I. Introduction

In this session, we are discussing two issues: severe impairment and the beginning of life. To take a position on either the theory or policy that should govern our ethical decision making, we need to consider both the moral status of the newborn and the relevance of severe impairment. In the brief time available, I will try to say something about both of these issues.

II. The Status of Newborn Human Life

The idea that it is always wrong to take the life of an innocent human being is something that we scarcely dare question. Yet philosophers ought to know that mere species and chickens, for instance, belong to another, to think that mere species and chickens belong to another. That difference, however, does not merely awareness but self-awareness, possibly the capacity for making random than to kill nonhuman animals, the difference must have something to do with the kinds of beings that humans are. And I would suggest, more specifically, that it is not merely awareness but self-awareness, or possibly the capacity for making plans for the future. Here we have, I believe, a reason for distinguishing between the wrongness of killing beings that is based on something that is clearly morally relevant. The fact that a being is capable of understanding that it has a "life" does make it worse, other things being equal, to end that life. Then, and only then do the beings have any conception of what it is to be killed by being killed, or have any capacity to desire for the future that are thwarted.

I use the term "person" to refer to those humans who have the higher mental capacities, whatever we may decide that are not merely awareness but self-awareness, or possibly the capacity for making plans for the future. Here we have, I believe, a reason for distinguishing between the wrongness of killing beings that is based on something that is clearly morally relevant. The fact that a being is capable of understanding that it has a "life" does make it worse, other things being equal, to end that life. Then, and only then do the beings have any conception of what it is to be killed by being killed, or have any capacity to desire for the future that are thwarted.

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harm it does to the parents, who have conceived the child, and already love it and wish to nurture it. The death of a newborn infant is generally a tragedy for the parents, not for the infant who has not even glimpsed the prospects of the life that might have been in store for it.

You might immediately object that even if a newborn infant is not a person, a newborn infant has the potential to become a person. But if this is supposed to be the reason why it is as bad to kill a newborn infant as it would be to kill an older human being, we shall have to acknowledge that the human fetus also has a very similar potential to that of the infant, and hence the same reason would make it very seriously wrong to kill a human fetus.

Some of you, of course, will endorse this conclusion. But let us note here that a lot of people do not, and without the influence of religion, even fewer would endorse it. To most people, there is nothing especially shocking about the statement that killing a disabled fetus is not morally equivalent to killing a person.

I do not think that the potential of a being is enough to make it wrong to kill that being. The world’s population has passed six billion and is heading for somewhere around 9 or 10 billion—a figure that will strain our planet’s resources to the limits of their capacity. We do not think it obligatory, or even desirable, for fertile couples to bring as many human beings as possible into existence, even though each one of them would, in all probability, become a unique, rational, self-aware human being. And on the same grounds, I do not think that the fact that a human fetus would, in all probability, become a unique, rational, self-aware being is a reason against having an abortion.

That is all I have time to say today about my views on the taking of infant life, before it is a person, is to prevent a life being lived. And that is something that many people like to do. And there is no lack of evidence about this. Why would we spend money in trying to find ways of overcoming spinal injuries, if we did not believe that it is better to be able to walk than not to be able to walk? And the same goes for almost everything that we currently regard as a disability.

Admittedly, there are some disabilities about which it is possible to argue. Some deaf people have rejected treatment to restore hearing in their children, arguing that if they become able to hear, they will no longer belong in the community of the deaf. This raises an interesting issue, somewhat akin, I believe, to the wishes of some religious communities to raise their children in ignorance of a world in which there are people who do not share their religious beliefs and way of life. Is this child abuse, or justifiable community autonomy, in regard to which the state should remain neutral? But I will not pursue these issues, here, because for most of what we regard as disabilities, there can be no doubt. For parents in wheelchairs to permanently cripple their children, so that they too would be in wheelchairs all their lives, would be child abuse.

At this point, of course, someone is going to think: Peter Singer says that it would be child abuse for parents to cripple their children. Yet he thinks that it is all right for parents to kill their children. Why is that not also child abuse? Isn’t it worse to be killed than to be crippled?

Here, I need to draw together the two threads of my argument. We are talking about severe impairment at the beginning of life. If a life is going to be lived, then it is wrong to make that life worse than it would otherwise be—and to injure children so that they cannot walk is to make their lives worse than they would otherwise have been. To kill a newborn infant, before it is a person, is to prevent a life being lived. And that is something that can be done in many ways—by not having a child at all, or by having a child but using genetic counselling to avoid having a child with a disability, or by having prenatal diagnosis and terminating the pregnancy if the child will have a disability, by...
about a newborn child. But I now think this is too arbitrary to work so I will merely say that these decisions should be made as soon after birth as the accurate diagnosis of the infant’s condition, and the parents’ need for due consideration, permits.

In closing, let me acknowledge that many people have written to me telling me that they have a child with a disability, and that the child has enriched their lives, and had a good life her-or himself. I have no doubt that this is often the case. But it is also quite often not the case. I have had some heartbreaking letters from parents who support my views. Here is one example, from a woman I shall call Mrs. B.

My son, John (not his real name), was born almost 2 1/2 years ago 11 weeks premature and weighing only 1 lb., 14 oz. They assured me that he would be fine; he would just need to catch up with other kids his birth age. That is not the case. John has spastic diplegia cerebral palsy with underlying right hemiplegia . . . , sensory problems, and speech delays. We don’t know what his level of intellectual functioning will be, although people tell me he will probably be of “normal” intelligence with perhaps numerous learning disabilities. He is certainly more functional than some children with CP and has at least a small chance at a reasonably “normal” life, but that is not the issue.

My husband and I love our son (middle of three), but had someone told me, “Mrs. B., your son will have numerous disabilities down the road. Do you still want us to intubate him?” my answer would have been no. It would have been a gut-wrenching decision, but it would have been for the best. It would have been in the best interest of John, of us, and of our other children. I am saddened beyond words to think of all he will have to cope with as he grows older.

If some couples find their lives enriched by bringing up a child with a disability, I would not wish to prevent them doing so-in fact, as I have said, I would want to ensure that they had the best possible support services. But I also believe that couples like Mrs. B. and her husband do not think this is best for them, the disabled child, or her family as a whole. Others should not force it upon them.

Comments on Severe Impairment and the Beginning of Life

Adrienne Asch
Welesley College

Peter Singer and I agree on at least one facet of his views regarding infants with disabilities and people with disabilities more generally: They are not his alone; parts of those views are shared by many within the fields of medicine and bioethics, not to mention the public at large. Therefore, if we are to deal with “the monster,” it is not Peter Singer, but the views he champions. With most of these views I do disagree.

Before examining Singer’s views about the moral status and quality of life for the three classes of infants Singer considers, let me comment on a view that underpins all of his assertions about the parent-infant relationship, regardless of the health status or moral status of the infant under discussion: the “replacement thesis.” Singer contends, as do others, that newborn infants (and fetuses during gestation) are replaceable. If one fetus is aborted, say for reasons of prenatal diagnosis of a disabling trait, or if an infant dies shortly after birth of a condition incompatible with life, no great psychological or social loss has occurred to the parents or family into which the fetus or infant might have come and been raised. If, however, we are discussing a wanted pregnancy or a longed-for birth, such an idea is utterly contrary to the experiences of most women and their partners and families. During pregnancy, and surely at the time of labor, delivery, and birth, almost all women who plan to raise the child they have carried, feel that they are already in some kind of psychological relationship with the baby they have borne. So, too, may their partners, who have spent months planning for the new member of the family. Thus, if a wanted child dies at birth, or if a parent chooses not to treat the medical conditions of a child that she or he has looked forward to raising, virtually all will experience great sadness and disappointment that will not
the existence of disabled people categorically simply because he urges us to avoid bringing children with disabilities into the world (Peter Singer, "A German Attack on Applied Ethics: A Statement by Peter Singer," Journal of Applied Philosophy, v 9, n 1, 1992, 88). However, his opponents rightly read him as suggesting that their burdensomeness to others sometimes makes the disabled unwelcome and therefore as threatening the public benefits on which their way of life depends. (It is no accident that political opposition to Singer first emerged from the left in Germany, where social welfare policy confers generous benefits on people who are classified as disabled.)

CONCLUSION: Singer advances several distinct reasons to show that disability weighs against prolonging people’s lives. But as we have seen, his arguments that disability is burdensome to the disabled individual and that it impedes communal connection with others do not warrant the conclusions he draws. The phenomena he cites are familiar, of course. He reminds us that some parents of disabled children want their offspring not to be alive. Similarly, in the Nazi concentration camps, mothers killed their babies to save them from worse suffering. And as Toni Morrison describes in Beloved, mothers killed their children rather than have them exist as slaves. Yet in these cases we do not conclude that the children were best off to die. Instead we acknowledge pressing obligations to repair any circumstance so evil as to make mothers believe that destroying their babies is the least worst choice. So should we for disabled children.

This leaves Singer’s last contention, namely, that disability matters so much we must be wary of its compromising (dis)abled people’s good. It is hard to imagine that Singer’s advancing this view will alter the allocation of health care or other U.S. benefits to people with disabilities, even were he able to command II of the vast influence Princeton exercises on our nation’s public policy through muses like Steve Forbes and Bill Bradley. Nevertheless, philosophers should view the political protests held at Princeton with more concern than they have evinced so far, especially if they take the construction of resource allocation schemes to be a main objective of scholarship in philosophy and medicine. Such allocation schemes are inherently political, so philosophers who address them inevitably will be viewed as affixing moral imprimatur to political positions. The fact that Princeton, a privatist first-tier university, withstood an attempted intervention (including intervention by the official who chairs the National Council on Disability, a federal agency) into its faculty appointment process should not lull us into supposing that the abstractness of philosophical positions always insulates us from the effects of political action.

**Relationality, Personhood, and Peter Singer on the Fate of Severely Impaired Infants**

Eva Feder Kittay

"The one thing having a child does is make a philosopher out of a parent.” So opens an op-ed piece in the aftermath of the infamous Baby Doe case, an infant with Down’s syndrome whose parents reluctantly made a decision to let their infant die. If having a child makes every parent into a philosopher, having a child with cognitive disabilities makes a philosopher who becomes a parent into a far humbler philosopher.

I was a philosophy graduate student when my daughter Sesha was born. She was picture-perfect at birth. It wasn’t until Sesha was four months old that we suspected a problem. At six months, our pediatric neurologist suggested that we visit another doctor for an assessment. This neurologist gave us the news straight up, no soda, no ice, no palliatives. A two-minute exam, and the words: “your daughter is severely to profoundly disabled.” When we returned home, I was violently ill. My poor husband had to care for both Sesha and me that terrible night. Now, I am not suggesting that I took the news worse because philosophy was a chosen trade. But loving Sesha and living the life of the mind forced me to think — to feel differently about that latter case. My own child could not share its measures could not even remotely approach that which had, I had thought, been my life its meaning. I had to reassess the meaning and value of cognitive capacities as the defining feature of humanity. I discovered that a love for one’s child transcended any denumerable set of defining characteristics. What it meant to be human, to have value as a person, would never be the same for me again.

The yardstick I bring to the truth and value of a philosophical position is its ability to embrace a person such as my daughter. Professor Singer’s views, I think, fall short. But first let me say that my views are not always at odds with Singer’s. Like Singer, I reject the sanctity of human life ethic when it insists on the moral impermissibility of abortion. This ethic also insists that hastening the death of infants, and adults who persist in a vegetative state or whose condition is terminal and who face a lingering and painful death is always morally impermissible. I think these positions are wrong and cruel, and that Singer is perfectly correct to challenge them and is courageous with other others figures centrally, which affirms the ethical integrity of this approach is preferable. But as Singer deploys it, I find it problematic.

I contrast my views with Singer’s, by:

1. Disputing that the concept of personhood is given by a denumerable set of attributes, especially ones that privilege cognitive capacities.
2. Questioning Singer’s coupling speciesism with questions concerning severe human impairments.
3. Challenging the primacy of the impartialist ethics that guides Singer’s project.

Instead I argue for a view of personhood in which our relationships to others figures centrally, which affirms species membership as having moral significance, and which affirms partiality as appropriate for certain ethical considerations. I take from a feminist ethics the care a number of key concepts that contrast with the ethics, old and new, that singer both attacks and adopts. An ethic of care stresses the actual relations we have to particular others and the need to maintain connection and to avoid harm. To privilege an abstract sanctity of human life above the particular concerns of the individuals who live these lives is to fail to attend to the needs, to fail to be responsive, to those whose lives are affected. The embryo may be human, but it is not a human life. To
own [biologica] or adopted. It isn’t clear that any child would receive the sort of intense concentration of attention and care that it requires to survive and thrive. So, at the very least, this form of distribution would not be very efficient or effective. Much better to have these vulnerable persons assigned to the care of a relatively few persons who behave not in impartial ways to them, but with partiality.

I understand the above arguments to mean that we cannot claim humans are not properly persons if they do not have the appropriate attributes. Therefore, we cannot claim that infants, whether or not impaired, and severely retarded human are not persons by pointing to their lack of the stipulated attributes. Then, defending the appropriateness of letting infants die or killing them, whatever their condition or ability, by claiming that they are not persons, will not do. This of course means that the justification of killing or letting severely impaired infants die because they are not persons also fails.

Singer recognizes that while the attributes necessary for personhood are not fully acquired until well after infancy, there are social considerations that demand that the baby be considered a person prior to their attainment. Yet, birth, he claims, is an arbitrary place to mark the beginning of personhood, for the full-term fetus is indistinguishable from the newly born babe, and other cultures often chose a time after birth to confer personhood.

If we take personhood to consist of satisfying a list of attributes, then birth is arbitrary. The full-term fetus differs from the newborn only in its physical separation from its mother and to the extent that it depends on mother’s milk for nutrition it isn’t even all that separate. If personhood is conferred, at least in part, by relationship then it is less arbitrary. While this being is still within, we don’t know it yet. The moment of birth establishes a point where relationship can begin in earnest, so to speak, it is the moment after which the care of a mothering person is necessary to sustain it and bring it into the human community.

Yet, birth is arbitrary even for forming a relationship with the baby. Relationship may be established prior to birth. Before birth, prospective mothers will speak of the fetus as “the baby.” Alternatively, relationship may be postponed until the infant is welcomed not only by the mother and father, but by the community.

Membership into the community solidifies personhood.

The question of whether our own society should move from accepting birth as the socially agreed-upon dividing line should perhaps be split, as it is in Hebraic law—after the case of the full-term baby and the very premature neonate.

I think a close look will reveal that the reasons for which other societies have postponed and still postpone personhood either fail to apply to our own situation (for instance, when the justification has to do with scarcity, harsh living conditions, or the need to space children) or are morally unacceptable on other grounds, such as sex discrimination (as when infanticide is selectively practiced on girls). An affluent society, with access to birth control, with resources to care for disabled persons, and a commitment to gender equality, such as our own, does not share the bases on which traditional societies have justified infanticide. The only remaining justification is based on the emergence of new medical technologies for premature neonatal care. As one mother Singer quotes puts it, “[sometimes] it is hard to distinguish a premature birth from a late spontaneous abortion.” Even here, I am not so sure. Many parents look at the tiny being in its sterile bubble with tubes and wires—I looking so unlike a baby and still see their son or their daughter. Once a parent sees the infant as her child, she sees the infant as a person.

If there are not very strong justifications for moving the line, decisions about the fate of the infant have to be made in light of the infant’s personhood. Then, who decides why a very ill and disabled infant should continue to fight for life? I agree with Singer that it must be the parents, together with the physician (although the role of the physician is very problematic). I think that a relational conception of personhood would demand that those who have the responsibility for the care of the child, usually the parents or he mother, must have the first, if not also the last word, about the fate of the infant. If they (and especially the mother) do not or will not take on this responsibility, they can, in generosity, relinquish it to another. Yet then, it remains the prerogative of the mother, in particular, to relinquish her responsibility to another. The mother who has made the connection to the child whose own personhood and interests are about (and so forever entwined with the child may judge—perhaps incorrectly, but it must be her judgment—that the child cannot have a worthwhile existence with her or another.

Parents faced with a child with severe impairments at the start of its life have to make terrible decisions in a very short period of time. And they have almost no time to educate themselves. The society at large aggravates the situation by providing so little in the form of understanding what a life with disabilities is like, what a family with a disability is like, and worse still, by providing so few resources to persons with disabilities and to their families. This makes the prospect of having to handle this situation so much more frightening than it need be. Furthermore, society does the family and the child a major disservice in so poorly preparing physicians to understand what it means to raise a child with severe disabilities, what sort of life a person with cognitive disabilities can lead. Such a person, in the best of all worlds can have a very wonderful life and can be the source of enormous joy for others as well. My daughter has a wonderful life and she, along with my son, is the light of my life, and my partner’s and her grandmothers’, and a person of central importance to the many who have helped care for her.

What would I say if I were in the nursery with the mother who, learning that her otherwise healthy infant has Down’s Syndrome, says to her husband, “I don’t want it, duch.” Do I think it was appropriate for the physician, hearing this, to sign the orders “nursing care only” and allow the child to quietly starve while under heavy sedation? Or, to do as Singer suggests would be still better, to actively kill the infant with a lethal injection?

Although I could not say to a mother faced with a very premature infant with severe medical complications, whose survival was uncertain and whose outcome would surely involve significant cognitive damage and medical problems, “Without a doubt, do everything to save this child!” I find it very hard to accept the actions of this family and this physician. It seems based on ignorance and prejudice and not a realistic assessment of the hardships of the family or the life prospects of the child. Furthermore there are increasing numbers of persons who could relate to a child with Down’s Syndrome, who could find joy there. In this case it would be more decent and generous to allow this particular infant the opportunity to form its connections to
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another—for the parents to relinquish him to others who could love him. Birth matters here because birth allows the infant to form relations to others than the mother, and when there are others there to fill the void left by the biological parents, there is some very important violation. Perhaps it is that all the consideration here is for the family and none for the infant. If the alternative were to consign the infant to an impersonal and inadequate institution, perhaps such a decision might be justifiable—because the concern was for the happiness or misery of the child that would grow up.

To insist on a relational concept of the person is not to say that when the relationship is not made there is nothing there—one can only create a relationship that makes personhood possible to the sorts of beings who can become persons. Those sorts of beings, I argued earlier are those whose possibilities are always our own possibilities. I may not become a person with Down’s Syndrome but I could become a person with the diminished cognitive faculties. Once we understand that such a life can still be a fully human life, one well worth living, it is harder to accept the fate of the child of the mother who whispered to her husband, “I don’t want it, duck.” But hers is a failure of moral imagination that indicts our society and its failure to acknowledge the full personhood and humanity of the many disabled persons. Although I do not mean to accuse Singer of excluding disabled adults from personhood, the marking of severely impaired infants as so easily excluded from personhood works to reinforce a prejudice which, as all prejudice, is vicious and harmful. When we conclude that sometimes an infant’s life is best ended, it is a person whose life we are thinking of, just as we sometimes come to this conclusion at other moments in persons’ lives. And as in the latter case, it is never only one individual’s life that is involved—the decisions are decisions for those individuals whose own personhood is intertwined with the life that hangs in the balance. When we make that choice, when we determine whether that life is a quality life, we must think beyond narrow prejudices.

The life of the mind surely has its charms—and is even indispensable as a part of the human project. But thinking, rational reflection, the high cognitive skills required even for rudimentary speech remain a part only, and most surprising to the philosopher, not even the most important part, of what it is to be human and what it means to participate in the highest value. I gleaned this in my early days with Sesha, while still a graduate student. In time, I became a philosopher. Graduate school, colleagues, books, writing, a lot of disciplined thinking turned me into one. However, Sesha, my profoundly cognitively disabled child has taught me my most important philosophical lessons—if she has not made me a better philosopher, she has surely made me a humbler one.

Note

11 This idea was recently affirmed in a Supreme Court decision; see Olmstead v. L. C. and E. W.

Autonomy, Informed Consent and the Use of Placebos

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Imagine the following scenario. You are ill and require medical attention. Upon reaching your physician’s office you are lead down a brightly lit sterile hallway and told to sit quietly in a drafty examination room. After some time, your physician enters and proceeds to inquire after your health, asking various perfunctory questions such as ‘Where does it hurt?’ ‘How long have you had these symptoms?’ etc. She continues with a comprehensive physical exam and then leaves the room. Some time later she returns and informs you that surgery has been scheduled to remedy your condition. Any questions you might have are either brushed off in a most cursory fashion or elicit an extremely technical response. Importantly, no other treatment options are discussed. In short, your physician has already determined the best course of treatment—after all, she is the expert—and it is your duty as the patient to submit, unflinchingly and without hesitation.

What upsets us about this picture? Prima facie, the most troubling problem is that the patient is given absolutely no voice in the choice of care, i.e., about what is to be done and not done to her body. This situation, of course, strikes us as morally abhorrent. After all, the patient, an adult of sound mind, is an autonomous being and not simply some sort of object in whom a medical change is to be effected. In contrast to the tradition of benevolent (or, as the case may be, not so benevolent) paternalism, wherein the physician was taken to be the best judge of a patient’s welfare, the locus of such judgments has now shifted to the patient. That is, because of our sentence, and more importantly, our sapience, each person is viewed as bearing a bundle of inalienable rights, most crucially the right to determine what happens to one’s body, over which no one, including physicians, may wantonly trample. Clothes are shed upon entering examination rooms; rights are not.

While its praises may be loudly sung, the value of the principle of respect for patient autonomy is largely negative in scope. The ethical fruits it brings to bear are largely preventative, in that, when consistently and universally acted upon, the likelihood of patient manipulation and exploitation is greatly diminished. Consider the radical informational asymmetry between doctor and patient; knowledge, after all, is power. In this sense, a patient is potentially at the mercy of his or her physician. As such, the patient must trust that the physician will act for his or her good—the very essence, as it were, of a fiduciary relationship. Respecting patient autonomy insures that this trust will not be abused—indeed it demands that the patient is ultimately the one who makes all major medical decisions. Once the physician comes to view his or her patients as autonomous beings who have the right to determine their course of medical treatment, he constrains his behavior accordingly. The physician may champion various treatment modalities and may even decry the patient’s choices as irrational (e.g., the hemmorhaging Jehovah’s Witness refusal of a blood transfusion), but, so long as the patient retains sufficient capacity, treatment may, under no circumstances, be forced.

In turn, the primary means of protecting patient autonomy has been reliance on the rigorous and stringent doctrine of informed consent. As is well known, in obtaining patient approval for treatment, simple acquiescence is, morally speaking, not enough. A genuinely informed consent requires that the patient be provided with the medical facts of the case and the various treatment alternatives available. Full disclosure appears essential. Furthermore, obtaining a freely given and