

# Ethics and Disability

## *A Response to Koch*

Peter Singer

My disagreement with Tom Koch's article begins with his title. To refer to a set of views as an "ideology" is to suggest that they come as a self-reinforcing package that is beyond reasoning and critical scrutiny. But bioethics is a branch of applied ethics, which in turn is a branch of philosophy, and the hallmark of Western philosophy since Socrates has been its willingness to question everything, including conventional beliefs, no matter how unpopular such an approach may make one. Many disability advocates, too, defend their positions with arguments that are open to rational scrutiny. Instead of characterizing views held by bioethicists and disability advocates as ideologies, therefore, it would be more fruitful to examine the arguments that they put forward in defense of their positions.

I also find it unhelpful to speak of "mainline bioethics" as if there were an established position in the field. I wish it were true that most bioethicists accepted my views, but I doubt that that is the case. Many bioethicists, especially Roman Catholics, some Protestants, and Orthodox Jews, support the traditional doctrine of the sanctity of human life. Others, like Adrienne Asch, Eva Kittay, and Stephen Post, hold views that are shared by disability advocates. Let's focus instead on the positions advocated by particular individuals. Obviously, in what follows, I can speak only for myself.

To examine arguments fairly, it is first necessary to set them out accurately. Unfortunately, Koch often gives prejudicial misreadings of positions that I and others hold. Here are some examples:

1. *I don't hold that anyone with a disability "will be necessarily disadvantaged."* That would be an absurd claim. In unusual circumstances—for example, when all able-bodied people are conscripted to fight in a dangerous war—having a disability may be an advantage. I would argue only that, other things being equal, being able to walk, to move one's arms, to hear, to see, to recognize other people and communicate with them, are advantages. It is true that at the start of someone's life, we can never know how that life will turn out. Nevertheless, in deciding whether to conceive a child, to implant an embryo, to terminate a pregnancy, or to maintain the life of

an infant, we have to make decisions based on probabilities, not on certainties.

2. *I've never put forward a "definition of the individual as a discrete, self-reliant, self-conscious person with at least an equal store of goods as others."* Again, that would be an absurd position to hold. Being unable to walk, see, or hear does not mean that one is not an individual.

3. *Nor do I hold that "protected personhood"—not my expression, by the way—is a conditional category based on attributes "that are at least equal to those of the mundane norm."* The definition of *person* that I hold is, as I have written in *Practical Ethics* and other works, derived from John Locke's definition of a person as "a thinking intelligent being that has reason and reflection and can consider itself as itself, the same thinking thing, in different times and places." Here I agree with at least one of the meanings of *person* given in the *Oxford English Dictionary*, namely, "a self-conscious or rational being" (see Note 1). It follows that such abilities as being able to see, hear, or get out of bed have nothing at all to do with whether one is a person, nor with whether a person's right to life should be protected.

4. *I do not hold "a Darwinian assumption that noncompetitive variations are unproductive and to be avoided."* If Koch had read any of the books in which I discuss the significance of evolutionary theory for ethics, he would have seen that I have firmly and repeatedly rejected the fallacy that evolution has any kind of moral direction, or that from the fact that evolution takes place, we can derive any value-judgment about what we ought to do (see Note 2).

5. *There is nothing in the logic of any arguments I have put forward that "prevents any argument from experience."* On the contrary, as a consequentialist, my ethical arguments depend on a careful estimate of what the consequences of our actions are likely to be, and for that we must be guided by experience. That many people in the deaf community argue that their lives are as full as those of people who can hear is certainly a relevant fact. On the other hand, there are also deaf parents who seek help for their deaf children, to restore their hearing, or to obtain a cochlear implant. And certainly most people all over the world—not just bioethicists—believe that to be unable to hear is a misfortune. It is hard to imagine hearing par-

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ents reacting with indifference when a doctor tells them that she believes their child may be deaf. Of course, that “normal” reaction may be mistaken. But the views of some members of the deaf community do not settle the issue.

6. *It is not true that the choice I offer prospective parents “is a false one because the only rational choice would be . . . to avoid the harm that causes suffering necessarily resulting from difference.”* As already noted, I don’t believe that suffering “necessarily” results from having a disability. (A parenthetical digression: I wish Koch and other disability advocates would abandon the use of the term “difference” when referring to disability. “Difference” is a much broader term. Presumably, Koch doesn’t really think that I believe that suffering necessarily results from, say, having red hair, or perfect pitch, or being able to play 20 games of chess simultaneously while blindfolded, but these characteristics certainly make one “different” from the norm. The fact that Koch knows, and you, the reader, know, that these differences are not what he is referring to, shows that we all know that disabilities are not simply “differences.” Why pretend that they are?) To return to the substantive point, however: I think prospective parents of a child with a disability can rationally choose to go ahead with the pregnancy. A pregnant woman may not wish to have an abortion. Or the couple may be very keen to have a child and unsure if they will be able to conceive another one. More significantly for the topic we are considering, and contrary to what Koch says about my position, in my view it is reasonable to claim that some disabilities do not lead to suffering. Arguably, Down syndrome is an example. Many parents claim that their Down syndrome child enjoys life as much as their children without Down syndrome. If the couple believe that they would be just as happy with a child with Down syndrome as with a child without it, it could be rational for them to choose to continue a pregnancy after being told that the fetus had Down syndrome.

Let us move to the substantive arguments that need to be discussed if we are to make progress with this topic. First, I need to indicate why I do not accept the view that all human life is equally to be protected, irrespective of whether it is the life of a being capable of reading this article or the life of an anencephalic infant who will never even be able to notice her mother’s smile. One way of getting to the fundamental problem with the traditional view of the sanctity of human life is to ask yourself: “Is it worse to kill a human being than it is to kill, say, a chicken?” Unless you are a vegetarian, you are certainly going to say yes, it is. And even if you are a vegetarian—as I am—you are very likely going to think—as I do—that what happened in New York and Washington, D.C., on September 11, 2001, was a greater tragedy than what happens daily at a slaughterhouse. But why? Unless we take refuge in religious teachings, which not all of us share, the answer has to be because of some difference between humans and animals. That difference, however, cannot merely be the fact that we belong to one species and chickens belong to another. To

think that mere species membership alone could make such a crucial moral difference would be a kind of species-racism—more briefly, species-ism. Suppose there were intelligent Martians, very like us, loving, caring, thoughtful beings, entirely peaceable and friendly to us, but of a different species. Would it be acceptable to kill them, just because they are not members of our species? Surely not.

So if it is worse to kill human beings at 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 must have something to do with the higher mental capacities that humans have—capacities that nonhuman animals do not have. This cannot be merely the capacity to feel pleasure or pain, or to suffer from the severing of a relationship, like that between mother and child, for birds and mammals have these capacities. To give us a reason for thinking it much worse to kill typical humans than it is to kill beings of other species, the capacities must go beyond these. What could they be? They might include 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,” and of having hopes and plans for how that life will go, does make it worse, other things being equal, to end that life. Then, and only then, are we ending the life of a being that knows it is alive, and can see itself as existing over time. Then, and only then, does the being have any conception of what it might lose by being killed, or have any capacity to have desires for the future that are thwarted by being killed.

But at this point it will become obvious that while *typical* humans—for example, those who were killed in the terrorist attacks on September 11—have these capacities, and have them to a degree that a nonhuman animal does not, *some* humans do not have them. Newborn infants, for example, do not have them. And, while you might immediately object that a newborn infant has the *potential* to become a being with intellectual capacities far superior to those of any nonhuman animal, if this is supposed to be the reason why it is as bad to kill a newborn infant as 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.

Those opposed to abortion will, of course, endorse this conclusion. But let us note here that a lot of people do not endorse it, and without the influence of hard-line religious teachings, even fewer would endorse it. In any case, I do not think that the potential of a being is enough to make it wrong to kill that being. The world population has now passed 6 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. Admittedly, this point needs further discussion; for that, see the relevant chapter of *Practical Ethics*.

Koch, incidentally, never explains why his rejection of “the ideology of difference” does not obliterate the difference between chickens and humans as thoroughly as he wishes to obliterate the difference between normal humans and those with Down syndrome, or those with even more severe conditions, such as anencephaly. His entire account seems to assume that only human beings matter. But for this he surely owes us an explanation, and it evidently cannot be one based on the superior intellectual capacities of cognitively normal human beings.

For the reason I have just quickly sketched, I do not think that killing *any* fetus or newborn infant is morally equivalent to killing a rational and self-conscious being. This does not mean, of course, that killing fetuses or infants is a matter of moral indifference. On the contrary, to kill a fetus or an infant is normally very wrong indeed. The wrong, however, consists primarily in the harm it does to the pregnant woman, or the parents, who have conceived the child and already love it and wish to nurture it. The death of a fetus or a newborn infant is generally a tragedy for the parents, not for the fetus or infant, who has not yet even glimpsed the prospects of the life that might have been in store for it. Or, we could put it this way: To the extent that the death of a fetus or newborn infant is a tragedy for that being, it would also have been a tragedy if the fetus or infant had never been conceived. It is an impersonal loss, because the fetus or infant is not yet a person.

What difference, then, does disability make to our life-and-death decision-making for newborn infants? I became interested in the treatment of severely disabled newborn infants in the late 1970s, when I learned that it is common practice for doctors to deal with such cases by “letting nature take its course.” This means that no operations are performed and no antibiotics given, and the babies die slowly over many days, weeks, or even months. Parents often are not consulted but simply told that there is nothing that can be done for their child. This seems to me an evasion of moral responsibility, and often grossly inhumane. Yet, on investigating the prospects for some of the more severely disabled infants, I had to accept that it was not always good to prolong life, no matter what its prospects might be. Sometimes it was reasonable to decide that a life that had barely begun should not continue. But who should make this difficult decision? The infant, of course, cannot.

The parents are, in normal circumstances, the people most affected by whether their infant lives or dies, and they should, on the basis of the fullest possible information, have the principal say in the decision about whether the resources of modern medicine should be used to keep their child alive. I accept that doctors may have an unduly negative view of life with a particular disability. I therefore urge parents in doubt over

such a decision not to rely only on information from their doctors, but to contact groups representing those with the particular disability, or the parents or caregivers of those with the disability, to broaden their sources of information.

Nevertheless, parents will still sometimes decide, on reasonable grounds, that it is better that the child not live. What should happen then? When the publicity over my views about the treatment of severely disabled newborn infants was at its height, shortly after I took up my appointment at Princeton University, in 1999, I received a phone call from a doctor who directs a neonatal intensive care unit and deals with such cases every day. He told me that after consulting with parents, if they agree that it is better that their child not be kept alive, he will turn off respirators, and even withdraw the tubes that supply the baby with food and fluids. But he will not give the baby a lethal injection. He said that he sees an important moral distinction there, but he could not explain to me in what it lay. I told him that I could understand why, psychologically, he perceived the two as different, but that I could see no important moral distinction between allowing death to occur by the deliberate withholding of available medical treatment and actively intervening to hasten death and ensure that it came swiftly and humanely. I still think the latter course, precisely because it does involve less suffering, is often the morally better one to take.

Not all doctors, of course, are as ready as this doctor was to consult with parents and withdraw treatment, even when the prospects for a baby are very poor. Around the same time that I spoke to the doctor, I received an e-mail from a woman I will call Mrs. B:

My son, John [not his real name], was born almost 2½ years ago 11 weeks premature and weighing only 1 lb 14 oz. They assured me that because he was already 29 weeks and had no intracranial hemorrhages 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 . . . , has sensory problems, and has 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 for John, for us, and for our other children. I am saddened beyond words to think of all he will have to cope with as he grows older.

This is not the only letter of this kind I have received, and I do not think that Mrs. B is an atypical mother. Despite the natural tendency to love and cherish one's child, and to make the best of the hand that life has dealt one, some parents of children with severe disabilities judge the lives of their children to be such that it would have been better if they had died at or soon after birth.

Koch might still argue that such parents believe that their child's disability is likely to make that child's life worse than if he or she did not have that disability, and that this belief is a mistake. Here we come to the most fundamental issue raised by Koch's article. Is it a mistake to believe that a serious disability makes it likely that a child will have a worse life? To give up this belief is more revolutionary than many disability advocates seem to recognize.

Consider what we would have to give up if we were unequivocally to reject the idea that it is a bad thing for a child to have a serious disability. Prenatal diagnosis to allow women to terminate their pregnancy if the child has a serious disability would have to go, of course. So too would the selective termination, by nontreatment, of the lives of seriously disabled newborns. No doubt Koch would support the abandonment of these practices, widespread as they are. That is, however, only the beginning of the changes we would have to make. If serious disability has no tendency to make one's life worse, there would be no reason to fund research into preventing, or overcoming, disability. That would save governments all over the world significant sums of money. Doctors could forget about advising women who are considering pregnancy to take folic acid to prevent spina bifida and anencephaly, as these conditions would not, on this view, disadvantage their children. Nor need we require the manufacturers of alcoholic beverages to go to the expense of printing the labels that currently inform the American public that "according to the Surgeon General women should not drink alcoholic beverages during pregnancy because of the risk of birth defects." Pregnant women could feel entirely free to drink as much as they wished, secure in the knowledge that there was no reason to believe that any of the conditions that the Surgeon General calls "defects" would be likely to make their children worse off. Rubella immunization programs could be dropped because rubella is a serious disease only in its impact on the fetus, not

for the person who has the illness. Pharmaceutical manufacturers would not have to test new drugs to see if they produced fetal abnormalities. Doctors could once again prescribe thalidomide as a useful sleeping aid, even for pregnant women.

Does Koch accept that all these changes in policy would be reasonable? If he does, I expect that he will find himself in the minority even among those with disabilities, and he will certainly not find much support in the community as a whole. If he does not think all these changes would be reasonable, he owes us an account of why that conclusion is not implied by his denial of what he calls "the ideology of normalcy."

Though the commonsense view is not always correct—for example, I think that humans have an unjustifiable bias in favor of members of their own species and are not justified in always giving them higher status than they give to any nonhuman being—in this instance, I am on the side of commonsense when it declares that, other things being equal, it is better not to be disabled.

Finally, to ensure that I am not misunderstood, I would like to say again, as I have said many times before, that my views on the termination of a human fetal or newborn life have no bearing on the right to life of self-aware people with disabilities. They should be given the fullest possible support from the community in integrating into the community, and in living and working as normally as they possibly can. By those standards, most nations, including the United States, still have a long way to go.

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#### NOTES

1. See Peter Singer, *Practical Ethics*, 2nd ed., Cambridge University Press, Cambridge, 1993, chapter 4.
2. See, for instance, *The Expanding Circle: Ethics and Sociobiology* (Farrar, Straus and Giroux, New York, 1981); *How Are We to Live?* (Prometheus, Buffalo, NY, 1995); and *A Darwinian Left* (Yale University Press, New Haven, 2000).

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