

SYMPOSIUM ON THE UNIVERSAL DECLARATION OF HUMAN RIGHTS AT SEVENTY
GERMLINE ENGINEERING AND HUMAN RIGHTS

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With the ever-increasing range of medical technologies at our disposal to mediate the processes of life, from conception to death, comes an ever-increasing number of decision points about human control of fate. And as we debate altering our fate—whether dictated by a deity or by chance—the discussion frequently devolves into a question of whether we may alter not only our own fate, but also that of our children. The advent of genome editing, whether by older methods or the newer, often more easily used methods employing CRISPR, has only made debating the controversial possibility of heritable “germline” editing more urgent. The advent of genome editing, whether by older methods or the newer, often more easily used methods employing CRISPR, has only made debating the controversial possibility of heritable “germline” editing more urgent. On the eve of the Second International Summit on Human Genome Editing, held at the end of November 2018 in Hong Kong, a startling and disturbing story began circulating - a Chinese researcher announced the first births of children whose genomes had been edited at the embryonic stage.¹ The work (assuming the claim can be verified) suffered from myriad problems, beginning with the lack of a compelling medical need, and including inadequate preclinical research, lack of peer review, flawed subject recruitment and consent procedures, and an apparent disregard for both formal and informal rules governing genetic manipulation of embryos.² The summit’s organizing committee issued a statement, distinguishing this experiment from what would be a responsible translational pathway forward.³ But not surprisingly, others around the world immediately called for a global, enforceable prohibition on such genetic engineering. On the occasion of the Universal Declaration on Human Rights (UDHR)’s seventieth anniversary, this essay argues that the current human rights law on germline editing misunderstands both the mechanisms of genetics and the moral basis for human rights, suggesting a more nuanced approach as we move forward and keep pace with new gene-editing technologies.

International Rules Applicable to Germline Editing

Genome editing⁴ is a group of technologies that can be used to change an organism’s DNA, by adding, deleting, or altering genetic material at a particular location in its genome.⁵ If done in any cells other than gametes (sperm or

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¹ Marilyn Marchione, [Chinese researcher claims first gene-edited babies](#), AP Wire (Nov. 26, 2018).

² Andrew Joseph and Sharon Begley, [China halts genome editing research that led to claimed birth of CRISPR babies](#), Stat News (Nov. 29, 2018).

³ [On Human Genome Editing II: Statement by the Organizing Committee of the Second International Summit on Human Genome Editing](#) (Nov. 29, 2018).

⁴ It is also commonly referred to as “gene editing,” though genome editing is the more comprehensive term.

⁵ Most commonly this is in reference to DNA found in the nucleus of the cell, but it could also be used to edit the DNA in the mitochondria.

egg) or embryos, it is called somatic editing, and affects only the person receiving the therapy. If done in the nuclear DNA of gametes or early embryos, however, the effect will be felt in every cell of the resulting person's body, including that person's own gametes. This "germline" editing would thus be heritable, and its effects passed down to subsequent generations.

The 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, better known as the Oviedo Convention, was written by the states of the Council of Europe to address the intersection of human rights and biomedical developments. As the most salient instrument on human rights in the biomedical field, it aims to protect the "dignity and identity of all human beings," and describes itself as building on the Universal Declaration and its progeny.⁶ But the Oviedo Convention is notable among binding international human rights instruments for its focus not only on the individual and society, but also on the species itself.

As suggested in the preamble and expanded upon in the treaty commentary, advances in genetics offer not only hope for prevention and cure of disease in an individual, but also a risk of unwanted societal effects and even a perceived risk to the integrity of the species. As stated in the explanatory notes to the Convention, "Whilst developments in this field may lead to great benefit for humanity, misuse of these developments may endanger not only the individual but the species itself." Therefore, states included an article that has immediate bearing on the permissibility of using genome editing to prevent disease or disability in one's children, and in future generations.

Article 13 reads, "An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and *only if its aim is not to introduce any modification in the genome of any descendants.*"⁷ In other words, even if done with the best of intentions, to ward off devastating—even lethal—conditions, the Convention allows no "germline" alterations that would affect descendants.

Many debates about germline editing focus on possible effects on the individual, on society, and on the species. But threading through these discussions, in scholarly literature and in domestic laws written to conform to the Oviedo Convention, are two distinct sets of arguments. The first speak to particular applications and not to the concept itself, where risks to individuals and possibly to society are weighed against possible benefits. In both the United States⁸ and the United Kingdom,⁹ influential advisory reports have concluded that, unless it is impossible to overcome the risks, a reasonable policy response lies in regulation to ensure the risks are reasonable. The second set of arguments are principled objections, divorced from this sort of balancing. But both reports noted that these arguments tend to suffer from an imperfect concept of the human genome, one not supported by either molecular biology or evolutionary theory.

The Risks of Particular Applications of Germline Editing

With regard to the possibility of particular applications causing physical harm to individuals living in the future, one can perform a traditional risk-benefit assessment, albeit with the stakes raised by the large number of future people affected and with skepticism that we can confidently predict the effects. But prediction and management of risks is a common feature of most planning, as is evident, for example, in debates surrounding energy production from processes ranging from dams to nuclear power plants, both of which pose a risk of catastrophic failure with multigenerational effects on the environment and nearby populations. Rather than allowing uncertainty to slide

⁶ [Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine](#), Apr. 4, 1997, E.T.S. No. 164 [hereinafter Oviedo Convention].

⁷ *Id.*, art. 13 (emphasis added).

⁸ NAT'L ACAD. OF SCI., ENG'G, & MED., [HUMAN GENOME EDITING: SCIENCE, ETHICS AND GOVERNANCE](#) (2017).

⁹ NUFFIELD COUNCIL ON BIOETHICS, [GENOME EDITING AND HUMAN REPRODUCTION](#) (July 2018).

toward paralysis and prohibition, a better approach has been to develop increasingly sophisticated means of calculating probabilities and incorporating ongoing risk monitoring and mitigation strategies.

A different objection to germline editing goes directly to how the emerging potential to make targeted biological changes in our children and descendants might affect someone's sense of autonomy and personal dignity. As noted in the report by the UK Nuffield Council on Bioethics:

Choosing someone else's genetic endowment (other than probabilistically, through the choice of a reproductive partner) might be analogous to a kind of enslavement, except that the limitations on their freedom take the form of a biological characteristic rather than a physical constraint or psychological oppression. On such a view, the intervention offends against the essential dignity and nature of the person as a free and independent human being.¹⁰

In essence, this argument rests on a claim that germline editing interferes with what Joel Feinberg coined as a child's "right to an open future."¹¹ The concern here is that a child might feel less unique or less free simply by knowing that some of his or her traits were chosen or deleted by someone else, regardless of whether it was effective or done with the child's welfare in mind. To the extent that human rights are founded on notions of autonomy and dignity, this could be seen as a violation of those rights. Dignity, in particular, is often used to question whether germline editing ought to be permitted. But dignity is rather undefinable.¹² It is not based on capacities, as this would deny the dignity of the unconscious and the mentally ill. But neither can it be based simply on embodiment of a particular genome, given that the human genome is constantly changing. If it is, instead, a metaphysical concept, then the editing of the child's genome does not intrinsically undermine that dignity, and, to the extent the edit is done to guard or enhance the capacities of the future child, neither is it a hindrance to autonomy.

Parents have children for all sorts of reasons, including a desire for some sort of immortality, an effort to strengthen the marital bond, or to provide company for an existing child. And parents make choices that radically shape life's possibilities for their children, in ways that are no less profound and no less permanent as those embodied in genes. Early childhood nutrition, stress, education, and socialization can have lifelong effects, not just psychological but physiological, including alteration of brain structure and vulnerability to obesity and heart disease.¹³ As Feinberg argues, the acceptability of parental choices rests on whether they serve to expand a child's capacities and prospects, or narrow them. And it is on this basis that both the U.S. National Academies of Sciences, Engineering and Medicine and the UK Nuffield Council found that if germline editing were to be ethically defensible, it would have to be limited to those changes that were for the welfare of the future child.¹⁴ This would encompass changes aimed at preventing serious disease and disability.

Beyond this would be insertion of traits that go beyond therapeutics and tend toward enhancing otherwise healthy conditions, a possibility often described as creating "designer babies," which, even if done for the welfare of the child, strike many as an intrusion on autonomy and a threat to social stability. Concerns about such editing could be softened by a closer look at the genetics involved. In 2017, experimental evidence suggested that inserting a desired trait into a human embryo might not result in expression of the insert, but instead would result in

¹⁰ *Id.*

¹¹ JOEL FEINBERG, *The Child's Right to an Open Future*, in WHOSE CHILD? (William Aiken & Hugh LaFollette eds., 1980); JOEL FEINBERG, *FREEDOM AND FULFILLMENT* 76-97 (1992).

¹² Ruth Macklin, *Dignity is a Useless Concept*, 327 BRITISH MED. J. 1419-20 (2003).

¹³ The Committee on Psychosocial Aspects of Child and Family Health, Committee on Early Childhood, Adoption, and Dependent Care, and Section on Developmental and Behavioral Pediatrics, *The Lifelong Effects of Early Childhood Adversity and Toxic Stress*, 129 PEDIATRICS 232 (Dec. 2011).

¹⁴ NAT'L ACAD. OF SCI., ENG'G, & MED., *supra* note 5; NUFFIELD COUNCIL ON BIOETHICS, *supra* note 6.

expression of the trait found on the other chromosome, thus blunting any effort to “design” the resulting child.¹⁵ Further, genetic code is not a blueprint that perfectly predicts phenotypic outcomes. As the author of a review looking back at Erwin Schrödinger’s book “What Is Life?” wrote:

This isn’t how it works: you can’t read the arrangement of the body’s organs in the genome. The information functions as a resource, not a step-by-step guide. To acquire meaning, it must have context: a cell’s history and environment. Tracing how the phenotype emerges from interactions of genes with each other and with their environment is the key puzzle of modern genomics.¹⁶

Other concerns about germline editing revolve around fear that it will lead to societal intolerance of imperfection, turning children into commodities that are rejected when not perfect, rather than the subjects of parental love, and that it will result in stigmatization of those who are disabled. These concerns are not unfamiliar. They were raised in the 1970s, when amniocentesis led to fear that children nonetheless born with Down’s syndrome would be even further stigmatized. Instead, what had been a common practice of institutionalization and even neonatal euthanasia has given way to mainstreaming.

These concerns were raised again in the 1980s, when in vitro fertilization (IVF)¹⁷ was viewed as unnatural. Yet parent-child relations have not in fact been harmed and access to IVF has now been declared to be a human right by the Inter-American Court of Human Rights.¹⁸ Nor (despite some anecdotes about egg donation) has artificial insemination led to a large-scale rush to find “superior” gametes. Surveys show that most people simply want donors who will resemble the nongenetic rearing parent. In the 1990s, when “preimplantation genetic diagnosis” was developed so that in vitro embryos could be biopsied and those with deleterious traits left ungestated, there was concern that parents would use the technique for ever more trivial reasons. In fact, the technique continues to be used almost only for serious conditions.¹⁹ And in the United States, Congress passed the Americans With Disabilities Act during the very same years when genetic screening began to allow for fewer children to be born with disabling conditions. Instead, there was greater acceptance of disability as another aspect of human diversity. What followed was tremendous progress toward making workplaces, homes, and public facilities accessible so that those with disabilities would no longer be isolated from the wider community.

The feared consequences of using germline editing also includes a more profound version of stigmatization of disability, coupled with a fear of creating whole classes of superior and inferior people. It reflects a distrust in human action on a population-wide scale, borne of the tragic experiences with eugenics in the United States, Germany, Japan, and elsewhere. “The ultimate fear is of intentional modification of the human genome so as to produce individuals or entire groups endowed with particular characteristics and required qualities,” says the Explanatory Note to the Oviedo Convention. But if this fear is about exacerbating inequities or creeping toward biological caste systems, population biology mathematics quickly demonstrates that any change made in a limited number of cases now will have little effect on the global frequencies and every edit would be subject over the course of generations to the same forces that cause all traits to change over time, due to mutation and genetic recombination.

¹⁵ Hong Ma et al., *Correction of a Pathogenic Gene Mutation in Human Embryos* 548 NATURE 413 (2017); Dieter Egli et al., *Inter-Homologue Repair in Fertilized Human Eggs?*, 560 NATURE E5 (Aug. 8, 2018).

¹⁶ Philip Ball, *Schrödinger’s Cat Among Biology’s Pigeons: 75 Years of What Is Life?*, NATURE (Aug. 29, 2018).

¹⁷ In IVF, eggs are fertilized in a laboratory and grown until ready for transfer to a woman who will gestate them until birth.

¹⁸ Center for Reproductive Rights, *Inter-American Court of Human Rights Declares Costa Rica’s Ban on In-Vitro Fertilization a Human Rights Violation* (Dec. 21, 2012).

¹⁹ Another less frequent use is to select only embryos that will produce a child of a particularly desired sex, which the Oviedo Convention would prohibit.

In sum, by the early twenty-first century, there has been a half century of experience with new technologies predicted to alter human relations and give people a power that they would inevitably abuse, but which did not in fact result in these dystopian futures. Despite this, the same predictions are made about the consequences of germline editing. The evidence of recent history suggests otherwise.

The Fear of Altering the Meaning of Being Human

Beyond these concerns, there is also a sense that editing somehow interferes with the very notion of a “human” genome and violates something like “species integrity.” But to better understand this instinctive response, it is helpful to distinguish two kinds of editing. The first would give the individual a trait that is healthy and known to exist among humans. The second would be the more fanciful possibility of creating traits that lead to capacities wholly unknown in humans.

The first situation, of editing done to simply introduce a familiar, healthy trait, i.e., a “wild type” trait, would in no way disturb the range of traits now associated with being human, and cannot alter how we define our species. Indeed, even traits unfamiliar to us as a species may nonetheless be perfectly consistent with our notion of humans. The concept of species integrity often implicitly incorporates a static vision of a human genome that contains only “human” genes that are transmitted vertically from generation to generation. But this is an overly simplified picture and, indeed, a misleading one. Evolution is not a branching tree, but rather a complicated pattern, with recursive and horizontal transfers of material, between generations and between species.²⁰

The complicated history of the human genome demonstrates just how changeable the human genome has been, to the point that not all of it—and not all of us—are purely “homo sapiens.” Paleogeneticists have recently documented the extent to which different kinds of humans inter-bred, so that a “human” genome today will contain not just traits associated with homo sapiens, but also those of Neanderthals and Denisovans, who had previously been viewed as entirely different, reproductively isolated populations that died out while homo sapiens developed and thrived.²¹

The possibility of using editing to develop not just traits but actual capacities alien to humankind raises the most visceral concerns. This possibility has led to “transhumanism,” a field focused on both mechanical and biological enhancements of human bodies and minds to extend human capacities beyond current limits to make people “better than well.”²² Taken even further is the imagined future in which the very essence of what is typical of the species has been transformed. As if to make the point, in 2017, a new publication arrived whose editors note that “the boundaries between human and ‘the other’, technological, biological and environmental, are eroded and perceptions of normalcy are challenged.”²³

The objection here is not to physical risks, nor even to societal disruption, but rather that this will fundamentally undermine, or even redefine, the meaning of “human” as a species concept. From this may come the conclusion that by altering the meaning of “human,” one has undermined the foundation for “human” rights.

Of course, this supposes that human rights are recognized based solely upon an organism’s genetic makeup. But as Margaret Riley points out, the advent of editing and the theoretical possibility of resurrecting Neanderthal man or of generating primates with enhanced cognitive abilities akin to our own (so-called “humanzees”) will force a

²⁰ David Quammen, *The Scientist Who Scrambled Darwin’s Tree of Life*, N.Y. TIMES (Aug. 13, 2018).

²¹ Viviane Slon et al., *The Genome of the Offspring of a Neanderthal Mother and a Denisovan Father*, 561 NATURE (Aug. 22, 2018).

²² Humanity +, *About Humanity +*.

²³ J. POSTHUMAN STUD.: PHIL., TECH., MEDIA.

confrontation with the genetic essentialism that underlies a one-to-one correspondence between homo sapiens and human rights.²⁴ As Peter Mills of the UK Nuffield Council has written:

[I]t is not the ‘nature’ that is the basis of human rights but the ‘human’, which is, in the end, political [W]hatever the ground of ‘human’ rights is, it should be seen as a threshold rather than a property exclusive to natural kind or class. It follows, therefore, that such rights as are currently enjoyed by humans should equally extend to a non-human, a posthuman or even an artificial intelligence, who is capable of being welcomed into our moral community.²⁵

Indeed, animal rights activists have argued for years that such rights ought to be based upon capacities rather than species membership, so (for example) the right to be free of pain is relevant to every pain-capable animal.

Conclusion

The preamble to the Oviedo Convention speaks of the need to “respect the human being both as an individual and as a member of the human species” and to recognize “the importance of ensuring the dignity of the human being.” Prohibiting germline editing is not necessary to respond to these goals. While attention must be paid to protect the well-being and open future of the child and of future generations, germline editing may offer yet another way to be responsible midwives to those who come next. Understanding that homo sapiens is a species with blurry boundaries, and that we carry within us genetic traits that trace back to Neanderthals and even far more primitive life forms, should make us question whether germline editing in any way undermines the basis for according human rights, and indeed, whether being human is essential to human rights at all.

²⁴ Margaret Riley, *CRISPR Creations and Human Rights*, 11 L. & ETH. HUM. RIGHTS 225 (2017).

²⁵ Peter Mills, *Genome Editing, Human Rights and the ‘Posthuman’*, NUFFIELD COUNCIL ON BIOETHICS (2017).