilities are neither intrinsically good nor intrinsically bad for an individual. With some possible exceptions,<sup>9</sup> they are intrinsically neutral. This should not be a very controversial claim in light of the fact that the leading theories of well-being (hedonism, desire-fulfillment theory, perfectionism, and objective list theory), which purport to tell us what things are intrinsically and basically good or bad for us, do not identify disabilities as being intrinsically good or bad for us.<sup>10</sup> So, the Standard View is false on the intrinsic interpretation as well.

#### 4. CONCLUSION

The Standard View tells us that being disabled tends to be a bad for a person. We have offered a partial explanation of why we cannot make true generalizations about disability's instrumental or comparative goodness, badness, or neutrality. This gives us reason to reject the Standard View on the instrumental and comparative interpretations. The intrinsic interpretation of the Standard View should also be rejected, though not because it is impossible to make a true generalization about the intrinsic value of disability. The reason is simply that it is far more plausible that most disabilities are intrinsically neutral. Beyond that claim, we should resist the temptation to make broad and simple generalizations about the relationship between disability and well-being.

#### NOTES

1. Ron Amundson, "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics," 103.
2. See Stephen M. Campbell and Joseph A. Stramondo, "The Complicated Relationship of Disability and Well-Being," which is forthcoming in a special issue of *Kennedy Institute of Ethics Journal*. In that essay, we offer a systematic and detailed critique of the Standard View, discuss a probabilistic variant of the Standard View, and examine some practical implications of our conclusions about the relationship between disability and well-being.
3. Here we follow Barnes, "Valuing Disability, Causing Disability."
4. This is a variation of an example presented in Amundson, "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics," 109.
5. Granted, it is possible to have a high-impact trait whose effects are so harmful (e.g., causing agony and an early death) that it will consistently ruin the life of anyone who has it. Those can be cases where a high-impact trait and variations needn't yield great variation in well-being. However, a modest amount of empirical observation reveals that most disabilities are not like that. They are compatible with achieving many of the things widely regarded to be the goods of life, and there are countless cases in which individuals with disabilities have lives that would be regarded prudentially good on any remotely plausible view of well-being.
6. To qualify as *overall* instrumentally bad for a person, a thing must involve a greater balance of instrumental harm (leads to intrinsic bads, prevents intrinsic goods) over instrumental benefit (leads to intrinsic goods, prevents intrinsic bads). A similar qualification applies to intrinsic badness.
7. A clarification about our use of "neutral." In the context of discussing well-being, this term is most naturally taken to refer to the space between prudential goodness (what is good for a person) and prudential badness (what is bad for a person). To say that a trait is neutral in this sense is to say that it is either (i) neither good nor bad for a person, or (ii) good and bad for the person to roughly the same extent. This is how we will understand and use the term "neutral."

8. The so-called "Non-Identity Problem" introduces further reasons why it is difficult to generalize about disability's comparative value, though this issue is beyond the scope of this essay.
9. Some disabilities may essentially involve features that are, arguably, intrinsically good or bad for a person. Examples may include fibromyalgia or major depression.
10. For more discussion of this point, see Campbell and Stramondo, "The Complicated Relationship of Disability and Well-Being."

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## Toward a Critical Theory of Harm: Ableism, Normativity, and Transability (BIID)

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#### ABSTRACT

Body Integrity Identity Disorder (BIID) is a very rare condition describing those with an intense desire or need to move from a state of ability to relative impairment, typically through the amputation of one or more limbs. In this paper, I draw upon research in critical disability studies and philosophy of disability to critique arguments based upon the principle of nonmaleficence *against* such surgery. I demonstrate how the action-relative concept of harm in such arguments relies upon suspect notions of biological and statistical normality, and I contend that each fail to provide normative guidance. I then propose a critical theory of harm, one marked by substantive engagement with both empirical and reflective inquiry across the sciences, social sciences, and humanities. I conclude by discussing implications of a critical theory of harm and how it might enrich ongoing debates in bioethics, philosophy of disability, and the health humanities more broadly.

#### KEYWORDS

Harm, BIID, Transability, Ableism, Disability, Philosophy of Disability, Bioethics

Unless we can put ourselves in the place of another, unless we can enlarge our own perspective through an imaginative encounter with the experience of others, unless we can let our own values and ideals be called into question from various points of view, we cannot be morally sensitive.

–Mark Johnson<sup>1</sup>

When I judge the other, I simultaneously direct toward her that stream of negative affect that cuts off my feeling of kinship from her as a fellow living, suffering, joyful creature.

–Teresa Brennan<sup>2</sup>

Normative ethical theories have historically emphasized their principles while deemphasizing their exemplars.<sup>3</sup> In other words, whether framed as a question of virtue, duty, or utility, such theories focus more on the *ideals* that determine the worth of ethical action and less on the *people* for whom such action is intended to be praiseworthy.<sup>4</sup> This is not merely to say that Aristotle, Kant, and Mill, and, often, their followers operate with insufficient or problematic accounts of subjectivity or assumptions about human nature—a claim scholars in feminist theory, critical race theory, and critical disability studies, among other fields, have argued at length for years. Following Gregor Wolbring, I find it illuminating to frame this more specifically as a neglect of the role *abilities* and *ability expectations* play in normative ethical theorizing.<sup>5</sup> Such neglect has led to wide-ranging oppression and discrimination, including and especially the historical, systematic exclusion of people with disabilities from all canonical models of flourishing.

Normative theories implicitly assume that ethical exemplars (whether Aristotle’s *phronimos*, Kant’s good-willed rationalist, or Mill’s sensing calculator) possess certain abilities. Although typically underdetermined and undertheorized, these abilities prove determinate for the content and form of the ideals to which the respective ethical subject is prescriptively beholden. Depending upon the historical epoch or author in question, these abilities might be demarcated as or at least assume specific forms of “rational” thought, ambulation, hearing, seeing, speaking, emotional regulation, or any number of abilities afforded by class position, gender, sexuality, race, locale, and so on. In this paper, I focus on experience that in many respects blurs the lines of ability and disability: transability or BIID. It is an experience that unsettles intuitions concerning which abilities matter, how they matter, and why they matter at all. It is an experience that gets to the heart of how we think a body should be to be good and to do good. It is thus an experience that, by my lights, prompts a reevaluation of not only canonical ethical ideals and exemplars, but also the lived experience of being *subject* to the assumptions and prescriptions of normative theorizing.

While a significant literature in bioethics and other fields has arisen around BIID, only a small portion engages the breadth of work across critical disability studies and philosophy of disability, a tendency sadly and problematically still true of much bioethics literature more generally.<sup>6</sup> In this paper, I draw upon the latter fields to contribute to arguments for the support of surgeries for people with BIID. Because I find extant positive arguments persuasive, I here provide a negative account that critiques arguments based upon the principle of nonmaleficence *against* such surgery. I demonstrate how the action-relative concept of harm in such arguments relies upon suspect concepts of biological and statistical normality, and I contend that each fail to provide normative guidance. I then propose and outline a

critical theory of harm defined by substantive engagement with both empirical and reflective inquiry across the sciences, social sciences, and humanities. I conclude by discussing implications of a critical theory of harm and how it might enrich ongoing debates about the relation of disability to harm and well-being in bioethics, philosophy of disability, and the health humanities more broadly.

## I. TRANSABILITY — BIID (BODY INTEGRITY IDENTITY DISORDER)

You wake up in a cold sweat. A hand lays dead upon your face. After a few hazy seconds of delirium, you realize it is your own. But it is also not your own. It is “asleep,” as one says, and while one knows perfectly well that it is one’s own hand, “it” feels unwelcome and alien. In this moment of derecognition of one’s body, one perhaps approaches, however imperfectly, the experience of transability or BIID: body integrity identity disorder.<sup>7</sup>

BIID is a rare condition characterized by an intense desire or need to move from a given state of ability to one of relative impairment, most often through amputation.<sup>8</sup> As Sabine Müller notes, “psychologists, psychiatrists, and neurologists offer quite different explanations for the amputation desire: they discuss whether it is a neurotic disorder, an obsessive-compulsion disorder, an identity disorder like transsexuality, or a neurological conflict between a person’s anatomy and body image, which could stem from damage to a part of the brain that constructs the body image in map-like form.”<sup>9</sup> That is to say, there is serious disagreement over the nature, definition, diagnosis, etiology, and prognosis of BIID. Since around 2008, cognitive neuroscientists have argued that, at least in some cases, it is a neurological, body-mapping problem caused by a failure to represent one or more limbs in the right superior parietal lobule.<sup>10</sup> It should be noted that the scientific literature focuses far more often on limb amputation than other forms of transability (including blindness and deafness) and also that within the transabled community, well-known hierarchies of disability appear. For example, no one is reported to desire epilepsy or cystic fibrosis; none desire an “invisible” disability or an “unhealthy” disability, to use Susan Wendell’s indispensable distinction.<sup>11</sup> The question of the *desirability* of a given embodied condition is thus front and center. There is disagreement whether those with BIID simply desire (or need) to be impaired in a specific manner; whether they desire to be socially disabled such that they are recognized to have a certain identity, the privileges and stigmas attendant with it, and are afforded participation in the relevant communities; whether they simply desire their body to be “in alignment” with how they “feel” their body should be; whether and how this relates to erotic desire either of themselves or others as amputees; whether it is some combination of these factors; or whether the desire is something else entirely. Bioethics literature, however, by and large assumes this desire to be pathological in nature, whatever its explanation.

Take the example of deafness by contrast. A number of decades ago, the desire to be deaf would likely have been pathologized across the normative board. Yet, with increased awareness of Deaf (with a capital D) culture,

it is well documented that deafness is experienced by numerous people as a positive and intrinsically valuable cultural identity, not as audiological lack or loss. To my knowledge, no commentators regarded as “pathological” the desires of the couple who in 2004 made international headlines for wanting to select for a child with deafness for an IVF procedure.<sup>12</sup> The debates revolved largely around the ethics of that desire relative to the ableist world in which we live. Yet, if a congenitally hearing person desired or needed to alter their body such that they no longer hear, would this not be considered pathological and categorized as a form of BIID? But what if the desire to do so were expressed in terms of “deaf gain,” i.e., gaining the ability to more fully participate in Deaf culture?<sup>13</sup>

Unsurprisingly, BIID raises a host of obdurate quandaries for ethicists. Take, for example, the questions BIID raises in relation to identity and desire. As public discussions surrounding Laverne Cox, Caitlyn Jenner, and Rachel Dolezal attest, our “Western” cultural imaginary can make at least some space for the desire to “transition” to another gender identity and even (though far less so) between racial identities. Unsurprisingly, people disagree over the nature, legitimacy, and appropriateness of that desire, but the desire itself is, on the whole, imaginable. There seems to be, on the contrary, no such space for the desire of disability.

One of the more famous spokespeople for BIID is Chloe-Jennings White. She has actively and for years sought a surgeon to sever her spinal cord so that she might become paraplegic, and she has experienced the desire for paraplegia since she was a small child. For years, she has used a wheelchair because it feels “right” to her in a way that being upright and ambulating does not. While appearing as a guest on Anderson Cooper’s CNN show, “360,” at one point Cooper comments that White’s desire to become paraplegic is “completely inappropriate” relative to those for whom paraplegia is not a choice.<sup>14</sup> The audience responds with applause. As disability studies scholar Fiona Kumari Campbell frames discussions over BIID, the desire for disability is (today) simply too transgressive.<sup>15</sup> It is not simply that in “choosing” to be “disabled” one is desiring an object that the able-bodied majority do not find desirable; it is that one is desiring that which is thought to limit and counter desire itself—that which from the perspective of ableism can only be experienced as a constraint, as an unsolicited and unwelcome restriction, and, for that reason, as something to be actively avoided, repulsed by, or even feared.

One might counter that Anderson Cooper, his audience, and all those who might applaud at the inappropriateness of White’s desire are simply failing to be empathetic. One might counter that such persons should employ the golden rule: do unto others as you would have them do unto you. Bracketing whether or not healthcare practitioners (HCPs) should perform therapeutic amputation for people with BIID, if one were in White’s situation, would one not want such a surgery? The golden rule appears in some form in nearly every religious tradition across history, and part of its power, I would contend, is in its implicit exhortation to *imagine* oneself in the other’s situation.<sup>16</sup> It asks one

to be morally sensitive in the way Mark Johnson outlines in the opening epigraph. When applied to BIID, however, the problem emerges quite clearly. If one cannot possibly imagine wanting to be disabled, one cannot determine how one would want to be treated if one experiences BIID. As Anita Silvers notes, “our aversion to the very idea of being disabled forestalls our understanding the disabled from their perspective.”<sup>17</sup> Indeed, it forestalls our understanding of human corporeal variation and experience *tout court*. The golden rule fails to have prescriptive force when one cannot imagine another’s situation as the other testifies to experiencing it. Implicit in Cooper’s comment and the ensuing applause is not just disbelief in the veracity of White’s claims about her own experience, but a more thoroughgoing incredulity regarding the very *possibility* of her desire.

That desiring disability is culturally unimaginable is demonstrated in part through the widespread and vitriolic stigmatization of surgery for BIID. In 2000, an article in *The Atlantic* was titled “A New Way to Be Mad.”<sup>18</sup> In June 2015, an online article in the *National Review* ran the click-bait headline “Bruce Jenner’s Sex Change Is Self-Mutilation” for a piece entitled “People Who Cut Off Their Own Limbs (and Their Enablers),” wherein the author uses the example of transabled surgery to discount transgender surgery.<sup>19</sup> If one can only image a desire as pathological, one cannot imagine that desire as authentic. One can hide intolerance plainly in sight through the bastion of pathologization. Put otherwise, if another’s desire for X is judged by one as possible only if something is “wrong” with that person, one’s judgment of that person and their desire is shifted outside the auspices of social acceptability and typical constraints on moral praxis, specifically constraints which pertain to individual differences, choices, and the like. However, the moment one questions the norms and principles upon which such judgment is based, it is possible that oneself, not the other, is morally culpable.

Before I further address the role of pathologization with respect to transability, an important caveat is in order. I above defined BIID as a “rare condition characterized by an intense desire or need to move from a given state of ability to one of relative impairment, often through amputation.” I used the term impairment as a way of signaling the distinction common in disability studies between “disability” and “impairment,” typically referred to as the “social model” of disability.<sup>20</sup> “Impairment” indicates one’s particular embodied condition and “disability” names the social ramifications of a given impairment, ranging from stigma to oppression to numerous forms of inaccessibility or unequal access. With that distinction in mind, no one with BIID, as far as I’m aware, describes a desire for disability *per se*. Yet, tellingly, part of the resistance to support for surgery for people diagnosed with BIID is precisely through a conflation of that distinction. People living with disabilities who experience typical disability stigma might feel as though one with BIID who desires impairment is not sensitive to the extent to which that impairment will bring about significant negative social effects. However, testimony from people with BIID suggests this concern is ill-founded.<sup>21</sup>

Given the prevalence of different types of disability-based cultural practices and identities, from various disability sports to the Neurodiversity movement to Deaf culture, why don't more people with BIID explain their experience in terms of a cultural identity—as opposed to solely needing or desiring to change their bodily form to fit how they feel “in” their body? One explanation has to do with the current state of medical institutions, which are constitutively formed by what Jennifer Scuro terms the “ableist affections [of] neoliberal politics,” i.e., the ableism embedded in the consumerist swath of neoliberal values and the multitude of its geopolitical effects.<sup>22</sup> Given this state of affairs, it is only through the pathologization of the experience of BIID that such people can take safe steps to bring their bodily identity into alignment with their bodily form. Insurance, for example, typically won't cover procedures if they are not officially related to a documented and medically accepted “condition.” Another explanation is that even for this unique set of people who are seeking to impair themselves and thereby move into a state of disability in the social sense, even they are under the influence of various forms of disability stigma. Alternatively, perhaps instead of mere disability stigma, they are under the influence of the more encompassing ideology of the ableist conflation: the assumption that anything deemed a “disability” is intrinsically defined by and experienced as a “lack” and thereby a harm with respect to potential well-being.<sup>23</sup> For example, while it may be possible for there to be a blind community (based upon shared experiences), the idea of blind culture (the gainful, rich, and unique experiences relating to blindness that those who are sighted *lack*) might remain doubtful under such auspices. But, given evidence from the lives of people who experience blindness, that doubtfulness is itself doubtful and, I would argue, ultimately grounded upon ableist assumptions.<sup>24</sup> Having now discussed BIID and some of ethical issues it raises, I will turn to analyze arguments from harm against surgery designed to address it.

## II. ARGUMENTS FROM HARM AGAINST BIID SURGERY

Although harm is undeniably a central moral notion, it is not yet well understood.

—Guy Kahane and Julian Savulescu<sup>25</sup>

Arguments against surgery for BIID are often based on the principle of nonmaleficence, which holds that an HCP should not cause harm or injury to a patient, whether by acts of commission or omission.<sup>26</sup> This principle, enshrined in bioethics literature by Beauchamp and Childress' field-defining *Principles of Biomedical Ethics*, dates at least back to the Hippocratic Oath.<sup>27</sup> An influential article from 2009 in *The American Journal of Bioethics* by Sabine Müller, entitled “Body Integrity Identity Disorder (BIID)—Is the Amputation of Healthy Limbs Ethically Justified?” draws upon this principle in order to argue against a symptomatic approach to BIID. Müller contends that while surgery for elective amputation cures the primary symptom of BIID (the *feeling* of having an unintegrated limb), it does not address its underlying neurological cause.<sup>28</sup> She thus ultimately argues against surgery for BIID patients. Of the

seven published responses to Müller's article, just three definitively support the surgery, either as a last resort or as the only viable resort available today.<sup>29</sup> Those that do not support the surgery rely more heavily upon the concept of harm.<sup>30</sup>

For example, in their response to Müller's piece, Jolkowitz and Zivotofsky write, “the majority opinion [in Jewish Law, the perspective out of which their article is framed] permits cosmetic surgery based on the obligation to ‘love your neighbor like yourself’—in our mind, it is hard to argue that therapeutic amputation is an act of ‘loving your neighbor.’”<sup>31</sup> The implication is that therapeutic amputation is neither an act of love nor a neutral act, but one of harm. No argument is given for this claim. Müller appears, at times, to hold a similar view. Explaining the difference between GID and BIID, she writes, “genital surgeries on transsexuals aims for a normal, social [sic] accepted, not disabled form of human existence.”<sup>32</sup> Müller appears to here uncritically utilize the widely assailed medical model of disability, under which disability is considered an individual misfortune or tragedy resulting from genetic or environmental insult. Therapeutic amputation constitutes a harm for Müller because, unlike genital reassignment surgery, it seeks disability: that which is presumably a harm, abnormal, and not socially accepted.<sup>33</sup>

Upon critical reflection concerning the meaning of “normal” and “socially accepted,” it is not clear how Müller's argument holds up. While, for the sake of argument, one could claim that the end-goal of genital surgery correlates to a “normal” sex/gender binary, the desire to surgically change one's sexual anatomy, in and of itself, is today neither “normal,” nor “socially acceptable” in any general sense of those terms.<sup>34</sup> Furthermore, depending upon social judgment of one's physical appearance, dressing in clothing that aligns with social norms corresponding to a sex-assignment surgery might make one a target for hate crimes and significant social ostracization because of an “abnormal” and socially “unacceptable” appearance. By deploying a concept of disability wherein disability is conflated with harm—whether the “harm” of genetic defect, acute injury, chronic disease, or what have you—Müller's arguments traffic in ableism and disability stigma, however unwittingly. The argument is ableist, to be clear, insofar as it assumes, without evidence or argumentation, that the “standard” able-body is, *ceteris paribus*, in and of itself better than the non-standard, disabled body.<sup>35</sup>

Jozsef Kovacks, also working with a medical model of disability, argues against Müller that *both* GID and BIID create “from a healthy body a seriously disabled one” insofar as GID causes an “invisible, but very serious disability” by depriving an otherwise “healthy person from the possibility to reproduce.”<sup>36</sup> Setting aside whether or not—or how—GID is an instance of disability, Kovacks then goes on to clarify that since most HCPs support sex-reassignment surgery, the “paternalistic prohibition to provide surgery for BIID patients mirrors our own aversion of physical disabilities.”<sup>37</sup> Kovacks concludes, “if BIID is a valid psychiatric disorder, then BIID sufferers do not exchange their health for disability. They exchange the suffering caused by their mental disorder for the suffering caused by a physical disability.” Although

I find Kovacks' argument more convincing than Müller's and less problematic in certain respects, the lack of rigor and awareness with respect to the concept of disability is glaring in the work of both authors. The assumption that the primary or most relevant differences introduced by therapeutic amputation-related impairments are questions of individual physiology and not societal conditions ignores the very foundation of the disability rights movement as well as over fifty years of disability studies scholarship ranging across the humanities and social sciences. This body of work and activism suggests that in numerous cases of disability, it is societal conditions that primarily and negatively affect the flourishing of people with various impairments.<sup>38</sup> That is to say, especially once one takes into serious consideration the empirical contingency of current forms of material-social environments and the various accesses they afford, hinder, or prohibit, the harm is often less the impairment, if at all, and more the societal configuration and responses to non-normate embodiment. Taking this seriously would mean, for example, that one is also or perhaps even more concerned about wheelchair accessibility, disability rights, and social discrimination for a post-amputation Chloe-Jennings White than one is about the ethics of that amputation.

### III. NORMALITY AND HARM

If, as the discussion above demonstrates, some bioethicists deploy an uncritical concept of harm in relation to understandings of disability and, by extension, BIID, what of those who analyze the concept of harm itself? In "The Concept of Harm and the Significance of Normality," Guy Kahane and Julian Savulescu [K&S] work to understand the normative difference between varying phenomena people claim as harmful or potentially so.<sup>39</sup> They note that while there is strong intuitive or common sense support for claims that (1) the presence of severe intellectual impairment, paraplegia, blindness, or early death are harms, claims that (2) lacking a statistically high IQ, great artistic talent, or longevity below 130 do not have such support. The relevant difference in the examples, they argue, appears to be biological normality. Yet, and this is crucial, they dismiss biological normality outright as normatively relevant. "The moral insignificance of biological normality and abnormality seems so obvious on reflection, is so widely accepted, and has been vigorously and, to our mind, conclusively argued, that we will simply assume it here" (320). They instead argue that while "normality does matter," it doesn't do so in "the way many assume." There is "no deep *intrinsic* normative difference between the items on (1) and (2), yet [one can] still hold that there are nevertheless morally important differences between the two lists." "Statistical normality," they continue, "while lacking inherent moral significance, can nevertheless matter *derivatively*." I'll call this the *weak statistical normality* [WSN] argument: statistical normality provides, or at least tracks, a thin, derivative, and "non-intrinsically moral" measure for normative judgments (323). My aim is to show that the WSN is not normative; statistical normality is merely descriptive. Like biological normality, it should be dismissed as a normative ground.

Of what, precisely, is weak statistical normality derivative? It can't be derivative of biological normality, since that was rejected as having moral significance. Is it derivative

of the intuitions in question? If so, it holds no more normative weight than any set of intuitions do, and I am not convinced intuitions, in and of themselves, hold any *prima facie* normative weight, whatever their descriptive value.<sup>40</sup> Even if one takes moral intuitions as bearing upon the methodological origins of a naturalized ethical inquiry into normativity, that they are intuitions about a *historically oppressed group* makes them suspect for any critical inquiry, naturalized or not. Given the horrifying and deeply entrenched history of ableism across intellectual traditions, East and West, any responsible ethicist should be profoundly distrustful of philosophical intuitions about disability and, *a fortiori*, intuitions about disability originating from non-disabled people.<sup>41</sup> And, as I argue in more detail below, the concept of harm (as with the concept of "severity" or "disease" or a host of other terms deployed today by too many bioethicists without sufficient critical analysis) is long overdue for critical inquiry if it is to avoid not only the ableist, but also the racist, sexist, and classist, et al., medical practices and theories against which bioethics historically arose as a distinct discipline in the first place.

The fulcrum of the WSN appears shortly thereafter: "limitations of resources mean that we can rarely promote wellbeing in all possible ways. We have to choose . . . this is a question about distributive justice" (325). But limited resources mark an empirical condition pertaining to the application of normative principles—that there are limited resources does not itself help one determine *which* resources should be allocated to whom or in what quantity. Thus, I agree that statistical normality is important, but it is important for descriptive ethics, not normative ethics. Because K&S, it seems to me, ultimately end up slipping from the descriptive to the normative in their assessment of the worth, however limited, of statistical normality—the way and extent to which it "matters," as they put it—they oversell its import. To take another example, they claim, "to the extent that items on (1) [severe intellectual impairment, paraplegia, blindness, or early death] tend to make people's lives significantly worse than the lives of *most* others, considerations of justice might give priority to the prevention or correction of these conditions." That would be a consideration derived from descriptions of states of affairs in the world, not normative considerations or principles.<sup>42</sup> It might suffice as grounds for policy-makers or politicians who seek to appease what they imagine as their constituency, but it is not a ground for ethicists.

All sorts of things *tend* to make people's lives significantly worse under current states of affairs (some such things, for example, pertain to race, gender/sex, ethnicity, religion, class, geographical location, etc.), but ethicists today do not attribute intrinsic moral worth to many such tendencies and for good *normative* reasons. To repeat, given the prevalence of ableism, ethicists concerned about questions pertaining to disability and normativity should have a *prima facie* distrust of descriptive accounts of wellbeing pertaining to disability originating from or primarily informed by the experience of the non-disabled. This holds as well for accounts originating from people with disabilities who have not been exposed to anti-ableist ways of thinking and disability-positive communities.

Disabled or non-disabled, our intuitions are deeply unreliable as normative grounds. Humans exhibit *durability bias*, the tendency to overpredict the duration of affective reactions, however grounded, to future events. Furthermore, this is due in part to *focalism*, the tendency to focus too much on an event in one's immediate attentional field and not consequences of other future events.<sup>43</sup> In short, we *predictably* misremember, misrepresent, and mispredict both past and future states of happiness and sadness, pleasure and pain, in relation to singular events, not to mention complex sets of events.<sup>44</sup> Focalism also contributes to *pain catastrophizing*, the fact that we regularly overestimate the intensity and duration of pain.<sup>45</sup> This further suggests that we significantly mischaracterize, mispredict, and generally misestimate the meaning of any phenomenon we *assume* to cause pain; this includes the vast range of phenomena we categorize as "disabilities," phenomena we, thanks to the ableist conflation, fallaciously associate or equate with pain and suffering.<sup>46</sup> To the extent that we deploy applications of abstract statistical norms to our own happiness and thereby pose normative determinations concerning its attainment, we—given psychological evidence about our memory and prognostications concerning well-being—are not relying on *thin* knowledge or *thin* norms: we are relying on little more than fictions. Statistical normality is not sufficient for predictions of happiness and, *a fortiori*, sufficient as a ground for normative judgment, even if only in reference to questions of distributive justice.

As K&S themselves note, the ultimate problem that efforts of such a kind face is the fact that "it's not especially clear how to draw a distinction between good and bad lives, as opposed to better and worse ones. It is controversial whether and how to draw a line between those lives that are worth living and those that are not—but it's at least clear that the latter must contain extreme, unremitting suffering that can't be relieved" (322). If that (absolutely crucial) distinction is *not especially clear*, then is not the ethicist in the same position as any other researcher before a complex, ambiguous, and normatively fraught phenomena? Given the remarkable unreliability of intuitions, especially as they relate to hedonic considerations, one must substantially engage empirical and reflective research on these issues, both positive and critical in nature. One must also, given the entrenchment of ableism, give extra weight to the testimony of those who actually experience the conditions, states, or forms of life to which bioethicists refer. I hope to have demonstrated that more engagement with the body of work across critical disability studies and philosophy of disability would benefit a host of bioethical debates, especially those involving concepts of harm and well-being.

#### IV. TAKING ABLEISM IN (BIO)ETHICS SERIOUSLY

A naturalized ethics, one which grounds its principles in the concrete experiences of the beings for whom its prescriptions are thought to bear, is an ethics beholden to the structures and singularities of experiences. Thus, while I do not deny that statistical normality plays a practical role with respect to normative judgments, I think a better route to ground such judgments is through a critical synthesis of empirical and reflective evidence about lives attested

to be or not be worth living. Given the pervasiveness of ableism, substantial disability education (including, but not limited to, literatures in critical disability studies, disability life writing, and philosophy of disability) is needed to *even begin* to understand what it might mean to live a life involving congenital blindness, Ehlers-Danlos syndrome, or specific forms of autism, for example, much less the normative considerations concerning the possibility of selecting for or against such forms of life.

I agree with K&S that "we need the concept of harm for both explanatory and predictive purposes (its theoretical use), and to mark certain kinds of reasons for action and attitude (its normative use)" (323). But, as I have demonstrated, the use of "harm" to discount therapeutic amputation for people with BIID is an instructive counterexample to both the normativity of statistical normality and the common-sense deployment of harm as a prescriptive principle. Relatedly, we should be very worried that there are a host of conditions that were previously thought to be suffered and constitute harm that, with critically informed research, prove, in fact, fruitful, gainful, and rich forms of life.<sup>47</sup> If it is indeed the case, as I find it to be, that "it is controversial whether and how to draw a line between those lives that are worth living and those that are not," then we need much more critical empirical and reflective work on the experience of lives on or near that line—a line, it bears continually repeating, that is more often than not drawn intuitively by the able-bodied and thus drawn with what should be *prima facie* suspicion, not support.

Across academic scholarship, especially of a critical sort, there is consensus, if any can be said to exist, about a very small subset of lives not worth living. Accordingly, bioethicists should have very little confidence in judgments over lives deemed not worth living or lives said to have intrinsically or necessarily low QOL. There is an alarming lack of what Eva Kittay insightfully terms *epistemic responsibility* and *epistemic modesty* on the part of a wide swath of bioethicists when it comes to judgment about non-normate lives, about lives lived with and through disability.<sup>48</sup> If bioethicists and ethicists more generally wish to have a better grasp on the conditions and particularities of lives worth living, more critical reflection is required concerning the way in which the concept of harm has historically been used to end lives, not enrich them.

#### NOTES

1. Johnson, *Moral Imagination: Implications of Cognitive Science for Ethics*, 199.
2. Brennan, *The Transmission of Affect*, 119.
3. This paper is a significantly revised and expanded form of a presentation given at the 2016 Society for Disability Studies and at the 2016 Eastern APA as part of a session for the Society for Philosophy of Disability. I am grateful to each audience for constructive and provocative feedback. Jennifer Scuro and Lauren Guilmette gave insightful and incisive feedback at every stage of the project. David Peña-Guzmán and Katherine Davies also provided extremely helpful comments on its penultimate draft. This piece forms part of a much larger project, stemming from my dissertation and its revision into monograph form, that focuses on the history of what I call the "ableist conflation": the conflation of disability with pain and suffering. More specifically, this is the assumption—attested across myriad philosophical traditions and epochs—that disability is a harm and concomitant

with pain and suffering. See also Joel Michael Reynolds, "'I'd Rather Be Dead Than Disabled': The Ableist Conflation and the Meanings of Disability" (forthcoming).

4. Philosophers including Eva Kittay, Anita Silvers, Licia Carlson, Martha Nussbaum, and Shelley Tremain have each done significant work critiquing and/or amending such ideals.
5. Wolbring, "Ethical Theories and Discourses through an Ability Expectations and Ableism Lens: The Case of Enhancement and Global Regulation"; Wolbring, "Ability Privilege: A Needed Addition to Privilege Studies," *Journal for Critical Animal Studies*.
6. Stramondo, "Why Bioethics Needs a Disability Moral Psychology."
7. As I discuss below, "transabled" is a term some people who have been diagnosed with or experience what is categorized as BIID use to identify themselves. Transability, then, is not identical with BIID. The latter is a medical diagnosis, one which is still being contested along with terms such as apotemnophilia and somatoparaphrenia et al. "Transability," on the other hand, is a more politically charged marker of identity and, depending upon one's situation, also community. See note 10 below. Because it is currently the most accepted term in the literature of bioethics and philosophy of disability, I primarily use the term BIID throughout this paper.
8. No sufficient statistical research has been carried out to determine the precise percentage of people living with BIID. Estimates, however, suggest that it is well below 1 percent of the population.
9. Muller, "Body Integrity Identity Disorder (BIID)—Is the Amputation of Healthy Limbs Ethically Justified?"
10. Research on BIID has exploded in recent years, including scholarship in fields ranging across sociology, psychology, cognitive neuroscience, critical disability studies (including, especially, English and literary theory), bioethics, philosophy of disability, feminist philosophy, queer theory, and trans\* studies, among others. I thus take what I highlight here to be in no way exhaustive. After finishing this paper, I became aware of the dissertation of Christine Marie Wieseler, "A Feminist Contestation of Ableist Assumptions: Implications for Biomedical Ethics, Disability Theory, and Phenomenology" (University of South Florida, 2016, <http://scholarcommons.usf.edu/cgi/viewcontent.cgi?article=7629&context=etd>). The fifth and final chapter focuses on BIID and, besides being remarkably insightful, it is the most comprehensive analysis I have read on the subject. Needless to say, I highly recommend it. The first research, as far as I'm aware, on what is now called BIID is: John Money, Russell Jobaris, and Gregg Furth, "Apotemnophilia: Two Cases of Self-Demand Amputation as a Paraphilia." With respect to neurological literature, one of the first studies is Brang, McGeoch, and Ramachandran, "Apotemnophilia: A Neurological Disorder." The following article attempts to bring together the psychological and neurological findings: First and Fisher, "Body Integrity Identity Disorder: The Persistent Desire to Acquire a Physical Disability." For a critique of the epistemology of neurological etiologies with respect to such phenomena, see Fisher and First, "Examining the 'Neuro-' in Neurodiversity: Lessons from Body Integrity Identity Disorder." For key pieces in queer and trans\* studies, see especially, Susan Stryker and Nikki Sullivan, "King's Member, Queen's Body: Transsexual Surgery, Self-Demand Amputation, and the Somatechnics of Sovereign Power," in Nikki Sullivan and Samantha Murray, *Somatechnics: Queering The Technologisation of Bodies*, Queer Interventions; Baril, "'How Dare You Pretend To Be Disabled?' The Discounting of Transabled People and Their Claims in Disability Movements and Studies"; Baril, "Needing to Acquire a Physical Impairment/Disability: (Re)Thinking the Connections between Trans and Disability Studies through Transability"; Arfini, "Instructions for Becoming Disabled: A Narrative Analysis of the Project of the Transabled Body (Istruzioni per diventare disabili. Un'analisi narrativa del progetto sul corpo transabile)"; Arfini, "Transability." For work in critical disability studies, see Noson, "From Superabilità To Transabilità: Towards An Italian Disability Studies"; Stevens, "Interrogating Transability: A Catalyst to View Disability as Body Art." In sociology, Jenny L. Davis has written insightfully and extensively on the topic: Davis, "Morality Work Among the Transabled"; Davis, "Narrative Construction of a Ruptured Self: Stories of Transability on Transabled.org"; Davis, "Prosuming Identity: The Production and Consumption of Transableism on Transabled.org." In legal studies, see Mackenzie and Cox, "Transableism, Disability and Paternalism In Public Health Ethics: Taxonomies, Identity Disorders, and Persistent Unexplained Physical Symptoms"; Mackenzie, "Somatechnics of Medico-Legal Taxonomies: Elective Amputation and Transableism."
11. Wendell, *The Rejected Body: Feminist Philosophical Reflections On Disability*; Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities."
12. Spriggs, "Lesbian Couple Create a Child Who Is Deaf Like Them."
13. Bauman, *Deaf Gain Raising the Stakes for Human Diversity*. I will return to the question of disability-gain or what Elizabeth Barnes calls "good-difference" views of disability below. Barnes, *The Minority Body*, Studies In Feminist Philosophy Series. I should add that I highly, highly recommend that book for anyone wishing to educate themselves concerning ongoing arguments in philosophy of disability.
14. "Why Chloe Needlessly Spends Her Life in a Wheelchair," on *Anderson Cooper 360°* (CNN, 2012).
15. Fiona Kumari Campbell, *Contours of Ableism: The Production of Disability and Abledness* (New York: Palgrave Macmillan, 2009). Part of this relates to the question of the relationship of BIID to erotic desire. See De Preester, "Merleau-Ponty's Sexual Schema and the Sexual Component of Body Integrity Identity Disorder."
16. Gensler, *Ethics and the Golden Rule*; Wattles, *The Golden Rule*.
17. Silvers, "Reconciling Equality to Difference: Caring (F)or Justice for People with Disabilities," 37.
18. Elliot, "A New Way to Be Mad."
19. Tuttle, "People Who Cut Off Their Own Limbs (and Their Enablers)."
20. There are, in fact, multiple social models, and for any given form of it, there is vigorous debate across the breadth of disability studies' scholarship over its meaning, scope, etc. There is a copious literature debating the merits and many meanings of this distinction which I cannot engage here. As a primer, see Davis, *The Disability Studies Reader*, 4th ed. The newest, fifth edition of the DSR is forthcoming.
21. In addition to her other work cited above, this is especially clear in Davis, "Narrative Constuction."
22. See Scuro, "The Ableist Affections of a Neoliberal Politics," *APA Newsletter on Philosophy and Medicine* (Current Issue); Scuro, "Thinking of Bhopal: Women's Bodies as Waste-Sites."
23. I address the conflation of various forms of disability with lack and harm at length in Reynolds, "'I'd Rather Be Dead Than Disabled.' See note 3 above. I am grateful to David Peña-Guzmán for pushing me on the possibility of a more general ableism (beyond mere disability stigma) potentially at work in the lack of identification with "disability" by those diagnosed with BIID.
24. Despite the large amount of research on BIID, I find that more analyses of the lived experience of people with BIID is requisite, especially qualitative sociological and critical phenomenological research (see note 10 above, especially the work of Jenny L. Davis). In relation to my claim regarding blindness, see Reynolds, "On Being Outside The (Normate) Body: Merleau-Ponty's Aveugle and Crip Phenomenology," forthcoming.
25. Kahane and Savulescu, "The Concept of Harm and the Significance of Normality," 318. On the leading body modification website "Modblog," a person going under the pseudonym Jason is interviewed about the "accident" he successfully staged in order to cut off his right arm below the elbow with a power tool. Jason identifies himself as a "body-integrity-disorder (BIID) dude" and says, "for sure it's not rational to want to cut off your arm or leg. There's no argument you can make that life will be easier, or that you'll be more capable doing anything." Larratt, "One Hand Jason: BIID Interview in BME/News."
26. Some distinguish between disadvantage and harm, a practice I will not follow here.
27. Beauchamp and Childress, *Principles of Biomedical Ethics*, 7th ed. What is called the "harm principle" originates from John Stuart Mill (*On Liberty*, 13). In political philosophy since, including offshoots or variations ranging from critical theory to critical international relations theory, there is significant discussion over the role and nature of this principle and the concept of harm it assumes. I cannot address these issues here. See, e.g., Brincat, "The Harm Principle and Recognition Theory."

28. She assumes such neurological research to have reached sufficient consensus for biomedical decisions to be made based upon that research.
29. Jozsef Kovacs, Jenny Slatman, and Guy Widdershove, and Neil Levy. Avi Cramer leaves open whether surgeons are morally permitted to perform the surgeries. See Volume 9, Issue 1, of the *American Journal of Bioethics*.
30. Because of the breadth of literature on BIID and given the space and aims at hand, I focus here on examples of how harm is used from this set of articles (Müller's target article and the seven responses to it). While my aims with respect to an analysis of harm in extant literatures are thus modest, I take the implications I draw, if convincing, to have significant ramifications for the concept of harm in general and its use across bioethics in particular.
31. Jotkowitz and Zivotofsky, "Body Integrity Identity Disorder (BIID) and the Limits of Autonomy," 56.
32. Müller, "BIID—Aqua Fortis for Scientific Explanations of Psychic Phenomena?," w4.
33. Some scholars distinguish between action-relative and effective-relative forms of harm. On an action-relative account of harm, "harm" picks out cases where an action makes one worse off than one would have been in the absence of that action. On an effect-relative account of harm, "harm" picks out cases where the effects of an action are held to bear negatively on one's well-being irrespective of how would fare in the absence of that action. I found the following article very helpful on this topic: Gardner, "On the Strength of the Reason Against Harming." It is instructive to note that scholars arguing about BIID seem to slip between these two senses of harm or be unaware of the distinction entirely. Some hold therapeutic amputation for BIID to constitute a harm *even if* the person with BIID claims they are better off after it: an effect-relative account of harm. Others hold therapeutic amputation for BIID to be a harm insofar as they find it implausible that it will make that person's life better off than it would be in the absence of the amputation: an action-relative account of harm. Because all those in the debate hold amputation to be a harm in some sense (unlike views on many forms of body modification), proponents of therapeutic amputation employ an action-relative account of harm and argue that we have reason to believe it *will* make that person's life better off. I find much more to be said on this topic, but there is not space to do so here.
34. Despite, as I argued above, being imaginable, being something which *at least some* cultural spaces deem legitimate, defensible, and/or understandable.
35. On the multiple issues such ableism raises especially in a biomedical decision-making context, see Reynolds, "The Ableism of Quality of Life Judgments in Disorders of Consciousness: Who Bears Epistemic Responsibility?"
36. Kovacs, "Whose Identity Is It Anyway?," 44.
37. *Ibid.*, 45.
38. As my phrasing indicates, this is by no means true for all cases of disability, especially those concomitant with severe illness or chronic pain. See, e.g., Reynolds, "Feeding Upon Death: Pain, Possibility, and Transformation in S. Kay Toombs and Kafka's *The Metamorphosis*"; Patsavas, "Recovering a Cripistemology of Pain: Leaky Bodies, Connective Tissue, and Feeling Discourse."
39. Kahane and Savulescu, "The Concept of Harm and the Significance of Normality." Citations to this article appear in text hereafter.
40. This is not to say that intuitions are not useful for descriptive ethics and thereby for an origin point of inquiry into normative concerns—it's just to say that the content of intuitions do not in and of themselves bear normative weight simply by *virtue of being intuitive* to a given set of people. For those who would immediately invoke debates over the is/ought distinction, the "prima facie" qualification I employ is extremely important for the specific arguments I make here as well as my general positions regarding that relation more generally (which, given the space and aims at hand, I cannot detail).
41. E.g., see Tremain, *Foucault And The Government of Disability*; Carlson, *The Faces Of Intellectual Disability: Philosophical Reflections*.
42. There is yet another issue that impedes the WSN. The examples of both (1) and (2) are both biologically and statistically exceptional—they fall on the edges of the phenotypical bell curve for *homo sapiens*. As the authors note at one point, substances or genetic manipulation could make the abilities of (2) a live option for those with enough societal and economic resources in the near future. That the examples of (2) could quickly move closer to being of a kind with (1) should give even more pause to the merit of statistical normativity. In short, while biological normativity is little more than dogmatic prejudice, statistical normativity is little more than such prejudice held in the sway of an ethics of comparativity. In another passage, after discussing how the *descriptive* nature of statistical normality accounts for its theoretic use (its use for providing explanations and predictions of wellbeing), Kahane and Savulescu turn to discuss its normative use, which they gloss as its ability to mark reasons for action and attitude (323–24). They note that "harm and disadvantage are not only explanatory notions. They also typically have normative significance" (324). "Typically" with respect to who and what domain? I agree that such concepts are typically *thought* by many bioethicists to have normative significance. But, to repeat a point from above, the application of the concept of harm to justify all sorts of horrors across biomedical history suggests that the way in which harm and disadvantage *typically* have and have had normative significance is itself fraught and should precipitate *prima facie* suspicion, not support. While, to be clear, there is much to appreciate in Kahane and Savulescu's article and in their genuine efforts to engage research in disability studies as well as testimony from people living with disabilities throughout their inquiry, I am left unconvinced that there is a meaningful moral distinction between biological normality and statistical normality.
43. Wilson et al., "Focalism: A Source of Durability Bias in Affective Forecasting." See also discussions of *focusing effect* in Schkade and Kahneman, "Does Living in California Make People Happy? A Focusing Illusion in Judgments of Life Satisfaction."
44. Wilson, Meyers, and Gilbert, "'How Happy Was I, Anyway?'" A Retrospective Impact Bias."
45. Day and Thorn, "The Relationship of Demographic and Psychosocial Variables to Pain-Related Outcomes in a Rural Chronic Pain Population."
46. See notes 23 and 3 above.
47. Lantos, "Trisomy 13 and 18--Treatment Decisions in a Stable Gray Zone."
48. Kittay, *Love's Labor: Essays on Women, Equality, and Dependency*. Put otherwise, there needs to be, specifically and especially for able-bodied bioethicists, what Lauren Guilmette terms "curiosity deployed in the mode of care" for the myriad and vast range of experiences of disability. Guilmette, "Feminist Philosophies of Disability, Foucault, and the Ethics of Curiosity"; Guilmette, "In What We Tend to Feel Is Without History: Foucault, Affect, and the Ethics of Curiosity."

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## Curiosity-as-Care: Feminist Philosophies of Disability, Foucault, and the Ethics of Curiosity

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### ABSTRACT

Feminist philosophers of disability, such as Shelley Tremain and Licia Carlson, have utilized elements of Michel Foucault's work to unpack everyday dynamics of marginalization and misrecognition against the bodily ambiguities of others. Thus, Carlson (2010) reclaims curiosity from the stigma of violation and/or exploitation of difference, reframed as the *care* one takes for, as Foucault (1980) puts it, "what exists and could exist; a readiness to find strange and singular what surrounds us." Following these insights from feminist philosophers of disability, this paper develops an ethics—or, more precisely, an *ethos*—of resisting curiosity's normalizing violence: the desire to pinpoint deviations on a grid, and of cultivating curiosity's virtue, potentially transformative interest in the lives of others. I consider the virtue of curiosity in light of the 2008 debate between Peter Singer and Eva Feder Kittay—arguing that Singer demonstrates a failure of curiosity in the lives of disabled persons—and I conclude by drawing on resonances with Rosemarie Garland-Thomson's work on staring: the "intense attentiveness" of the stare, which—while often loaded with assumptions—offers "supple and effective raw material" for the shifting of learned perceptual frames, as well as for engaging with those who may not look back, or may perceive differently.

### KEYWORDS

Feminist Philosophy of Disability, Foucault, Curiosity, Affect, Ableism

Staring's strange pattern of interest, attention, and engagement, the mobilization of its essential curiosity, might be understood as a potential act of be-holding, of holding the being of another particular individual . . .<sup>1</sup>

If, in an ableist cultural paradigm, perceptions of disability excite various affect scripts of disgust, pity, and/or fear of one's own bodily vulnerability, how might one productively engage and disrupt these scripts? This paper develops "curiosity" as an epistemic and ethical virtue following the insights of feminist philosophers of disability in conversation with Michel Foucault. By "virtue," here, I build upon Judith Butler's description of "Foucault's virtue" linked

to a notion of critique—"the risking of established order"—which engages the limits of the moral community in a given culture.<sup>2</sup> Foucault's virtue is his willingness to question the interpretive cultural frames through which some lives become unintelligible as human lives, monstrous and pathologized. As the affective spark of this virtue, Foucault invokes "curiosity" as the unifying aim of his work.<sup>3</sup> While Western philosophers have historically belittled curiosity as a mode of knowledge-acquisition, they have also demonstrated a failure of curiosity in their thinking about disability. This failure is especially the case with intellectual disabilities, which challenge the discipline's hierarchically rationalist self-conception.

Thus, feminist philosopher of disability Shelley Tremain claims that Foucault's value for analyzing disability cannot be overstated, as his genealogical critiques of disciplinary power and biopower bring under examination the simultaneous obsessive study and forgetting of a culture's "abnormals," who are categorized and separated off "as (for instance) physically impaired, insane, handicapped."<sup>4</sup> And Licia Carlson begins *The Faces of Intellectual Disability* with Foucault's reclamation of curiosity as the *care* one takes for, as Foucault writes, "what exists and could exist; a readiness to find strange and singular what surrounds us."<sup>5</sup> Following these insights, this paper develops an ethics—or, more precisely, an *ethos*—of resisting curiosity's normalizing violence: the desire to pinpoint deviations on a grid, and of cultivating curiosity's virtue: a potentially transformative interest in the lives of others.

I begin from a famous example of disability perspectives colliding with the taken-for-granted, implicit norms of established "biomedical ethics": the controversial 2008 exchange between Peter Singer and Eva Kittay following Singer's utilitarian arguments about the comparative moral status of animals and of people with disabilities, especially intellectual disabilities. Here, I draw upon the epistemic virtues Kittay aptly raises in response to Singer, which emphasize modesty—a restraint Singer's crude comparisons lack. I extend Kittay's sense of epistemic virtue to consider our striving and desirous capacities for interest—what Foucault would call "the will to know"—which must be encouraged and redirected as well as properly restrained in the discernment of what breaks with expectation. This affective force behind the desire to understand can lead to violence—the desire to pin down and hierarchize—as it can also spark a transformative mode of attention, one which (following Foucault) I name curiosity-as-care. I extend Kittay's critique to note that Singer's claims exhibit not only a lack of epistemic humility, but also an exemplary failure of curiosity in his engagement with what he does not understand. That constitutes an ethical failure in Foucault-Butler sense of "virtue" noted above; as Butler paraphrases Foucault: "Moral experience has to do with a self-transformation prompted by a form of knowledge that is foreign to one's own."<sup>6</sup>

Western philosophy, especially biomedical ethics, has for the most part historically promoted an ableist configuration of "man" as not only rational but also self-sufficient and independent, framing disabled lives as synonymous with suffering and, in bioethical discourses especially, as

questionably “worth living.” Along these lines, the utilitarian philosopher and animal rights advocate Peter Singer has argued in various outlets that *some* animals have higher cognitive capacities than *some* people with intellectual disabilities;<sup>7</sup> therefore, he argues, these animals ought to be considered bearers of greater moral worth than those living with disabilities, and animal suffering through forms of human consumption should be appropriately curbed.<sup>8</sup> I envision Singer before a big and clumsy Scale of Moral Worth, politely asking the bonobos and the elephants to sit still as they hold down the balance, throwing their weight against a shrouded figure of “suffering” whose value does not register, given the configuration of the Scale. While the cause of animal rights should not be diminished or tossed aside, here Singer utilizes a broad spectrum of lived experiences as rhetorical support for the inclusion of animals in the moral community. Licia Carlson aptly names this move *conceptual exploitation*: Singer uses a figuration of the “intellectual disabled” to make a point about what he calls “speciesism” and the relative moral status of animals.<sup>9</sup>

In “The Personal is the Philosophical is the Political,” Eva Kittay reflects on her 2008 exchanges with Singer and the utilitarian ethicist Jeff McMahan. Drawing on her own lived and embodied experience of that exchange, Kittay’s style of writing underscores the affective dimensions of their respective knowledge claims. Thus, she *shows* how their thinking oversteps by offering the reader her own embodied experience of the conversation, what it *felt* like to debate these questions of moral worth and dignity concerning lives like that of her own daughter. And yet, importantly, Kittay’s affective response of nausea includes but extends beyond her *personal* feeling to the *philosophical* and *political* implications of these disparate frames of reference. She argues that, beneath offensive claims about “livable lives,” the “ethics of killing,” and the relative inferiority of people like her own daughter, their fundamental problem stems from a failure to adhere to epistemic principles of humility in philosophizing. As she writes, they neglect the virtues of inquiry: “epistemic responsibility: know the subject that you are using to make a philosophical point, and epistemic modesty: know what you don’t know.”<sup>10</sup> Thus, Kittay criticizes the hubris of Singer and McMahan to presume to know the cognitive impairments they write about, having never substantially interacted with a cognitively disabled person or considered spaces and practices that might cultivate his or her interactive capacities, which are no more set in stone than the possibilities of those marked “able.”

My claim extends Kittay’s critique of this failure of epistemic modesty. I argue that Singer fails to take *curiosity* in the lives of children and adults with intellectual disabilities. Kittay recounts an exchange about where Singer brings his classes on field trips and just how far he is willing to drive. Singer takes his students to a neonatal unit in New Brunswick, roughly half an hour from Princeton, as Kittay writes:

[P]resumably to learn that physicians quietly believe that they should not be keeping some of these neonates alive. Here all one sees of cognitive disability is a tiny creature, more fetus than infant, lying in a bubble-like environment,

with tubes coming out of all the infant’s orifices and monitors ringing, clinking, and clanging. To offer a different picture, I invited him to come and visit the Center for Discovery, a community composed of group homes for people with very significant and multiple disabilities approximately two hours from New York City (and an hour and a half from Princeton, NJ), which is now home to my daughter, Sessa. Here people with cognitive disabilities live flourishing lives, work, and are well cared for, not warehoused.<sup>11</sup>

In response to Kittay’s offer, Singer declines because, as he says, “It’s a little further than New Brunswick.” When Kittay then offers to arrange his visit, he replies from an insistently “neutral” position, “I would like you to tell me what it is—just in terms of the argument that I presented—what it is that I would see there that would challenge the argument I presented.” Kittay can only begin to imagine where to start. The difference in these orientations to the same subject is stark. Is one of them “right”? This depends on what kinds of truth we believe are not only possible but, furthermore, relevant to “ethics” as such, and how far we are willing to drive to encounter them.

Singer’s response demonstrates a failure of what Kittay calls epistemic modesty and, by extension, of what, following Foucault, I call “curiosity-as-care.” Singer applies a normative principle of minimizing suffering, laden with ableist assumptions,<sup>12</sup> and Kittay responds that this application itself bears a violence—that it, in fact, *hurts* her—and thus breaks with the epistemic virtues she names: in order to care *well* for another being, one must have concrete knowledge of what one is talking about. The point of this violence, lost on her interlocutors in this debate, is not that Singer and McMahan *hurt her feelings*; rather, it is that they failed to engage experientially with—that is, failed to be *curious* about—those whose lives hang in the balance when prominent bioethicists make claims about their relative moral worth.<sup>13</sup>

By caring, I think this means more than just failing to sympathize, to do the imaginative work of envisioning himself in Kittay’s position (which he also clearly fails to do). Kittay’s discomfort registers—as Singer’s responses fail to grasp—the harms this mode of discourse enacts. This is not *just* a philosophical misstep, i.e., saying something wrong; rather, he fails to respond to Kittay’s pain on the basis of his insistence that he’s rationally “gotten it right.” What does it mean to be right? And what narcissistic ego-maintenance do we perpetuate as the *affect* of doing philosophy when an exchange of ideas loses sight of the people who are speaking (and of those excluded from the conversation)?

Here, I complement Kittay’s epistemic virtues with Foucault’s analysis of the “will-to-know” animating knowledge-acquisition and his ethics of “curiosity-as-care,” which motivates his attention to the archive of those judged, labeled, and forgotten by history, and which demands the re-channeling of this interest in addition to the Socratic restraint of humility. Kittay’s epistemic virtues mark the responsibility of defining limits, and her care ethics already contains this other-regarding element that works to discern

the context of another's claims; we cannot properly care by imagining that others want the same things we want, that my pleasure is the same as yours, or that your suffering could be quantified and comprehended by me as such. Insofar as "sympathy" and "empathy" move analogically—insistent that we must be somehow the same for me to invest my attention, interest, and/or care in you—these harmonies fall short of their ethical spark. At the other extreme, fearful of the partialities and potential projections of feeling, ethics clings to the abstract formality of reason and denies (or seeks to overcome) these affective and sensory capacities to feel with others. With Foucault, we can return to those virtuous capacities in a different register. Foucault's critical project self-consciously reflects on his own position and direction of interest in analyzing the archives of abnormals. Curiosity toward those judged and forgotten by history opens another venue for ethics, one that takes seriously and cultivates the affective movements of the will-to-know. Beyond identification, when we come to care about the "other" only insofar as he or she bears some resemblance to ourselves (i.e., appears "sympathetic"), Foucault's virtue of "curiosity-as-care" offers a different way out of this rift, one that builds on Kittay's account of epistemic virtues in her debate with Singer.

Curiosity finds its root in the Latin *curiosus*, an etymology suggesting care and diligence but which, in its modern incantations, has been eclipsed as impatient prying, with condescending connotations of "curiosity shops." Unlike sympathy, which finds grounding in commonality, curiosity marks an engagement with *difference*,<sup>14</sup> toward which one may react violently or compassionately, against which one may shore up one's own boundaries, or through which one might find those boundaries questioned and even transformed. Foucault writes that curiosity has been central to his work: negatively through his attention to the cruel excesses of disciplinary power, biopower, and the medical-moral gaze, but also positively as an unsettling mode of attention. As he writes, "not the curiosity that seeks to assimilate what it is proper for one to know, but that which enables one to get free of oneself."<sup>15</sup>

First, regarding Foucault's critical work on the *violence* of curiosity, Ellen Samuels has recently deepened this critique by analyzing cultural *fantasies of identification*, which conceptually cling to the dream of an immutable and knowable body.<sup>16</sup> In the grip of this bio-political curiosity, disability becomes not only an object to be identified, but also "the symbolic *anchor*" that enables the identification of bodies as such.<sup>17</sup> How we conceive of disability in turn frames our interactions with bodily difference; thus, while the *medical model* flattens and depoliticizes disability as "personal tragedy," as in the arguments of Singer, the social model in turn fails to be curious about the irreducible particularities of singular embodiment as themselves shaped by power relations. While we may at first glance prefer the *social model* insofar as it recognizes that ability takes shape through a built environment and institutions, which it diagnoses as structured to serve some and not others, Tremain and others have argued that its nature/culture distinction of bodily "impairment" and socialized "disability" abandons the body to the supposed value-neutrality of medical interpretation (a space heavily

mediated by ableist norms of what a body can do).<sup>18</sup> Following Samuels and Tremain, then, it appears that a "web of social control" distributes medical intelligibility as it also generates the specifying feeling of an individual identity—I am *this* and not *that*, intelligible not only to others but to myself only in the context of this web. The violent curiosity of biopower forms the outer limits of the rationalist modern subject, desirous to pin down and diagnose what it does not understand.

Second, regarding Foucault's recuperation of curiosity, we can follow Carlson in turning to his anonymous 1980 interview, "The Masked Philosopher," in which Foucault describes curiosity as "a new vice that has been stigmatized," but one that pleases him; he writes of "curiosity" as a mode of "care":

It evokes "concern" . . . the care one takes for what exists and could exist; a readiness to find strange and singular what surrounds us, a certain relentlessness to break up our familiarities and to regard otherwise the same things; a fervor to grasp what is happening and what passes; a casualness in regard to the traditional hierarchies of the important and the essential. . . . I dream of a new age of curiosity.<sup>19</sup>

I take Foucault to mean that curiosity, when deployed in the mode of *care*, decenters the disembodied rationalist ego by recognizing gaps in understanding and, rather than filling those gaps with familiar taxonomies, allows that one has yet to get it right. Finding oneself fallible and out of alignment with the experiences of others, *shame* can often manifest in the disruption of our previous interest, when we find that our existing taxonomies have been misapplied. Yet, the gap registered by shame need not be a mark of failure but, rather, a space for growth that must be tolerated, even celebrated.<sup>20</sup> Curiosity becomes a virtue at those moments when the smooth grooves of the habitual and the given fall off the rails. In such moments of instability, one might fit one's new object into pre-existing frames of identification or might instead crack open the sedimented background of the familiar. Epistemic responsibility does not mean that one *avoids* matters about which one is ignorant, but requires—in addition to the restraint of modesty—a generative and responsive interest in that which at first seems inscrutable. Foucault would call this epistemic virtue curiosity-as-care.

Deeply resonant with Foucault's curiosity-as-care, Rosemarie Garland-Thomson observes how "staring" and, furthermore, "beholding" can shift the habitual givens of frames of perception. The subjects about whom Garland-Thomson is concerned are those sighted and neurotypical beholders for whom the stare is an unthinking response. She explains four aspects of staring: first, a physiological response to disturbances in the visual status quo; second, an impulse rich with culturally specific histories; third, a manifestation of a social relationship; and fourth, a conduit to knowledge.<sup>21</sup> Complicating and enriching the meaning of agency in the staring encounter, Garland-Thomson explores the aesthetic and performative strategies of "vigilante stares" in response to the frequent stares of others; she writes, "Rather than passively wilting under intrusive and

discomforting stares, a staree can take charge of a staring situation, using charm, friendliness, humor, formidability, or perspicacity to reduce interpersonal tension and enact a positive self-representation.<sup>22</sup> Garland-Thomson augments Elaine Scarry's analysis of "strange encounters" as disruptions of the *status quo*, reframing "beauty" as engagement with novelty.<sup>23</sup> The "intense attentiveness" of the stare, while loaded with stereotypes and assumptions, offers the possibility of breaking and recasting our inherited frames of interpretation. At its root impulse, staring is an expression of interest in the lives of others. The ethical question, then, is how one directs that interest.

Singer's failure of curiosity about people living with intellectual disabilities is akin to what Garland-Thomson describes as the misrecognition and disregard of "Looking Away." She cites anthropologist Robert Murphy's *The Body Silent*, a study of his own experience of quadriplegia, which "points out that looking away from people who make us uncomfortable differs from granting them visual anonymity. Looking away is an active denial of acknowledgement rather than the tacit tipping of one's hat to ordinary fellow citizens expressed in simply not noticing one another."<sup>24</sup> Singer's inadequate curiosity about the lives of those with intellectual disabilities, while still factoring them into the utilitarian calculus of the greater good, is a missed tipping-of-the-hat, if you will, to the people his argument conceptually exploits. Singer does not stare but *looks away*.

What should happen in that moment of the stare? Could the irreducibility of another person's distinctiveness, which elicits the stare, also provide the impetus for a fleeting moment of solidarity? We risk falling into neurotypical assumptions of human connection at the moment we take the stare to be anything more than an *instance* of such intersubjective insight, one possible mode, and we surely enact the hubris of ableism to presume that the other should look, let alone stare, in return.<sup>25</sup> Yet the unpredictability and openness of the stare excites Garland-Thomson who finds, again quoting Murphy, that the presence of disability "robs the encounter of firm cultural guidelines, traumatizing it and leaving the people involved wholly uncertain about what to expect from each other."<sup>26</sup> The wondering stare, while potentially misguided and full of missteps, can be the first step in one's desire to understand someone. Gentle in its *beholding*, this looking must be balanced, as a defining feature of an ethical encounter, with humility, or what Kittay describes as "epistemic modesty": to know what you don't know about another, and to respect that gap; to ask questions, but not simply with the hope of showing oneself to be sensitive. The curious interlocutor recognizes what she does not know and would rather learn from a willingness to be wrong, to be *corrected*, than to get it right.

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#### NOTES

1. Garland-Thomson, *Staring: How We Look*.

2. Connecting this discourse to the more easily recognizable language of "virtue ethics," Butler (2001) and Foucault (1978, 1984) both find virtue appealing as an ethical paradigm because it does not issue moral maxims or principles but rather develops a style of being through practices over time. These practices may in turn offer ethical discursive space to be critical of established principles, critical of existing norms.
3. In her description of Foucault's virtue as a practice of critique, Butler also cites Foucault's *History of Sexuality*, Volume Two (1984), the same paragraph that invokes curiosity as the motivating force of his work. Thus, of Foucault's "virtue" she writes that it seeks "to explore what might be changed, in its own thought, through the practice of a knowledge that is foreign to it" (8–9).
4. Tremain, "Foucault, Governmentality, and Critical Disability Theory," 5.
5. Carlson, *The Faces of Intellectual Disability: Philosophical Reflections*, 325.
6. Judith Butler, 2001.
7. Notably, Singer, "Speciesism and Moral Status."
8. Singer's utilitarian ethics, incompatible with Bentham's founding utilitarian equalization of moral concern for the pleasures and pains of all sentient beings, counter-intuitively (for a defense of animal rights) follows Mill's more famous variation of utilitarianism in insisting that lives with cognitive capacities—here, he includes many animals—experience pleasures of a "higher order" than others.
9. Carlson, "Philosophers of Intellectual Disability: A Taxonomy," 318.
10. Kittay, "The Personal Is Philosophical Is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield," 401.
11. *Ibid.*, 404.
12. Cf. Reynolds, "'I'd Rather Be Dead Than Disabled': The Ableist Conflation and the Meanings of Disability," forthcoming.
13. Philosophical claims have effects beyond academic debates; thus, Taylor writes, regarding this debate over *lives worth living*, that philosophical assessments have "real and sometimes deadly material consequences, insofar as they inform policies on genetic testing, euthanasia, selective abortion, and rights to bodily integrity." Taylor, "'Lives Worth Living': Theorizing Moral Status and Expression of Human Life."
14. Cf. Guilmette, "In What We Tend to Feel Is Without History: Foucault, Affect, and the Ethics of Curiosity," 284–94.
15. Foucault, *History of Sexuality, Volume Two*, 8.
16. Samuels, *Fantasies of Identification: Disability, Gender, Race*, 3.
17. *Ibid.*, 21.
18. Tremain, "On the Government of Disability."
19. Foucault, "The Masked Philosopher," 325.
20. My understanding of "shame" and "interest" is enriched by the work of Sedgwick, *Touching Feeling*; Ahmed, *The Cultural Politics of Emotion*; and Shotwell, *Knowing Otherwise: Race, Gender, and Implicit Understanding*.
21. Garland-Thomson, *Staring*, 13–15.
22. *Ibid.*, 84.
23. *Ibid.*, 201.
24. *Ibid.*, 83.
25. It would repeat the hubris of ableism to expect that the other person will return one's gaze. The rich recent literature on neurodiversity, which far exceeds the examples listed below, raises important challenges to our cultural presumptions of eye contact, which follow an implicit model of mutual recognition predicated on sameness. For a more responsive mode of engagement with 'alterity,' see Scuro, "The Consequences of a Heliocentric Epistemology," who uses Levinas' ethics to question the "interestedness" of the eye and its tendencies toward objectification, insensitivity, and lack of receptivity to

the singularity of individuals. For an apt first-person narrative of these neurotypical assumptions in social settings, as well as the internalization of this ableism, see Brown, "Hello, Internalized Ableism." For an innovative conversation about and across neurological differences, concerning neurodiversity and emotional connection, see White and Boue, "Autism, Art, and the World Behind the World."

26. Garland-Thomson, *Staring: How We Look*, 86.

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## The Ableist Affections of a Neoliberal Politics<sup>1</sup>

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As I lay on the operating table immediately following my C-section, having just kissed my newborn daughter (but unable to touch her) as she was whisked off to be monitored and measured, the doctors standing over my open abdomen paused before they began the tubal ligation that I had—due to a difficult history with pregnancy—voluntarily requested. Through the surgical mask, my obstetrician asked, "You want me to do just the one ovary, right?" In my haze, I panicked. I had almost hemorrhaged and died in a prior pregnancy, I had also miscarried, bled through at least half of both of my other "successful" pregnancies; so the idea of chancing pregnancy after making it to this delivery, at that moment, had me beside myself. Before I could respond, he and his partner began to laugh. It was just a joke.

I narrate my experience with "failed" and "successful" pregnancies in graphic novel form in a project titled *The Pregnancy ≠ Childbearing Project*.<sup>2</sup> At the heart of this project is an attempt to "disentangle" the phenomenon of pregnancy from the expectations of childbearing. An intimate part of this narrative, and the philosophical analysis that follows it, is the way in which the medicalization of the body permits an uncritical practice of *affective indifference* when it comes to the work of caring for and attending to liminal bodies. I rest this indifference on the lap of neoliberalism. What I was able to describe in this project is how women who don't fulfill the paternalistic and pedestrian demands of childbearing expectations become *invalidated* and *suspicious* in their pregnancies. Neoliberalism is a system that demands and expects childbearing to be the "proper function" of women,<sup>3</sup> otherwise validation and virtue are withheld.

It is this "affective indifference" that I want to read here as sign of the more problematic, unpacked "ableist affection" for the *normative as natural*. Neoliberal ideology and its cultural expression favor this equivocation:<sup>4</sup> the natural as most desirable and fit and the unnatural as it provokes disgust and disdain. George Monbiot recently captured the problematic qualities and concealed pervasiveness of neoliberalism, generally speaking:

Its anonymity is both a symptom and cause of its power. It has played a major role in a remarkable variety of crises: the financial meltdown of 2007

[and 2008], the offshoring of wealth and power . . . the slow collapse of public health and education, resurgent child poverty, the epidemic of loneliness, the collapse of ecosystems, the rise of Donald Trump. But we respond to these crises as if they emerge in isolation, apparently unaware that they have all been either catalysed or exacerbated by the same coherent philosophy; a philosophy that has—or had—a name. What greater power can there be than to operate namelessly?

Inequality is recast as virtuous. The market ensures that everyone gets what they deserve.<sup>5</sup>

Neoliberalism is the context for the sum total of modern medical care—its research, its investments, its day-to-day operations. Yet, through the lens of a phenomenological ethics, as Emmanuel Levinas argues it, “Note must be taken of this anti-humanist or non-humanist tendency to link the human to an ontology of anonymous being. It is a tendency characterizing an entire era that, while reflecting upon anthropology, is suspicious of the human.”<sup>6</sup> Judith Butler adapts the Levinasian demand of non-indifference when she argues: “The derealization of loss—the insensitivity to human suffering and death—becomes the mechanism through which dehumanization is accomplished.”<sup>7</sup> Butler uses *precariousness* as the existential term that manifests in the uneven and arbitrary *precarity* determined by socio-political identity; a system which determines which bodies and persons can and will, or should and might, count. With this, Butler calls for a “new bodily ontology.”<sup>8</sup>

Pro-life politics is a cultural phenomenon that emerges out of neoliberalism; an agenda that has nothing to do with me as far as I would concede it, yet it has everything to do with who I am, determining who I ought to be, in part, because it allocates value for what are considered “successful” or “failed” pregnancies. Neoliberalism makes the joke of the doctors so very *funny* in tying off one ovary and “saving the other,” and although is the stuff of disempowerment for me, is an affirmation of their authority as clinicians—so, “hardy har har”; the joke is *on me* and *on top of me*. To this point, I cite Simon Springer’s “Fuck Neoliberalism”:

Why should we be more worried about using profanity than we are about the actual vile discourse of neoliberalism itself? I decided that I wanted to transgress, to upset, and to offend, precisely because we *ought* to be offended by neoliberalism, it is entirely upsetting, and therefore we *should* ultimately be seeking to transgress it. Wouldn’t softening the title be making yet another concession to the power of neoliberalism? . . . Fuck that.<sup>9</sup>

One indication of this system of dehumanization is in the reading of post-partum depression for women of color; this is a condition that makes their lives more precarious and—when it comes to the concern for the lives of these women—is *less urgent* when it comes to basic care. By this I mean that *grievable lives* are *more valuable* in a neoliberal system in how it grants privilege: a system privileging those most productive—even in their capacity for reproduction.

Privilege is granted to those who willingly get pregnant, who raise “happy and productive” children, and who are willing to take sole responsibility for their health and welfare as if also a moral choice. What is most neglected in this model of reproductive ability is how the “precarity of life” comes to *bear on some more than others*, especially in the triaging of harm. There is an existential vulnerability in that we each and all *depend on anonymous others* for our existence, our sustenance, and our humanization.

Precairousness is the ontologically complicated source of ableist affections and phobias—the fertile ground of ableism to expand exponentially and in its multiplicity. In my *Pregnancy* project, I argue that the subjection of pregnancy is a position in which *she cannot escape*, yet the social and cultural narratives for pregnancy have been organized such that the paradox of being “yourself and yet no longer yourself” is classified and contained in a series of scripted expectations, developmental goals, and milestones. In other words, the depth and existential significance for what I describe as a possibility for *loss* that accompanies every *pregnancy* is usually glossed over, “taken care of,” and “handled.”

It should not be seen as objectionable that she-who-is-pregnant is disconnected from the normal and medicalized expectations and outcomes of a pregnant body. Furthermore, it should also not be objectionable if she is “depressed,” unfulfilled, if not also grief-stricken in post-partum whether or not it is a “successful” pregnancy with the outcome of a “healthy” baby.<sup>10</sup> Yet, if *contentment* and *satisfaction* are not the outward and obvious outcomes of childbearing, the cultural signals start to manifest as a need to “save the baby” and “fix the mother.”

For this reason, neoliberalism also withholds of the grievability of some women’s lives while privileging other lives *less disposable* and additionally *more grievable* for reasons of class, race, and national status, a divide compounded by the increasing marginalization of liminal identities and queer bodies.<sup>11</sup> To be clear, this intersection constructs the disposability of lives in the way it exposes precarity unevenly; it continues to render women invisible and their lives more precarious but does so *effectively*. From Adriane Nieves, describing post-partum care for women of color:

We are woefully underserved by mental health professionals and social services that reside in our communities—for a variety of reasons. Many of the women I spoke to were dismissed, rebuffed, or had their mental health concerns during pregnancy and the postpartum period downplayed by their doctor, pediatrician, pastor, and/or social worker.<sup>12</sup>

Testifying to post-partum experience, when it conflicts with the dominant narrative of childbearing expectations, is often *not possible* in shame and blame culture. Women are “set up” because a neoliberal society validates only *results*; and if one cannot meet the desired outcomes and expectations in a way that resonates as *normal* and *natural*, the response is fundamentally ableist. This ableism is in the perceived deficit of persons who do not fit in with the

neoliberal grand scheme of individuality, productivity, and able-bodiedness; instead, perceived deficits and disabilities are met with a generalized, patronizing, curative model of “care.”<sup>13</sup>

In my forthcoming monograph, tentatively titled *Addressing Ableism: Philosophical Meditations through Disability Studies*, I examine the scale and scope of our neoliberal, Western affection for able-bodiedness as a necrophilic tendency, aligning it with what Kim Hall calls a “Western somatophobia.”<sup>14</sup> This neoliberal value system is ideologically compact, not open and fluid, and exercises itself efficiently in material and experiential ways, especially in how neoliberal subjects respond to one another. Teresa Brennan, in *Globalization and Its Terrors: Daily Life in the West*, describes this system as “a war between space and time . . . [in] the struggles that ensue not only between labor and capital, but between environmental survival and the depletion of the conditions for life”; it is a Pyrrhic victory of “human speed over natural time.”<sup>15</sup>

With the question of which lives are more sustainable and which are less so,<sup>16</sup> ableist affections as they are embedded in medical, educational, and service institutions might require a specific form of de-regulation,<sup>17</sup> especially when these particular kinds of affections are of the *normate* and for the sake of the *normate*.<sup>18</sup> I root this in a kind of accelerationism<sup>19</sup> that has developed in Western ideological thinking. When we have created a situation in which there is little or no time to rest, repair, reorient, learn, grow, think, we not only reject those body-minds that cannot keep up with the tempo of—as in keeping time with—daily life and its private and public demands, but then also exhaust ourselves and the world in a “depletion of energy.” Ableist affects manifest when we socially and politically undervalue persons in an assumption of disability and impairment and we further the conditions of disablement beyond whatever good or benign intention may be supposed;<sup>20</sup> it is built into the system because *neoliberalism is a fully ableist system*.

Eva Kittay, in her “Notes from the Battlefield,” defends the “invisible care labor that is done by people with disabilities and their families.”<sup>21</sup> This labor is both emotional and intellectual.<sup>22</sup> Kittay reconfigures how professional work is tied to personal life and demonstrates how both the personal and philosophical are never apolitical.<sup>23</sup> By reciting her exchange with Jeff McMahan and Peter Singer<sup>24</sup> over the moral and political value of “physically and cognitively disabled persons,” she shows how irresponsible and arrogant the attitudes were of these philosophical “authorities,” stating that there is a real “psychological cost” in engaging these debates with those who assumed they could objectively judge the value of persons based on how they have been diagnosed. She calls them *disablists*.<sup>25</sup>

As Sunaura Taylor states it, “In American rhetoric there is a strong emphasis on independence and self-sufficiency. . . . [But the] point is not that able-bodied people and disabled people are equally dependent, but rather that the dichotomy between independence and dependence is a false one.”<sup>26</sup> Disability studies scholars like Rosemarie Garland-Thomson, Aimi Hamraie, and Lydia Brown have done important work to outline this boundary between those dominant ableist

affections and normative dehumanization from how they oppose and oppress those rendered more precarious and vulnerable. The “disablist” embodies the scripts and suppositions that manifest out of ableist anxieties and its corresponding, manufactured “affections.”

In a Levinasian framework, there is a “scandal of indifference” in Western thought which is unable to attend or decelerate useless suffering in the world when it comes from a “fear of each for himself, in his own mortality” and this fear “does not succeed in absorbing this scandal.”<sup>27</sup> I am willing to be plain on this point: the most grievable body is an expression of the ideals of “able-bodiedness,” represented by white cis-male body, historically constructed as if only “he” has the strength to survive at will, covering up the interdependence on anonymous others. *Here we can think of the conjured image of the self-made man.*<sup>28</sup> The preservation and sustainment of these kinds of bodies and their corresponding desires/activities/needs are given priority and value over others, such that, for some, precarity can be *disposed-of*, yet, for others, in effect, precarity is *dispensed-to*. Although Butler does not address ableism<sup>29</sup> as directly as she does racism, nationalism, and American exceptionalism, she provides an important resource for thinking about how we have become “attached” to ableist ideologies, and, by Butler’s account, the distribution of the precarity and the value of a grievable life, over and over again, frames and “reframes” our “sociality.”

The cultural-social need to “name”—for naming what is unnamed—is a desire that I would like to argue can easily and efficiently excite ableism if we are not critically attentive to it, encouraging disablist attitudes and forfeiting the value of ordinary, everyday, individual embodiment. One case in point is from Anita Silvers, “Philosophy & Disability: An Overview,” for *Philosophy Now*:

In *On Blindness*, an exchange between philosophers Bryan Magee and Martin Milligan, disability elucidates how we know what we know. Magee initiates the conversation to explore how much someone like Milligan, blind nearly from birth and with no memory of seeing, can understand from other people’s descriptions of visual experience. . . . In this discussion, rhetorical convention clearly privileges the sighted over the blind interlocutor, since Milligan is expected to bear the burden of convincing Magee that being blind is not a significant drawback in acquiring knowledge of the world. This rhetorical assumption prevails even though, as Milligan argues, blind people enjoy a more comprehensive standpoint on the subject than sighted people.<sup>30</sup>

Following the rhetorical assumptions of this exchange, all too common in mainstream perceptions of disability, I would like to suggest here that there is a more systematic epistemic injustice<sup>31</sup> embedded in these ableist affections. It also manifests in a need to “pass” as able-bodied in a society that only recognizes the “employable” or “employed.”<sup>32</sup> When I gave a talk about precarity and ableism to students at Emory University,<sup>33</sup> I asked about what a non-ableist future would look like. Having brought

to the fore their ableist anxieties, what I wished for them is that they not value themselves based on their potential employability, the stress of which can transfer deeply negative and long-term *affect*, shaping and framing how they feel about their lives in relation to the lives of others.

Ableist affections are quickly internalized in bad faith when we promote, especially in the context of higher education, nothing more than the neoliberal work ethic: to speed it up, never “rest,” and, predominantly and for the most part, “keep working.”<sup>34</sup> If neoliberalism remains unchallenged, what they will come to know of themselves—and what we effectively teach them—is how best to *perform* in able-bodied ways. We in academia would do well to take instruction from Shelley Tremain’s work, *Dialogues on Disability* (2016),<sup>35</sup> if we plan on shaping a future that is non-ableist and can attend to epistemic injustices, or, at least minimally, one that can *resist* and *confront* ableism.<sup>36</sup>

Ableist affections are exercised easily; they are acceptable and unquestioned, informing policy. As the health and human services professions move toward greater and greater economic efficiency, permission for affective indifference and ableist affections becomes possible; it is “licensed and practicing.”<sup>37</sup> But these affections are uncritically promoted in everyday language as well—in the demand for “fitness”—alternatively defining those who are “misfits,” or “freaks,” “stupid” or (for many women, a double potency) “crazy” or “psycho.” And without some basic literacy in the history of how ableist slurs can emerge,<sup>38</sup> one might think themselves quite clever to appropriate language that does not belong to them, and, with ableist assumptions and attitudes, feel comfortable to name others as they see fit. Particularly problematic is the lack of emotional maturity and general insensitivity that encourages social currency in ableist slurs, mostly in order to have a good punchline.<sup>39</sup>

Yet, with all seriousness, these ableist affections are not limited to name-calling or to jokes among colleagues, but is, especially for liminal bodies, *a matter of life and death*. Following David Pfeiffer, in “The Philosophical Foundations of Disability Studies”:

Any ontology which presents the world of experience as inferior to a world of divine law will lead to the oppression of people with disabilities. Any ontology which emphasizes ableism and normality dooms people with disabilities to destruction. Any ontology which presents an epistemology based on authority and conformity results in the death of people with disabilities.<sup>40</sup>

In my work, I raise the problem of ableist affections as it regards the work of diagnosis: the diagnosticians and their training, the patient who is handed over a life-changing diagnosis, the suspension of diagnostic thinking as an everyday way of thinking through one’s own able-bodied affections and internalized ableisms. Diagnoses are historically, socially, politically, economically, and philosophically loaded. They have been notoriously and heteronormatively gender-laden, as argued by Ehrenrich and English in *Complaints and Disorders: The Sexual Politics*

of *Sickness*. They cite one narrative that was of particular interest to me:

[If] a woman should choose to devote herself to intellectual or other “unwomanly” pursuits, she could hardly hope to escape the domination of her uterus and ovaries. . . . This was not mere textbook rhetoric. In their actual medical practices, doctors found uterine and ovarian “disorders” behind almost every female complaint, from headaches to sore throats and indigestion.<sup>41</sup>

Coupled with an affection for fixing and curing, the indifference and even patronizing, dehumanizing way in which the diagnosis may be handed over can have affective consequences that devastate. This is better understood if we follow Teresa Brennan in *The Transmission of Affect*, “By affect, I mean *the physiological shift accompanying a judgment*.”<sup>42</sup> Brennan takes care to distinguish *affect* from *feeling* in that while feelings are self-contained, affects are transferred socially and environmentally. In Brennan’s psychoanalytic account, social acts shape the body through biochemical responses.<sup>43</sup> The displaced energy in the reception of a life-altering diagnosis can thus change physiology. In the context of an ableist system, one that is historically sexist, misogynist, somatophobic, and racist, diagnostic judgments can be affective as energetic; as energetic, the handing over of these judgments can “enhance or deplete.”<sup>44</sup>

Kittay recites an emotional and affective kind of nausea when hearing, reading, or thinking about her daughter being casually compared in moral status to an animal:

[The] impact . . . is devastating. How can I begin to tell you what it feels like to read texts in which one’s child is compared in all seriousness, and with philosophical authority, to a dog, pig, rat, and most flatteringly, a chimp; how corrosive these comparisons are. . . .<sup>45</sup>

What are the specific challenges facing someone in my position? There are essentially two. The first is to overcome the anger and revulsion that one feels when encountering the view that one’s disabled child . . . is less worthy of dignity, of life, of concern. . . . [and when] return[ing] to my daughter, Sesha, find[ing] myself trying to analyze the features that [distinguish her from these comparisons], . . . I would simultaneously shrink in disgust from such reflections.<sup>46</sup>

With Kittay, I want to argue is that if a medical or educational or administrative authority is in a position to hand over a diagnosis and is at the same time a “disablist” in that they rivet the diagnosis to the individual, then, dare we say *they have “written them [and their families and the labor of care] off”*? If so, then I argue that work of diagnosis rests on a real and consequence-bearing “*conceptual fallacy*.”<sup>47</sup>

The disaffected handing over of a diagnosis by a diagnostician who believes they can judge the essential qualities of a disease or disorder is a transmission of

ableist affections, no less hubristic even if polite and well-intended. For the patient, it is a situation that can be deeply affecting, if not also fundamentally disabling. As George Estrich says in his "Open Letter to Medical Students," "The tendency to equate diagnosis with personality has roots in medical history, and ultimately in the history of Western thinking about race"; it is a difficult history to which I add the complex problematic of Western "compulsory able-bodiedness."<sup>48</sup> If we can confront the ways in which we have become deeply affected by ableist attitudes shaped by the desires of and for able-bodiedness, then we could also free up the ways that this ableism is inherited—passed from clinicians to clients, doctors to patients, teacher to students, parents to children—as well as more actively and politically challenge the way it is compounded by the intersections of class, race, gender, national status, and other institutionally engendered liminalities.<sup>49</sup>

Tobin Siebers has given us a clear demand in *Disability Theory*, citing Michael Bérubé: "it might be a good idea for all of us to treat other humans as if we do not know their potential, as if they just might in fact surprise us, as if they might defeat or exceed our expectations."<sup>50</sup> Without vigilance for the "surprise" of the other, we miss the original ethical injunction in humanizing the proximal other, the anonymous other, the vulnerable other. I'm reading this as a need to address the *excedence*<sup>51</sup> of precariousness; when it comes to the situatedness of vulnerable embodiment, there is *no escaping* this existential fact and one *cannot evade* the demands for humanization against any and all inhumanity. Our sensitivity to precarity, to grieve vulnerability whenever it is enframed by systemic, thoroughly ableist inequities and injustices is neither "women's work" nor is it weakness. Butler makes it clear that the underestimation of this kind of necessary labor can be a source of violence.<sup>52</sup> So when we mistakenly think of grief—the grief that recognizes that liminal bodies and identities are as much grievable as they are also made precarious—as a "privatizing," apolitical affair, in a neoliberal system, we miss both the humanizing existential and the ethical demands of *interdependence*.<sup>53</sup> Butler states it well: "Let's face it. We're undone by each other. And if we're not, we're missing something."<sup>54</sup>

Neoliberalism is at the heart of all demands to "get over it" (whatever "it" may be) and "move on." Neoliberalism weaves itself into the perception of *failure in my pregnancies* and "frames me" for *having survived my pregnancies*, part and parcel of the ultimate failure in *expectation* for able-bodiedness as conditioned by our shame and blame culture.<sup>55</sup> In challenging ableist affections, in order to *excise* rather than *excite* ableism especially as it intimately connected to neoliberal ideology, is part of the larger challenge I offer here: to overturn the dehumanization and inhumanity of modern healthcare everywhere and anywhere it may reside without notice—and to do so without need of a punchline.

## NOTES

1. Many passages of this paper are excerpts from my two books forthcoming: *Addressing Ableism: Philosophical Meditations through Disability Studies* (Lexington Books) and *The Pregnancy ≠ Childbearing Project: A Phenomenology of Miscarriage* (Rowman & Littlefield International). My deep gratitude to Lauren Guilmette

and Joel Michael Reynolds for their careful and caring reading of this paper.

2. Forthcoming with Rowman & Littlefield International, March 2017.
3. To some degree, this implies the favoring of the fertility of white, affluent women. See the cases of the forced sterilization of poor women in North Carolina between 1929 and 1974, of *imprisoned* women in California between 2006 and 2010 (<http://www.ourbodiesourselves.org/health-info/forced-sterilization/>) and of *indigenous* women, narrated in Karen Stote's *An Act of Genocide: Colonialism and the Sterilization of Aboriginal Women* (Fernwood Publishing, 2015).
4. See Garland-Thomson on this point: "The concepts of misfitting and fitting guarantee that we recognize that bodies are always situated in and dependent upon environments through which they materialize as fitting or misfitting. Vulnerability is a way to describe the potential for misfitting to which all human beings are subject. The flux inherent in the fitting relation underscores that vulnerability lies not simply in our neediness and fragility but in how and whether that vulnerable flesh is sustained" ("Integrating Disability, Transforming Feminist Theory," 598).
5. Monbiot, "Neoliberalism—Ideology at the Root of All of Our Problems." Criticisms of this account of neoliberalism are limited to the defenses of free market economy, anti-academic sentiment and (continued) justification for economic inequality.
6. Levinas, *Outside the Subject*, 99.
7. Butler, *Precarious Life*, 148.
8. *Ibid.*, 2. Here it is important to note Butler's interview with George Yancy (*The New York Times*) taking the position that #blacklivesmatter does have a greater and justified demand than #alllivesmatter. See Yancy, "What's Wrong with 'All Lives Matter'?"
9. Springer, "Fuck Neoliberalism."
10. Caroline Lundquist does well in giving examples of and phenomenologically reading through cases of women who have "unwilling pregnancies" and either reject or deny them ("Being Torn," 140).
11. For more on this, see Susan Merrill Squire's *Liminal Lives* and Sara Ahmed's *Queer Phenomenology*. As Ahmed states it, "compulsory heterosexuality shapes what bodies can do. Bodies take the shape of norms that are repeated over time and with force" (91).
12. Adriane Nieves, "Women of Color and Maternal Mental Health: Why Are We So Underserved?" *Postpartum Progress*. Posted January 6, 2015, online: <http://www.postpartumprogress.com/women-color-maternal-mental-health-underserved>
13. Dana Lee Baker, in *The Politics of Neurodiversity*, has described the problem of care versus cure (146–50) and states that "an intriguing factor of the relationships between care and care-oriented agendas is the usually strong prevalence of unquestioned assumptions in the surrounding political and public discourse" (164).
14. Hall, Introduction to *Feminist Disability Studies*, 3.
15. Brennan, *The Transmission of Affect*, 143.
16. Butler, *Frames of War*, 42.
17. Although Butler argues that we do "not want to celebrate a full deregulation of affect" (*Frames of War*, 52).
18. Defined by Garland-Thomson as "the corporeal incarnation of culture's collective, unmarked, normative characteristics" ("Integrating Disability, Transforming Feminist Theory," 23).
19. I don't completely subscribe to a psychoanalytic reading of accelerationism, but an interesting summary here: "Acceleration is one of the features of capitalist subjugation. The Unconscious is submitted to the ever increasing pace of the Infosphere, and this form of subsumption is painful—it generates panic before finally destroying any possible form of autonomous subjectivation" (Bifo, "Accelerationism Questioned from the Point of View of the Body").

20. I want to add the somatophobic anxiety over the “fat” or “obese” body to this devaluation. See Harjunen, *Neoliberal Bodies and the Gendered Fat Body* (forthcoming), as well as Wisniewski’s “Paging Dr. Economicus: The Economics of ‘Obesity’ in the *Canadian Medical Association Journal* [CMAJ].” Harjunen notes that “fat activists who have studied this transition often emphasize that public concern about ‘obesity’ has been constructed by channeling medical discourse about health risks to create support for regulatory and policy measures” (24). She also implies that the medicalization of the fat body—what she describes as “weightism”—emerged because “discourse on the ‘obesity epidemic’ emphasized that all medical professionals should take responsibility for controlling obesity’s economic costs,” (31) which could be read, as I argue it here, as exciting ableist affection and Western somatophobia. Wisniewski concludes, citing Guthman’s argument in *The Fat Studies Reader*, that
- As Guthman . . . reflects, “the extent to which neoliberalism writ large produces economic and cultural Others indicates that ‘obesity’ may be the trope of our times”. . . . The example of the CMA’s discourse on obesity makes it apparent that the inequalities created when fatness is categorized as a form of deviance do not disappear even when the aim of the commentator is to confront other social inequalities that are exacerbated by neoliberal governance. (40)
21. Kittay, “The Personal Is Philosophical Is Political,” 606–07.
22. *Ibid.*, 613–15.
23. *Ibid.*, 624.
24. *Ibid.*, 621–22.
25. *Ibid.*, 612.
26. Taylor, “Interdependent Animals,” 112–13.
27. Levinas, *Entre Nous*, 192.
28. An excerpt from Brian Miller and Mike Lapham’s *The Self-Made Myth: The Truth About How Government Helps Individuals and Businesses Succeed*: “Despite what [Donald] Trump may espouse, his success would in no way possible without his father, the general public, and the U.S. government. Unfortunately, Trump decided to forget or selectively ignore these truths while forming his political philosophy, a sentiment made particularly clear during his brief bid for the 2012 Republican presidential nomination.” Reposted on Alternet.org (July 29, 2012; accessed May 28, 2016). Available at [http://www.alternet.org/story/156234/exposing\\_how\\_donald\\_trump\\_really\\_made\\_his\\_fortune%3A\\_inheritance\\_from\\_dad\\_and\\_the\\_government’s\\_protection\\_mostly\\_did\\_the\\_trick](http://www.alternet.org/story/156234/exposing_how_donald_trump_really_made_his_fortune%3A_inheritance_from_dad_and_the_government’s_protection_mostly_did_the_trick)
29. It is worth noting her conversation with Sunaura Taylor transcribed in Astra Taylor’s *Examined Life* (The New Press, 2009), titled “Interdependence.”
30. Silvers, “Philosophy and Disability: An Overview,” *Philosophy Now* (Jun/Jul 2016). Available at [https://philosophynow.org/issues/30/Philosophy\\_and\\_Disability\\_an\\_overview](https://philosophynow.org/issues/30/Philosophy_and_Disability_an_overview)
31. See Rachel MacKinnon’s “Allies Behaving Badly: Gaslighting as Epistemic Injustice,” available at [https://www.academia.edu/8423524/\\_Allies\\_behaving\\_badly\\_Gaslighting\\_as\\_epistemic\\_injustice](https://www.academia.edu/8423524/_Allies_behaving_badly_Gaslighting_as_epistemic_injustice). I’ve also argued elsewhere that epistemic injustices are starting points for new theory construction; see Scuro, “Theory Can Heal.”
32. The medicalization of disability permits a culture that diagnoses and fixes everything, and with constant appeal to economic viability and “success.” What I think contributes to a deepening of ableist anxieties was the fear of being not employable, underemployed, or of becoming unemployed, despite being educated. See Pieper and Mohammadi, “Ableism and Racism—Barriers in the Labour Market.”
33. Thank you to the Disability Studies Initiative (DSI), particularly Joel Michael Reynolds, and to the Emory Center for Faculty Development and Excellence at Emory University for inviting and hosting me.
34. There is a crisis in the delivery of disability services in higher education today. DS scholars have done the good work of outlining this crisis, but it is not clear that the academic community has heeded this call. See, for example, Lalvani and Hale, “Squeaky Wheels, Mothers from Hell, and CEOs of the IEP.”
35. For example, her interview with Zara Bain, available at [http://philosophycommons.typepad.com/disability\\_and\\_disadvanta/2015/05/dialogues-on-disability-shelley-tremain-interviews-zara-bain.html](http://philosophycommons.typepad.com/disability_and_disadvanta/2015/05/dialogues-on-disability-shelley-tremain-interviews-zara-bain.html)
36. The *resistance* then *confrontation* with ableism “wherever it resides” are focal points for my work in *Addressing Ableism*.
37. In the graphic novel section of *The Pregnancy ≠ Childbearing Project*, I narrate my experience with a receptionist that made me wait for the doctor and delayed my urgent care as well as an obstetrician who blamed my pregnancy complications on my weight gain. Testimonials regarding the words and deeds of those who are in service professions indifferent, ableist, and/or racist abound. In *Addressing Ableism*, I argue that the current model of diagnostics—as a way of thinking and making judgments about patients, symptomology, narratives of non-normative experience, etc., is a harbor for the dual biases of *non-diagnosis* (as in, “there is nothing wrong with you”) and *misdiagnosis*, the latter of which can create situations of great harm and precarity.
38. See Brown’s “Violence in Language: Circling Back to Linguistic Ableism,” in which they state: “This isn’t about policing language or censoring words, but about critically examining how language is part of total ableist hegemony. This is about being accountable when we learn about linguistic ableism, but it is also about being compassionate to ourselves and recognizing that to varying extents, we have all participated in ablesupremacy and ablenormativity. This is about understanding the connections between linguistic ableism and other forms of ableism, such as medical ableism, scientific ableism, legal ableism, and cultural ableism.”
39. For example, my colleague Dan Smith, in his review of Donovan and Zucker’s *In a Different Key* (2015) and Silberman’s *NeuroTribes* (2016), quips at the end of his review that having “autism” doesn’t really mean anything anymore because of the pervasiveness and range of what can be considered “under the spectrum.” He mistakenly assumes it fair to state, “Not long ago, a friend used a term I’d never heard to describe a co-worker. Her co-worker was a little brusque and unsociable and she thought he might have just a bit of an autistic impairment. The term she used was ‘Splashperger’s’.” Full text posted by *London Review of Books*, 38, No. 10 ( May 19, 2016): 11–15. Available at <http://www.lrb.co.uk/v38/n10/daniel-smith/call-a-kid-a-zebra>
40. Pfeiffer, “The Philosophical Foundation of Disability Studies.”
41. Ehrenrich and English, *Complaints and Disorders*, 29.
42. Brennan, *The Transmission of Affect*, 5. My emphasis.
43. *Ibid.*, 7.
44. *Ibid.*, 6.
45. Kittay, “The Personal Is Philosophical Is Political,” 621.
46. *Ibid.*, 610; 612.
47. *Ibid.*, 616. My emphasis.
48. Garland-Thomson, “Integrating Disability, Transforming Feminist Theory,” 34, citing Robert McRuer, “Compulsory Able-Bodiedness and Queer/Disabled Existence,” in *Disability Studies: Enabling the Humanities*, ed. Rosemarie Garland-Thomson, Brenda Jo Brueggemann, and Sharon L. Snyder (NY: MLA Publications, 2002), 88–99.
49. I argue in *Addressing Ableism* that the “scope and scale” of ableism includes *institutional* and *intergenerational* operations.
50. Citing Bérubé’s “Citizenship and Disability” in *Dissent* (Spring 2003): 52–57.
51. Levinas coins this term as a play on the idea of transcendence, but instead signifying “the need for escape” (*On Escape*, 54).
52. Butler, responding to the question of her commitment to non-violence, especially when “the subject is formed out of violence,” states that non-violence is already a conflicted position coming from an “injured, rageful subject.” She clarifies this: “It is crucial to distinguish between (a) that injured and rageful subject who gives moral legitimacy to rageful and injurious conduct, thus transmuting aggression into virtue, and (b) that injured and rageful subject who nevertheless seeks to limit the injury that

she or he causes, and can do so only through an active struggle with and against aggression" (*Frames of War*, 171–72).

53. See Sunaura Taylor's "Interdependent Animals: A Feminist Disability Ethic-of-Care," in which "dependency is a reasoning that has been used to justify slavery, patriarchy, colonization and disability oppression" (114). She reads a suspicious and ableist "logic" in the argument for sustained dependency—the idea that those living beings dependent on others for survival get negative characterizations like being a "burden," "stupid," or, as she states it, "chillingly" comparable to "domesticated animals" (115). The danger of this thinking is that it is not possible to "liberate" these communities from exploitation because they are defined in and by the assumed right to resources and perhaps even moral empathies of independent and able-bodied persons. To this she states:

*The ways in which romantic and conservative notions of self-sufficiency, productivity and independence are entangled in contemporary discussions of animal welfare and sustainability is troubling. . . . The idea that some dependent individuals are less valuable and more justifiably exploitable because they are understood as burdens who offer nothing of value back to their communities . . . has had a long and troubling history for disabled humans as well. (117–18)*

These notions—self-sufficiency, productivity, and independence, as I argue it in *Addressing Ableism*, are key concepts in neoliberal ideology.

54. Butler, *Precarious Life*, 22–23.
55. I argue this in "A Phenomenological Reading of Miscarriage," which is a good part of my work in *The Pregnancy ≠ Childbearing Project*: "When you have been raised and groomed to believe that pregnancy is equivalent to—if not also inherently entails—the phenomena of labor, childbirth, motherhood wrapped up in a *mythos* of unconditional love and desire, anything short of these expectations of equivalence becomes a site of harm and humiliation. My project is intended to be an outright condemnation of our shame and blame culture, especially when it is a gendered phenomenon—an unnecessary bearing down on women and girls for no other reason than their anatomical differences with men."

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