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Human Rights and American Bioethics: Resistance Is Futile

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Notes

- 1. Annas GJ. American Bioethics: Crossing Human Rights and Health Law Boundaries. New York: Oxford University Press; 2005:24.
- 2. See note 1, Annas 2005:24.
- 3. Baker R. Bioethics and human rights: A historical perspective. Cambridge Quarterly of Healthcare Ethics 2001;10:241–52. Roberto Andorno shares this view, calling human rights "the last expression of a universal ethics," and "a 'lingua franca' of international relations"; Andorno R. Biomedicine and international human rights law: In search of a global consensus. Bulletin of the World Health Organization 2002;8012:959–63.
- 4. For example, the United Nations' *International Covenant on Economic, Social, and Cultural Rights* (1966), and the corresponding *Covenant on Civil and Political Rights* (1966).
- 5. See note 1, Annas 2005:40.
- Lomasky L. Persons, Right, and the Moral Community. Oxford: Oxford University Press; 1987:3.
- 7. Arras JD, Fenton EM. Bioethics and human rights: Access to health-related goods. *Hastings Center Report* 2009:39(5):27–38.
- This section of the paper is drawn largely from Fenton EM. Genetic enhancement—A threat to human rights? *Bioethics* 2009;22(1): 1–7.
- 9. See note 1, Annas 2005:37.
- 10. See note 1, Annas 2005:51.
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- 14. Some level of physical similarity is assumed in claiming that two individuals stand in a relationship of justice to one another. But genetic enhancement technology will not produce humans so different from us that this relationship of justice will not obtain. We may be more different from an unenhanced and severely mentally disabled individual than we are from an enhanced individual with a better memory, yet, because we recognize the severely disabled person as standing in the relationship of justice to us, then we will also recognize the enhanced individual as a subject of justice.
- 15. Not all fictional accounts of a genetically engineered future are pessimistic. The X-Men comics, for example, portray the social and political conflicts between humans and "mutants," who are said to represent the next stage of human evolution. Importantly, the nonhumans and X-characters are portrayed, like the humans, as full agents, and peaceful coexistence among them all is viewed as possible and desirable in spite of prejudice against the mutants on the part of the unmodified humans.
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Human Rights and American Bioethics: Resistance Is Futile

GEORGE J. ANNAS

The Borg are always confident that humans will be assimilated into their collective hive and therefore that, as they say, "resistance is futile." In *Star Trek*, of course, the humans always successfully resist. Elizabeth Fenton and

John Arras, like the Borg, resist the idea that humans are uniquely special as well as the utility of the human rights framework for global bioethics.¹ I believe their resistance to human rights is futile, and I explain why in

this essay. Let me begin with their subtitle, because we do seem to agree that popular culture is a powerful aid to understanding human actions and motivations.

Fenton and Arras select the sitcom Curb Your Enthusiasm to illustrate their view of the proper relationship between American bioethics and human rights. Their selection is apt as Larry David (the cocreator of Seinfeld, who plays himself in the starring role in Curb) is the personification of the ugly side of American bioethics: He is an ego-centric, selfabsorbed, narcissistic exhibitionist who is constantly making up rules and seeking to impose them, and his own prejudices, on others. He also marginalizes and satirizes religion, is wedded to our dysfunctional medical care system, does not travel well, and is totally unconcerned with global issues.

Curb may also have come naturally to mind because it frequently deals with bioethics issues—at least when they directly impact Larry. A series of shows, for example, were devoted to trying to decide if Larry would provide a kidney for his best friend, Richard Lewis. Larry, of course, wanted nothing to do with being the donor, and aside from telling his wife Cheryl that they should "have healthier friends," suggests other allocation schemes that could save his kidney, including choosing the youngest eligible donor, the one who knew Lewis the longest, knew Lewis the most intensely, the fattest, or the healthiest. Finally he decides to try to bribe the person in charge of the kidney waiting list to get Lewis moved up because, he is told, "If you're at the bottom of the list, you're fucked." Curb comes by its bioethics honestly. Seinfeld also played with bioethics. Perhaps most memorable is the scene in which Kramer tells Elaine that she is "perfect" to be the "executor of my living will.... You're a cold-hearted businesswoman, and when there's dirty work to be done, you don't mind stomping on a few toes."

I am not accusing Fenton and Arras of being cold-hearted or even of doing dirty work, but I do suggest that in stomping on my toes they have missed the big picture of the budding relationship between American bioethics and human rights as well as the nature of human rights themselves, and along the way have constructed a series of straw men that bear little, if any, resemblance to anything in American Bioethics. Most centrally, my project in American Bioethics was not to replace American bioethics with universal human rights, but, to use the bioethics word of the day, enhance American bioethics by helping to move it from a self-absorbed and self-referential worldview to a global one that reaches outward rather than inward. The final paragraph in my introduction to American Bioethics summarizes the project:

American bioethics must expand its horizons, both geographically and contextually: boundaries must be crossed, and alliances formed. The next step for American bioethics is to become international and universal, not as an imperialist project, but as a learning project. The thesis of this book is that the framework and language of human rights, especially the Universal Declaration of Human Rights, provides American bioethics with a path to move forward. The challenge for American bioethics is to work with international human rights advocates in imaginative ways to help make the world a more just and healthier place for all of us to live.2

Fenton and Arras do not disagree with the goal, only the means—arguing that we will not reach the goal of a more just and healthier planet by indulging in "uncritical enthusiasm" or "boosterism" on behalf of vague

human rights proclamations that attempt to "shoehorn" all moral problems into "that linguistic and methodological framework," thereby substituting human rights claims for "traditional ethical arguments." No one in their right mind would quarrel with these statements, and there is nothing to support any of them in American Bioethics. They focus on 3 of the 12 chapters in American Bioethics: Chapter 3, "The Man on the Moon," Chapter 4, "The Endangered Human," and Chapter 5, "The Right to Health." Their first essay concerns Chapters 3 and 4; Chapter 5 is dealt with in their second installation. Before responding to what I take to be their major concerns with using a human rights framework in the genetic experimentation arena, it is worth reviewing what human rights are, because America's bioethicists cannot (or at least should not) reasonably reject a human rights framework for specific global bioethics problems without understanding it.

The Human Rights Framework

The concept of universal human rights finds an early voice in the plays of Sophocles, but the movement in its contemporary form was born from the horrors of World War II and the establishment of the United Nations. The UN Charter proclaims as its primary purposes: "to save succeeding generations from the scourge of war; ... and to reaffirm faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large and small."

Just what those human rights consisted of was first articulated in the Universal Declaration of Human Rights, adopted by the UN General Assembly without dissent in 1948. This is the foundational document of international

human rights and has been followed by a series of treaties-international lawmost prominently the International Covenant of Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR). No law, and no treaty, is self-enforcing. But by signing these treaties, individual governments agree to change their domestic laws to bring their country into compliance with the provisions of the treaty. In this regard it is noteworthy that the majority of countries that have been founded since World War II have, like South Africa, incorporated major provisions of the ICCPR and the ICESCR into their own constitutions.

I have argued—and I am hardly alone on this-that American bioethics was also born from the ashes of World War II, specifically at the Nuremberg Doctors' Trial where American judges, American lawyers, and American physicians worked together to try to convict the Nazi doctors of murder and torture committed in the concentration camps under the guise of legitimate human experimentation.4 The Doctors' Trial was an application of the Nuremberg Principles, which themselves were articulated a year earlier at the International Military Tribunal that tried the major (surviving) Nazi war criminals: (1) There are such things as war crimes and crimes against humanity (e.g., murder, torture, slavery, genocide), (2) individuals can be held criminally accountable for committing them, and (3) following orders or the law of one's country is no defense.⁵

Born together, American bioethics and international human rights were separated at birth, but it is (I think) time to reunite the estranged twins who can work much more effectively together in the global health arena than they can separately.

In their essay, Fenton and Arras seek to resist this reunion in the area of "genetic technology" on the basis that human rights are too weak a reed on which to base a prohibition on genetic experiments aimed at producing better humans.

Human Rights and Genetic Engineering

Attacking my views on genetic engineering has become a minor cottage industry for the authors, and this is the third (the essay following this one is the fourth) time they have objected to my views on genetic experimentation as expressed in American Bioethics (the first two were sole-authored by Elizabeth Fenton—but in both she acknowledges John Arras for his assistance). They seem to protest too much. Nonetheless, sparking debate is a major goal of mine and the human rights movement in general. Moreover, the quest for a more specific philosophical grounding of human rights can (and should) be pursued, but not at the expense of postponing protection of human rights. Many philosophers have wrestled with this issue without attracting universal adulation, and the preamble to the Universal Declaration of Human Rights (UDHR) remains the most definitive foundational statement. It specifically calls for "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family" and notes that "contempt for human rights [during World War II] "resulted in barbarous acts which have outraged the of mankind" conscience (emphasis added). The UDHR itself is, I think, as good a codification of human rights as humans are capable of.

As to their views on my position that we need a global human rights framework to deal with prospects of inheritable genetic alterations, sometimes termed simply "genetic engineering," we may simply disagree. Nonetheless, it is useful to try to understand the locus of the disagreement. Fenton and Arras assert that they have "three significant problems" with my argument, but there is, I think, only one that has any weight-my reliance on human dignity as the foundation of human rights. I plead guilty and accept that my use of human dignity carries with it many, if not all, of the faults other commentators have found in it.8 But their suggestion that human rights requires a further analysis of human dignity to accept its claim of universality against a pluralistic world simply misunderstands the nature of human rights. The drafters of the UDHR, for example, explicitly and publicly declared that they were not going to seek agreement from all countries on the basis of human rights-which was a political statement designed to be the basis for legislation by individual countries. Thus countries were invited to agree to the substance of the declaration, without having to also agree that the rights so proclaimed came from God (however understood), reason, human commonalities, or some other source. In this regard the drafters of the UDHR were pragmatists, at least in the sense Richard Rorty uses this term when he observes, "On the subject of human rights, the pragmatist thinks that we should not debate whether human rights have been there all the time, even when nobody recognized them, or are just the social construction of a civilization influenced by Christian doctrines of the brotherhood of man [sic].... Pragmatists suggest that we simply give up the philosophical search for commonality."9I do not want to give up the debate on human dignity, or on the philosophical search for a single foundation for human rights, but neither is central to the world of international human rights, which welcomes

all who would adhere to its principles, regardless of their particular philosophy or religious or political belief system.

The other two "problems" are more interesting because they relate directly to genetics. The first has to do with the nature of the human genome and membership in the human species, the second with the prospects for genetic genocide.

As to the genome, the Arras and Fenton conclusions that I think membership in the moral community is governed by "the human genome, as it is currently constituted" or even (as they quote Mary Anne Warren) that "genetic humanity" is an independent criterion for "moral status," are assertions that cannot be located in any of my writings. As I put it in American Bioethics, "We do not live life on the molecular level, but as full persons. We will never be able to understand life (or how it should be lived, or what it means to be human) by exploring or understanding our lives or our bodies at the molecular, atomic, or even the subatomic level."10 And to see that it takes more than a genome to be accorded human rights (in my view), Arras and Fenton could usefully read Chapter 10, on "Partial Birth Abortion," to discover that I believe even a human genome combined with development to near birth is insufficient to confer human rights under existing human rights treaties. To my mind, human rights come with birth (as a "birthright"), and being born a human is sufficient (although not necessary) condition to possess human rights.

The confusion here seems to be between different concepts of what it means to be human—specifically, between the use of human as a descriptor of membership in a species (as determined, for example, by some commonality, like DNA or rationality) and the physical, mental, or psychological characteristics that qualify a non-DNA-based

humanlike entity as a possessor of human rights. This is, of course, the kind of question never considered on Curb, but was almost an obsession in the various Star Trek series: Is Spock (half-human and half-Vulcan) human or Vulcan? Is the android Data entitled to human rights? Must exotic sentient life forms that have robotic, vegetative, or other distinctly nonhuman bodies be accorded (human) rights?¹¹ These are all reasonable questions-but like questions of human dignity or agreement of a single basis for human rights, none of them need to be answered in a way that is persuasive to all humans, of all religions, in all countries, before acting to protect existing humans from war crimes and crimes against humanity, including enslavement or genocide. The real question, I take it, is really their second major problem—whether inducing inheritable genetic alterations poses a realistic threat of genocide, and, if so, is that threat (in magnitude and probability) significant enough to outlaw it?

It is in this context that I (and my colleagues Lori Andrews and Rosie Isasi) proposed a treaty on "Preservation of the Human Species" that would have outlawed cloning to make a baby and "using embryos or reproductive cells which have undergone intentional inheritable genetic modifications" to initiate a pregnancy. 12 Since the publication of American Bioethics, a treaty on this subject has been defeated and a substitute "Declaration on Human Cloning" adopted by the United National General Assembly in 2005. This Declaration (declarations are nonbinding) calls on all member states not only to prohibit cloning to make a baby and genetic engineering (provisions I and my colleagues strongly favored), but also to prohibit human cloning to make medicine-a provision insisted on by the United States, but one which I (and 34 countries that voted against the declaration) think is misguided and unnecessarily restricts important scientific exploration.

The absence of a treaty means that we revert to what I have termed "ethical arbitrage," individuals and corporations able to take their inheritable alteration experiments to the country with the laxest regulatory scheme. 13 The vote, in which each country has one vote regardless of size, also highlights a major problem in the UN structure dating from its own birth: using the human person as a model for the state and concluding from this metaphor that all states, regardless of size and population, must be treated as equal.

Here is the question I raised in supporting a treaty: "Can universal human rights and democracy, grounded on human dignity, survive human genetic engineering?"14 In thinking about how to answer this question I suggested (as others, including Lee Silver, have before me) that if genetic engineering was successful, it would lead to the creation of two separate species of humans: a standard issue human and a new "genetically enhanced posthuman," who would (or could) come to view the "standard human" as "heathens who can properly be slaughtered and subjugated."15 The offending sentence followed: "It is this genocidal potential that makes some species-altering genetic engineering projects potential species-endangering weapons of mass destruction, and the unaccountable genetic engineer a potential bioterrorist."¹⁶ And later, regarding policy:

My own view is that the boundary line that really matters is set by the species itself and that species-endangering experiments should be outlawed. We can take some actions on a national level, but we also need international rules about the new science, including not only cloning and genetic engineering, but also human-machine cyborgs, xenografts, and brain alterations. These could all fit into a *new category* of "crimes against humanity" in the strict sense, actions that threaten the integrity of the human species itself. This is not to say that changing the nature of humanity is always criminal, only that no individual scientist (or corporation or country) has the social or moral warrant to endanger humanity, including altering human in ways that might endanger the species.¹⁷

In attacking this position, Fenton and Arras argue that it is misguided and unhelpful to use the human rights crime of genocide in this context and strongly object even to my suggestion that there might be a new category of crimes against humanity, crimes involving endangering the human species itself. 18 In this regard they also argue that "whether a being reproduces sexually or by cloning is irrelevant, just by itself, to the moral status of that being." But this argument misses the point: It is not whether sexual reproduction is necessary to qualify members of an alien species as holders of (human) rights; it is whether changing this fundamental characteristic in the existing human species would predictably lead to major human rights abuses, in this case, genocide.

As to the centrality of sexual reproduction to humanity, we may simply disagree, but I do not think you have to agree with everything Freud wrote to see that human sexuality, including reproduction, is at the heart of human life and existence. Herbert Marcuse, in his philosophical inquiry into Freud's writing, for example, was not talking about genetic technologies or genocide when he argued that "the entire progress of civilization is rendered possible only by the transformation and utilizations of the death instinct and its derivatives.

... [It is] the punitive submission of the pleasure ego [sexuality] to the reality principle [that] assures civilized morality. In this transformation, the death instinct is brought into the service of Eros."¹⁹ Marcuse quotes Freud for the proposition that civilization cannot escape its "deadly component":

[W]e seem almost forced to accept the dreadful hypothesis that in the very structure and substance of all human constructive social efforts there is embodied a principle of death, that there is no progressive impulse but must become fatigued, that the intellectual can provide no permanent defense against a vigorous barbarism.²⁰

Freud was much more skeptical than most philosophers are of the ability of reason to control passion; but much of human rights is precisely aimed at that control, at inhibiting murder, torture, slavery, and genocide—the "barbarism" humans have historically (and contemporaneously) delighted in. In this context, Fenton and Arras nonetheless insist that we should view germline genetic engineering and its likely fruits through the lens of "pragmatic optimism." But what is it in the history of humans that permits this optimism? World War I, for example, was the war to end all wars, and World War II bred the human rights movement. Fenton and Arras suggest that breeding new subspecies of humans will not be that much different from each other than current variations in the human species "such as physical strength, intelligence, talents, aptitudes, and so on" and that these differences will, in any event, be protected by the very human rights doctrines they have criticized. In this argument, in which it seems they include their claim that "genetic interventions do not endanger [human] agency,"21 they

overlook the point that all of these embryo level experiments would be experiments on future children who could not consent. They thus seem to argue that humans should have unregulated autonomy themselves, but should simultaneously have complete dominion over children. The history of eugenics teaches us that unregulated genetic experiments are dangerous to children. Nor is either bioethics or human rights alone sufficient to prevent human rights abuses. As we have learned with the release of more and more CIA and military records, it took physicians and lawyers working together to justify torture both in the "black sites" and at Guantanamo Bay.²² Physicians and lawyers, upholding both medical ethics and human rights, could have, and should have, prevented this stain on our country's reputation.²³ Had they done so, it would have been an example of medical ethics and human rights working together and reinforcing each other.

Fenton and Arras may really believe (although they do not say so) that, if we abolished sexual reproduction, we could sublimate our urge to divide humans into groups justifying their subjugation and extermination. They also do not seem to realize that by privileging cloning over sexual reproduction, they abolish human evolution as well and fetishize the very entity they claim not to value: the current version of the human genome. Nonetheless, there is a potential (political) compromise. Our proposed treaty is based on the application of the precautionary principle to germline genetic engineering—and this means that new evidence could change the risk/benefit calculation in a way to permit the banned activity and that both the original ban and the lifting of it would have to be made by some globally accountable democratically elected entity (which, of

course, does not currently exist), not by me or any other human rights activist or philosopher.

The object of genetic engineering, of course, is not genocide, but the creation of a "better" human. Of course, the concept of a better human is no easier to articulate than the concept of human dignity. The real question I suggested in American Bioethics remains unanswered: Where do individual scientists and corporations get the moral warrant to engage in species-endangering experiments? Are good intentions combined with "pragmatic optimism" all that is required to put the species at risk? Although I will not be alive to see it, I think it may be reasonable to permit at least some limited experiments on germline genetic engineering if the world was able to go for a significant period of time, perhaps 50 years, without a genocide, and the experiment had been demonstrated to be safe in at least three generations of at least two nonhuman primate species.

Concluding Remarks

Ultimately Fenton and Arras conclude with the assertion that "the language of human rights does not and never will absolve us of the necessity of thinking together about what justice requires." Human rights proponents would agree, but add the words "acting" and "promoting," as in "thinking and acting together to promote what justice requires." Although it does not say much tell philosophers that our disagreements are mostly about language (what else could they be about?), the language of human rights is challenging because it does attempt to capture so much of human life.

Another episode of *Curb* thus provides a fit ending to this dialogue, where the participants seem to be talking a different language, or at least infusing words with incompatible meanings. At

a dinner party an argument breaks out. Two "survivors" argue over which had the most horrific experience, the survivor of a Nazi concentration camp or the "survivor" who endured weeks in the Australian outback on the TV reality show of the same name:

Colby: We spent days trying to survive. We had very little rations, no snacks.

Solly: Snacks, what are you talking snacks? We didn't eat, sometimes for a week, for a month ...

Colby: We couldn't work out when I was over there. They didn't have a gym.

Solly: A what? ...

Colby: Have you seen the show?

Solly: Did you ever see our show? It

was called the Holocaust!

Colby: Look, all I know I was damn close to that million dollars all right and everyone is back-stabbing me and trying to get me off the show.

Solly: You don't know nothing about

survival. I'm a survivor! Colby: I'm a survivor! Solly: I'm a survivor! Colby: I'm a survivor! Solly: I'm a survivor!

Only humans could both see in the Holocaust the necessity to respond with clearly articulated human rights that we are all responsible to respect, protect, and promote, and also use humor to encourage reflection on what it means to be a "survivor." I appreciate the concerns of Fenton and Arras and look forward to their commentaries on my upcoming book (which will be published shortly after these essays), Worst Case Bioethics, especially Chapter 1, "American Healthcare," Chapter 13, "Global Health," and especially Chapter 17, "Genetic Genocide."24 In the meantime, let me assure them that although "resistance is futile" the human rights call to bioethics is for cooperation, not the Borg's project of perfection through assimilation.

Notes

- 1. Fenton E, Arras J. Bioethics and human rights: Curb your enthusiasm. *Cambridge Quarterly of Healthcare Ethics* 2010;19:127–133 (this issue).
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- 16. See note 2, Annas 2005:38.
- 17. See note 2, Annas 2005:40.
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Wrong Again—Rejoinder to Annas

ELIZABETH FENTON and JOHN D. ARRAS

Different Agendas

It is clear from George Annas's response to our arguments that he has misunderstood and misrepresented our positions on several key points. We suspect that this may be due in part to significant