

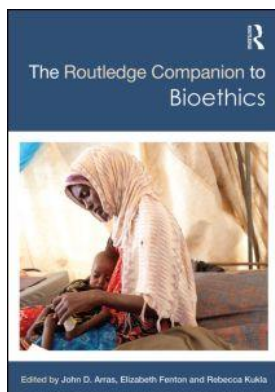
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## **The Routledge Companion to Bioethics**

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### **Bioethics and Human Rights**

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## Part II

# BIOETHICS ACROSS BORDERS

Throughout much of its history bioethics teaching and scholarship has focused on the domains of the clinic, hospital, or research protocol, often in a domestic or national context. More recently, however, and reflecting the trend of globalization more broadly, bioethics has become a global field as human health and the myriad factors that influence it increasingly transcend national borders. Some direct threats to health, such as infectious diseases or bioterrorism, can only be addressed through international cooperation; indirect threats to health are also now distinctly global, as the world's economies are intertwined in a complex web of global economic policies that influence quality of life along many dimensions. International multi-site clinical trials bring into play ethical considerations that often vary widely from country to country. The health care industry is now a global enterprise, as patients from wealthy nations seek cheaper care in less wealthy countries seeking new ways of generating tourist revenue. Health care workers migrate for better-paid employment, often leaving significant gaps in the health systems of their home countries. In keeping with this volume's emphasis on social justice the chapters in this section highlight the influence of massive global inequality on individual and population health.

The first chapter explores the relationship between bioethics and human rights, the most powerful and universal movement for global social justice. Elizabeth Fenton examines the arguments both of those who call for human rights to be the "lingua franca" of global bioethics, and those more circumspect about whether these two distinct domains can or should merge. Fenton lays out the philosophical and practical arguments on both sides of this debate, which serves as a useful entry point into considering other issues that arise when health, health care, and bioethics cross borders.

Fenton draws attention to a criticism sometimes leveled at bioethics, that it has focused largely on the problems of the wealthy and advantaged, and has devoted a shamefully small amount of space to health needs, concerns, and challenges in resource-poor settings. Kjell Arne Johansson's chapter confronts some of these challenges in the context of priority setting in resource-poor settings. Prioritization of scarce health resources is difficult and complex even in wealthy settings, but in low-income countries, where health expenditures are as low as 1/180th of those in high-income countries, the problems are even more acute. Johansson argues that while access to and quality of

health care in these settings is important, the distribution of other social goods, such as income and education, has a substantial impact on population health. This chapter highlights the issues of justice at the heart of priority setting in health and its impact on health at the population level, and in so doing exemplifies the broader bioethics scholarship that is critical to the future of the field.

The movement of both patients and health workers around the globe shines a light on a number of complex problems in global health delivery. I. Glenn Cohen provides insight into the legal and ethical challenges of patients seeking and receiving health care in foreign countries. These challenges are not limited to the individual patient, though issues such as safety, liability, and follow-up care are significant, but extend much more broadly to include the ways in which medical tourism depletes already impoverished local health systems, and the inequitable distribution of access to health care in home countries that pushes patients to travel overseas for needed medical care. The other side of the medical tourism coin is the global movement of health care workers, often from low- to high-income countries, and often facilitated by health systems in high-income settings. Nir Eyal and Samia Hurst's discussion of health worker migration lies at the intersection of global health policy and global justice, highlighting the often detrimental impact of health worker migration on population health while acknowledging its appeal for health workers from low-income countries. The authors explore competing ethical considerations, including whether health workers have a moral responsibility to remain in their home countries when need is great, whether they can be required to remain by more or less coercive policies, whether the individual liberty interests of health workers trump any obligation to remain, and the responsibilities of recruiting health systems to the countries whose workers they are recruiting.

The final chapter in this section addresses one of the most truly global contemporary problems of health and social justice. The phenomenon of climate change has not escaped serious moral analysis, but is less often couched in terms of bioethical concerns. Yet as Madison Powers argues, climate change poses some of the most significant contemporary threats to human health and wellbeing, ranging from disruption of agriculture and food production, to expansion of geographic zones at high risk for infectious diseases, and the differential impact of climate change on poorer nations. Implicit in the debate over climate change are issues that arise again and again in global bioethics, namely health and social justice, and moral responsibility. Powers' contribution shows the complexity of the debate over who should bear that responsibility and take the necessary steps to mitigate the injustices of climate change, injustices that are likely to have a significant impact on population health in the future.

# BIOETHICS AND HUMAN RIGHTS

*Elizabeth Fenton*<sup>1</sup>

Bioethics and human rights are deeply intertwined, not least because of their common origins in the horrors of war—both emerging from the post-World War II International Military Tribunal in Nuremberg, including the trial of “Nazi doctors”—but also because of their common desire to reduce human suffering and protect human health and wellbeing.

As bioethics increasingly turns its attention to issues of global health and social justice, the intersections with human rights are more numerous and more profound. Bioethics has most notably encountered human rights in terms of the human right to health care (see Chapter 1 in this volume), but the scope of the relationship is much broader. Some have argued, for example, that debates over human genetic engineering engage human rights at the deepest level, raising questions about what it is to be human and what forms of change might endanger the notion of humanity at the core of human rights (Annas 2005; Andorno 2002; Fukuyama 2002). And as our understanding grows of the many and varied factors that influence health, the human right to health care has been eclipsed by the more expansive human right to health (or “health-related goods”), that encompasses the social, economic, and political contexts in which we live. As others in this volume point out, bioethics has been somewhat slow to recognize the moral significance of these broader contextual factors (see Chapter 2 in this volume), but as it does so it is increasingly pulled into the powerful force field of human rights, particularly social and economic rights.

This chapter explores the relationship between bioethics and human rights from two perspectives. The first perspective is broadly enthusiastic about an intimate relationship between bioethics and human rights, with some authors considering human rights to be an important common ground or *lingua franca* for global bioethics, and others imagining a merger between these two fields. Also included in this perspective are critics of bioethics who urge the field to adopt a stronger human rights focus, paying greater attention to the social and economic contexts in which bioethical issues arise.

The second perspective is more circumspect about the relationship between bioethics and human rights. This circumspection is justified in part by philosophical problems raised by human rights themselves, and in part by resistance to the notion that the ethical analysis characteristic of bioethics might be exhausted by the moral concepts and language of human rights. Those who view the notion of a merger between bioethics and human rights with caution argue that a rights-based framework is just one lens through which to view issues of social justice in bioethics, and while sometimes critical,

it can also be unhelpful or inhibit other forms of moral reasoning. I will begin with a brief discussion of the “globalization” of bioethics, and note some important historical landmarks in the development of the relationship between bioethics and human rights.

### Bioethics Goes “Global”

Bioethics has gone global in one obvious sense. As a response to threats to health, bioethics must now consider pandemics that cross national boundaries; the doctor–patient relationship may involve doctors in India or Thailand treating “medical tourists” from the United States and Europe; health workers trot the globe seeking better pay and working conditions, leaving health care in resource-poor settings to the vagaries of the philanthropic and non-governmental organization sectors; drug trials take place all over the world, funded by vast transnational corporations, testing drugs that will be distributed under a range of complex international aid and trade agreements; biotechnology and climate change are truly global phenomena that will, at some point, challenge the health of every human being on the planet.

Bioethics has also gone global in a less obvious sense. Its concerns have moved beyond the individual patient and medical professional to the health of groups and populations, beyond health *care* to encompass all of human health and its relationship to “global” wellbeing, beyond justice for this or that patient to justice across a growing health gap between rich and poor, advantaged and disadvantaged.

Human rights are a natural fit with globalized bioethics in both of these senses. On the one hand, human rights provide a ready-made language and framework for navigating complex cultural and religious differences that arise when ethical issues cross borders; thus Lori Knowles describes human rights as a “lingua franca that can both facilitate and broaden international bioethics discourse” (Knowles 2001: 253). They also provide a legal framework that transcends domestic law and regulatory regimes; thus Roberto Andorno describes human rights as “the best, if not the only available grounds for the development of international legal standards for biomedicine” (Andorno 2009: 224). In the second sense, human rights are a powerful force of social justice, setting out the conditions of human wellbeing and flourishing. When serious attempts are made to ensure that all human rights, and particularly social and economic rights, are fulfilled, health and health equity are improved. Thus the failure to fulfill these rights is, as Paul Farmer and others have argued, one of the most pressing ethical issues for contemporary bioethics (Farmer and Campos 2004a).

In many respects the origin stories of bioethics and the modern human rights movement are inseparable. In a succinct summary of their history, Robert Baker highlights the argument made by an American physician at Nuremberg, employed by the prosecution, that unconsented human experimentation of the sort practiced by Nazi doctors was impermissible as a violation of ethical principles *and* human rights—he argued, in effect, that the ethical principles of the medical profession are mechanisms for protecting human rights (Baker 2001: 244). But this argument, that “transcultural” medical ethics could be grounded in human rights, was ignored in favor of “the myth of converging civilized opinion” condemning the Nazi doctors’ actions. The ethical principles of the Nuremberg Code were thus not grounded in human rights, and in spite of many parallels in the development of the two fields, Baker argues that “American bioethics has been ill at ease with the idea of human rights” ever since (Baker 2001: 247). Baker and others have called for bioethics and human rights to be reconciled; George Annas argues that

“it is time to reunite the estranged twins who can work much more effectively together in the global health arena than they can separately” (Annas 2010: 135).

In the last several decades a series of international bioethics documents invoking human rights suggests that a reconciliation between these two fields is indeed occurring. In 1997 the Council of Europe adopted the Convention on Human Rights and Biomedicine, which aims to protect individuals from the misuse of biology and medicine. This document echoes the emphasis of the Universal Declaration of Human Rights (UDHR) on human dignity, endorses certain principles, for example that “the interests and welfare of the human being shall prevail over the sole interest of society or science,” and issues substantive prescriptions, for example prohibiting the creation of human embryos for research, or human genetic modifications for anything other than preventive, diagnostic, or therapeutic purposes (Council of Europe 1997). Also in 1997 the United Nations Educational, Scientific, and Cultural Organization (UNESCO) adopted the Universal Declaration on the Human Genome and Human Rights, which again echoes the UDHR in emphasizing that human genetic research must “fully respect human dignity, freedom, and human rights” (UNESCO 1997). In addition to this document, UNESCO adopted the International Declaration on Human Genetic Data in 2003, which aims to protect individuals from the risks posed by collecting, storing, and using genetic data in the service of “human rights, fundamental freedoms, and respect for human dignity” (UNESCO 2003).

Most recent in this series of documents is UNESCO’s 2005 Universal Declaration on Bioethics and Human Rights (UDBHR). The aim of the UDBHR is to “determine those principles in the field of bioethics that are universally acceptable, in conformity with human rights as ensured by international law,” and, as far as possible, to “inscribe scientific decisions and practices within the framework of a certain number of general principles common to all” (ten Have 2006: 341). The UDBHR is significant, first, because it can be viewed as an achievement to have garnered agreement among virtually all states in the “sensitive area” of bioethics, and second because as a legal (though non-binding) document it encourages states to commit to common standards without forcing them to do so (Andorno 2007). A strong advocate of the UDBHR, Roberto Andorno is careful to note that its purpose is not to “invent new bioethical principles or to provide the definitive solution to the growing list of bioethical dilemmas.” Rather, it aims to provide one-stop guidance to states in the form of “basic standards” for responsible biomedical research and clinical practice that conform to international human rights law (Andorno 2007: 153).

### **Merging Human Rights and Bioethics**

The controversy surrounding the UDBHR (some of which will be explored further below) suggests that the document has achieved at least one of its aims, namely to open “a new agenda for international bioethics” (Ashcroft 2008: 38). I set aside this controversy for the moment in order to focus on the argument that the Declaration, and the related documents that preceded it, are part of a much-needed reconciliation or merger between bioethics and human rights.

A number of reasons have been given in support of such a merger. First is the notion that bioethics (particularly “American” bioethics) needs human rights to escape its limited domestic preoccupations; human rights can “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” (Annas 2010: 134). Human rights are a global language, in comparison to the parochial or ethnocentric languages of bioethics as practiced in different national or cultural contexts. The term “lingua franca” is used frequently, and Baker describes human rights as having “transcultural scope” that can “dissipate problems of moral parochialism” and free global bioethics from “the feckless dispute over whose principles are preferable” (Baker 2001: 250). In a similar vein, it is often argued that the success of the human rights movement is due in large part to the fact that adherents leave their philosophical commitments at the door; questions of deeper moral foundations for human rights are simply bracketed in favor of an “overlapping consensus” on the identification of the rights themselves. Principles of bioethics, treated similarly, may have the same success on the global stage. Of course these claims about human rights as the locus of consensus, sitting above the petty squabbles that muddy the foundational waters beneath, gloss over lingering and not insignificant disputes about human rights principles, but I take up this issue in more detail below.

Another reason in favor of a merger is that human rights give bioethics a broader and more socialized context in which to situate its traditional concerns, since they carry a greater emphasis on justice, social structure and social power (Ashcroft 2008). Human rights also have “great rhetorical, moral, and popular force” that can only enhance the power and reach of bioethics, and imposing the framework of international law on bioethics will produce tangible effects of this enhanced power, in the form of national action and the passage of national laws (Knowles 2001: 254). Moreover, as Thomas Faunce points out, the use of human rights law in cases relevant to bioethics, such as end-of-life decisions, reproductive technology, privacy, and informed consent, has established a body of interpretations of bioethics principles that can provide important guidance in difficult cases. Perhaps most significantly, human rights law lends credibility to the principles of bioethics, without which they can easily be ignored by the range of multinational organizations and corporations that increasingly control or influence the medical profession and delivery of health services (Faunce 2004).

Faunce explores other ways in which the assimilation of bioethics and human rights may advance bioethics, noting that human rights may be a more powerful mechanism for motivating a concern for social justice among physicians and medical students than bioethics alone. He goes on to argue that consensus documents that impose a human rights framework on bioethics, like the UDBHR, are the first steps in a process in which “the moral, political, and international law aspects of human rights begin to *subsume* medical ethics” (Faunce 2004: 177, emphasis added). His enthusiasm for this outcome is evident in his speculation that in the future an international bioethics convention will create “binding obligations on states under international law,” obligations to ensure that domestic legislation “on bioethics, public health, or the doctor/patient relationship conforms to international norms” (Faunce 2004: 177).

Although it is important not to become mired in linguistic differences, it is noteworthy that other proponents of merging bioethics and human rights have rejected Faunce’s notion that human rights will *subsume* bioethics. The term *subsume* connotes the loss of bioethics as an independently identifiable field, whereas Andorno and Baker, for example, view human rights as a necessary foundation or grounding for global bioethics (Baker 2001; Andorno 2009). Andorno argues that bioethics must be understood broadly, as both an ethical and a legal discipline; the UNESCO declarations and other similar documents are “an extension of international human rights law into the field of biomedicine” (Andorno 2009: 225, emphasis in original). Far from losing its identity, then,

on this view human rights bolsters bioethics, giving the field a stronger global presence and legal heft.

### The Human Rights Critique of Bioethics

In addition to arguments from within bioethics for a reconciliation with human rights, those in the human rights community, including activists and advocates of a human rights framework for health, have criticized bioethics in at least two ways for a lack of engagement with human rights. First, they argue that as a field deeply rooted in philosophy, problems in bioethics are too often approached through abstractions rather than through concrete realities; problems are analyzed in terms of the “mythical figure of the autonomous subject” and individual values and preferences, abstracted from the social context in which those individuals actually live (Ashcroft 2008: 43). Rejecting the biological individualism that views health and disease as “ascertainable in isolation from the broader context in which people live,” advocates of a rights-based approach to health argue that health is deeply tied to social, political, historical, and economic contexts, and suffering arises not only from biological causes but from “human choices about policies, priorities, and cultural norms, about how we treat each other and what we owe each other” (Yamin 2008: 47). Physician and anthropologist Paul Farmer argues that in its detachment from social context, bioethics has failed to appreciate the most challenging ethical problem in health, namely the large and growing health outcome gap between rich and poor. He calls for “resocialising” bioethics to draw more from relevant social science disciplines, such as economics, anthropology, and history (and perhaps less from philosophy) in order to fully understand the ways in which poverty, racism, and gender inequality impact on people’s choices, their vulnerability, and their access to equitable health care (Farmer and Campos 2004a: 27). Farmer’s chief concern, and that of the health and human rights community more broadly, is with the health of the world’s poorest and most marginalized, whom bioethics has failed “on numerous occasions, be it from lack of influence or failure to consider social justice.” Farmer urges bioethics to adopt a new focus on human rights, through which it can “engage other disciplines to ensure that social and economic rights for the poor are realized” (Farmer and Campos 2004b: 245).

The second, related, human rights criticism of bioethics is that it is too often detached from real human suffering in its analysis of health and human rights, and too often unengaged from the political struggles waged by human rights activists. Although Farmer’s criticisms extend to those working in human rights as well as in bioethics, his call for a more pragmatic and less theoretical approach to addressing social injustices is particularly powerful for disciplines like bioethics that are often more intellectual than practical. Treating the poorest of the poor in the world’s most under-resourced health systems, Farmer loses patience with endless theorizing or philosophizing about human rights, hand-wringing about cost-effectiveness, and repetitive data collection (“let’s just say no to more surveys sure to reveal the same problems already revealed by previous surveys”). He insists that the “traditional exhortatory role” of health and human rights be replaced by a focus on “prosaic” issues like supply chains for basic medical equipment, and immediate, short-term action to address the most egregious resource shortages that inhibit progress in areas such as maternal mortality: “We will need gloves. We will need sutures and antihemorrhagics. We will need drapes and hot, clean water” (Farmer 2008: 10). The call to action extends to bioethicists as well, whom Farmer argues should be



prepared to engage actively with problem solving on the ground, becoming “part of teams seeking to lessen the outcome gap by remediating access to effective medical care” (Farmer and Campos 2004a: 39).

Whether Farmer and other proponents of a human rights focus in bioethics view formal documents such as the UDBHR as progress is unclear. Critics of this document in particular have argued that its emphasis on individual liberty indicates a failure to take seriously issues of substantial inequality and collective action in efforts to promote health equity (Selgelid 2005), suggesting that Farmer and others would find little reassurance in this latest explicit “reconciliation” of human rights and bioethics. Other developments in the field may offer more hope, for example, a growing body of work in public and population health ethics, where the social determinants of health and health inequalities are given more attention than in traditional bioethics. Nevertheless, many in bioethics remain skeptical about human rights and their role in bioethics, both practically and theoretically, and this skepticism is the topic of the next section.

### **Resisting a Merger Between Bioethics and Human Rights**

Richard Ashcroft has provided a pithy summary of the sometimes “troubled” relationship between human rights and bioethics: “There is a bioethical critique of human rights; and a human rights critique of bioethics” (Ashcroft 2008: 38). Whereas Farmer’s challenge to bioethics is indicative of the latter, in this section I explore the criticisms bioethics has leveled at human rights theory and practice, and the extent to which it has resisted engagement with human rights. These criticisms can broadly be categorized as philosophical and practical.

#### ***Philosophical Problems***

A striking and much discussed feature of the development of the Universal Declaration of Human Rights is the fact that the drafters reached any agreement at all on such moral principles, given the vastly different moral, religious, cultural, and ethnic commitments that they brought to the table. Famously, one of the drafters reported that “we agree on these rights, *provided we are not asked why*” (Maritain 1949: 9, emphasis in original). This form of agreement on principles, where foundational commitments or justifications on which there is likely to be substantial disagreement are bracketed, is often referred to as an “overlapping consensus,” following political philosopher John Rawls’ use of the term to describe agreement on principles of justice in a pluralistic society (Rawls 1993, 1999 [1971]). Not surprisingly, this term has also been used in reference to the UDBHR, where again foundational issues are bracketed in order to arrive at “general principles common to all” (ten Have 2006). While there is much to be said for seeking common ground and consensus around principles of justice, there are substantial and difficult questions about whether such general principles are ever either “common to all,” or devoid of the sorts of theoretical commitments that undermine the claim of an “overlapping consensus” to have successfully bracketed foundational issues.

One of the central philosophical problems raised by both the UDBHR and the imposition of a human rights framework on bioethics more generally is the concern that human rights, far from being “neutral” with respect to foundational issues, are in fact rife with presumptions and theoretical commitments that many find objectionable. For example, a number of commentators have noted the emphasis placed in the UDBHR

on individual autonomy and liberty, which is viewed by some as a bias inherited from the Western Enlightenment tradition (of which human rights are a legacy) that ignores the strongly relational nature of individual lives and the extent to which family and social networks “ground and sustain individual identity” (Rawlinson and Donchin 2005: 262). Another criticism is that the UDBHR fails to give any indication of how conflicts between individual liberty and social welfare should be adjudicated; Michael Selgelid, for example, argues that it fails to recognize that in the health care context individual liberty must sometimes be sacrificed to achieve the common good (Selgelid 2005). Yet another criticism highlights the document’s somewhat clumsy attempt to show respect for cultural diversity by stating that cultural diversity and pluralism “are not to be invoked to infringe upon human dignity, human rights and fundamental freedoms” (UDBHR Article 12). Jing-Bao Nie argues that this statement sets up a false sense of antagonism between the notions of human dignity, human rights, and fundamental freedoms on the one hand, and non-Western cultures on the other, whereas in fact these notions are deeply rooted in many such cultures. The UDBHR thus perpetuates a myth that universal ethical ideals, such as human dignity and human rights, are incompatible with moral values in non-Western cultures (Nie 2005).

These criticisms of the UDBHR mirror criticisms of the notion of *universal* human rights more broadly. The notion of whether there can be universally shared moral principles is a perplexing one, but the extent to which human rights have been embraced globally lends it considerable support. Nevertheless, philosophers worry that even if universal or widespread support can be gained for a limited set of basic moral principles, the more these principles attempt to cover complex issues that implicate deep moral and political disagreement—issues that are the bread and butter of global bioethics—the less likely it is that they can be described as “universal.” Moreover, it is debatable whether supplanting local norms with the supposedly universal norms codified in the principles of the UDBHR is always a good thing. The cloak of universality lends the principles a higher moral status than may be warranted when they come into conflict with legitimate moral values at the local level.

Perhaps the most notoriously controversial aspect of human rights documents such as the UDBHR for philosophers is their grounding in the concept of human dignity, a concept that, despite receiving considerable attention in the literature, remains nebulous. Dignity is something of a lightning rod in the debate over human rights and bioethics, with passions running high on both sides. Defenders of the importance of dignity have described it as the “overarching principle” of international bioethics and biolaw, which is placed first on the list of principles in the UDBHR because it “embodies the central aim of the whole instrument” (Andorno 2009: 227). Detractors argue that dignity is a “useless” concept (Macklin 2003), or at least a slippery one, meaning very different things to different people and in different contexts. As such, it is deeply philosophically problematic to declare that certain practices, such as reproductive cloning, germ-line modifications, or the creation of embryos for research are or could be “contrary to human dignity” (such claims are made in the Universal Declaration on the Human Genome and Human Rights and the Convention on Human Rights and Biomedicine; dignity also plays a central role in the work conducted on human cloning by the United States President’s Council on Bioethics under Leon Kass (Kass 2002)). Without a clearer idea of what human dignity is, such statements are difficult to comprehend.

The extent to which the language of human rights and human dignity has been used to justify prohibitions in these areas constitutes one of the central reasons why many

philosopher-bioethicists are critical of the importation of human rights into bioethics. To claim that germ-line interventions or genetic enhancements, for example, are necessarily contrary to human dignity and therefore a violation of human rights is not only a weak argument, since dignity is always under-defined, but also a short-sighted and potentially destructive one. Given the power of human rights, grounding a prohibition on an action in human rights terms takes that action off the table. But future enhancements may have the capacity to *improve* human health and wellbeing: Do these potentially beneficial enhancements also endanger human dignity and violate human rights? Critics of the use of human rights to prohibit human enhancement argue that dignity is too imprecise a concept to ground blanket bans on complex technologies of this sort. Appeals to human dignity and human rights are no substitute for a more fine-grained moral analysis of the moral issues at stake (Fenton and Arras 2010).

Arguments about the foundational or philosophical commitments of human rights are sometimes dismissed as, at best, examples of the “harmless entertainment” produced by philosophers, “which if taken too seriously would look ridiculous” (Churchill 1999: 255), or at worst, as a way of postponing the protection of human rights in practice (Annas 2010), or undermining “the force of rights claims and instruments in practice,” by giving rights-abusing governments a reason to argue that supposedly universal and non-derogable rights may, according to the intellectual ditherings of philosophers, be neither of those things (Ashcroft 2008: 44). But concerns about the foundations of human rights are not so easily dismissed. Whether germ-line genetic interventions, for example, are or ought to be considered a violation of human rights is a significant question, but one that cannot be answered without a deeper and more precise understanding of what it is that human rights seek to protect. The standard answer “human dignity” is insufficient, since whether enhanced memory, intelligence or athleticism are contrary to human dignity is far from obvious. Moreover, to claim that human rights rest straightforwardly on the foundation of human dignity, with all its myriad interpretations, or any other singular notion of what it is to be human, can undermine the doctrine’s claims both to universality and political legitimacy. As Amy Gutmann observes:

If human rights necessarily rest on a moral or metaphysical foundation that is not in any meaningful sense universal or publicly defensible in the international arena . . . then the political legitimacy of human rights talk, human rights covenants, and human rights enforcement is called into question.

(Gutmann 2001: xvii)

Of course, it is precisely for this reason that questions of foundations are typically set aside in favor of overlapping consensus, but as the case of genetic enhancement shows, there are instances in which we cannot know whether something violates human rights simply by looking to the documents on which the consensus has been achieved. Similarly for questions about balancing individual liberty against social goods, on which there is no guidance in human rights documents. Unless we are willing to engage deeper foundational issues we have no way to answer these important questions; the notion that philosophical commitments can be checked at the door is a convenient, but ultimately unhelpful fiction.

Clearly the overlapping consensus on both human rights and the UDBHR is an imperfect one; and as Jonathan Wolff has pointed out, one response to “residual differences” in understanding and interpreting human rights is simply to “acknowledge the

limits of philosophical argument” and allow disputes to be resolved through democratic processes and legal doctrine (Wolff 2012a: 20). But the fact of disagreement about the foundations of human rights should not preclude further discussion. The literature in this area is rich with suggestions for what the foundations of human rights might be, including human agency, fundamental human interests, and basic human capabilities. A discussion of each of these arguments is beyond the scope of this chapter, but suffice it to say here that however we choose to understand the foundations of human rights, that understanding is highly relevant to the way in which human rights are practiced, interpreted, protected, and promoted in global health and bioethics.

### *Practical Problems*

Just as Paul Farmer has urged bioethicists to take up a more practical attitude with respect to human rights and social justice, so many bioethicists have argued that it is in the detail of practical ethical problems that a human rights approach in bioethics shows its limitations.

Over a decade ago Dan Brock drew bioethicists’ attention to the need for bioethics to broaden its purview beyond health care and establishing a right to it (Brock 2000). This limited focus is problematic, Brock argued, for two reasons. First, it fails to recognize the fact that differential access to health care is only one factor in persistent health inequities, and in many cases not the primary factor. The other factors, the social and economic determinants of health, should be as familiar to and of as much concern to bioethicists as access to health care. Second, the focus on a right to health care left most bioethicists, with prominent exceptions, silent on the complex moral problem of prioritizing limited resources for health. Recognizing that advocates of a human rights approach to bioethics view this approach as much broader than just the right to health care, Brock’s concerns about the failure to address prioritization problems under the human rights framework continue to be borne out.

To put this problem most simply, consider the government of a poor country trying to lower its rate of maternal mortality. Even accepting that all women have a right to the conditions necessary for healthy pregnancies and safe deliveries, a government with a small health budget faces numerous policy options that may all advance a right to health, but may benefit some women more than others. Exploring this problem in detail, Norman Daniels suggests that in such a case the policy options might include improving access to services for rural women, investing in expensive facilities in urban or population-dense areas, or investing in education for girls in secondary schools (Daniels 2008: 320). The problem in this case is that the notion of a human right to health justifies and perhaps demands each of these options, but where resources are limited to pursuing only one strategy, the human rights approach cannot tell us which to choose. While the human rights framework (both rhetoric and law) is essential for the mammoth task of getting governments to recognize their responsibility for creating social structures and institutions, and implementing policies that will advance the human right to health, it stops short of specifying how limited resources should be allocated so as to begin to realize that right. Limited resources mean that not all needs can be met; determining which needs will be met and which will not is a complex moral problem for which tools of analysis other than human rights are required. Discussing the role of human rights in the analysis of the determinants of health Venkatapuram, Bell, and Marmot argue that the power of the human rights framework is best used as a supplement to rather than as a

substitute for the analysis of the causes of ill health and mortality (Venkatapuram et al. 2010). Bioethicists might argue similarly that human rights should be viewed as a supplement to and not a substitute for a *moral* analysis of the prioritization of resources for health, which should include a concern for equality, for the worst off, for the victims of prior discrimination, for the results of cost-effectiveness analyses, and so on.

One of the most prominent and challenging areas in which the prioritization issue remains at the forefront is in the management of resources for the treatment and prevention of HIV disease. The health and human rights framework was forged in the early days of the HIV/AIDS pandemic, in which human rights were a bulwark against discrimination, prejudice, and ignorance. In spite of an early focus on prevention and the underlying social determinants of HIV transmission, with the advent of better and cheaper treatments for the disease the human rights agenda on HIV shifted from prevention to treatment, “driven by advocacy to respond to the dying individual regardless of the broader public health impact” (Mason-Meier et al. 2012: 264). While global policy on HIV continues to emphasize both treatment and prevention, the realities of limited health budgets, falling levels of donor funds, and increasing HIV incidence have led some to argue that universal life-long treatment efforts are unsustainable, and that a focus on prevention rather than treatment is a more cost-effective and morally justifiable strategy (Brock and Wikler 2009; Mason-Meier et al. 2012). From the perspective of the health and human rights framework this is a controversial argument. In de-prioritizing treatment in favor of prevention, what becomes of the right to health of those patients who are already sick and in need of treatment? Even if it is true that prevention saves more lives, and that, all things being equal, we should save more lives than fewer, are not those whose lives cannot be saved by prevention *entitled* to treatment under the human right to health?

This question demonstrates the shortcomings of the unmodified human rights framework. In their “ideal” form—i.e., as aspirational statements—human rights operate outside the limitations of budgets and “donor fatigue.” Talk of cost-effectiveness and saving the most lives is anathema to human rights advocates, who argue that cost ought not to stand in the way of meeting core human rights obligations; they argue that we should either shame drug companies, governments, and donors into lowering costs and funding essential health services, or impose duties on the international community to assist countries who cannot meet core human rights obligations on their own (Wolff 2012b). It is true that adding more money could solve many global health problems, and human rights advocacy has often shown that what is accepted as hard economic fact is actually a matter of social choice, thus broadening the scope of what is possible in global health. On the other hand, funds will *always* be limited relative to need, and there is a moral responsibility to allocate them carefully, human rights notwithstanding. In a South African case in which a man argued that his right to life and right to health entitled him to kidney dialysis at public expense, the court ruled that so long as a fair procedure had been followed, the denial of access to dialysis machines (which were insufficient to meet demand) did not violate those rights. Emphasizing the fact that even the right to health cannot overcome resource shortages, the court stated: “The state has to manage its limited resources in order to address all these claims. There will be times when this requires it to adopt a holistic approach to the larger needs of society rather than to focus on the specific needs of a particular individual within society” (Constitutional Court of South Africa 1997: 19).

Health resource allocation requires complex and morally challenging tradeoffs, tradeoffs for which human rights offer little substantive guidance. Filling this gap is the role

of moral analysis of the sort offered by Brock and Wikler, who build a case for prevention over treatment from careful consideration of the justifications for different moral principles. The answer to such questions requires substantive moral analysis, and cannot simply be read off the notion of the right to health (Arras and Fenton 2009).

This is not to say that human rights do not have an important place in a global HIV policy focused on prevention rather than treatment. As Mason-Meier et al. argue, the notion of *collective* rights provides a sounder foundation for large-scale public health efforts than do individual human rights (Mason-Meier et al. 2012). Under a collective rights framework the needs of the group or population are considered, thus balancing the rights of the sick to receive treatment against the rights of the well to be protected from disease. This is a significant shift that captures the complexities of prioritization problems, in which, under ubiquitous resource constraints, not all health needs can be met.

### Conclusion

In discussing his skepticism regarding the notion of a moral right to health, Gopal Sreenivasan articulates some important areas of common ground with advocates of that same right, including the moral importance of health for every human being and the moral importance of preserving or restoring health through social action (Sreenivasan 2012). Sreenivasan's argument is significant because it demonstrates the fact that skeptical questions about rights are not incompatible with endorsement of the moral values inherent in those rights. Critics of a human rights framework for bioethics are sometimes assumed to be anti-human rights (Annas 2010), but this is generally far from the truth. Many critics are broadly supportive of human rights yet seek greater clarification about what those rights are and how they should operate within a field such as bioethics. Ashcroft raises a number of questions about the UDBHR, for example, that might be on the lips of skeptics more generally: "Does the Declaration codify best practice? Or reflect international consensus only? Or interpret higher order norms for this specific context? Or declare a new agenda somewhat ahead of current policy and state context?" (Ashcroft 2008: 35). These and many other questions signify a need for further discussion and careful reflection; in this respect the UDBHR is best viewed as the beginning, not the end, of a complex conversation about bioethics and human rights.

There can be no doubt of the moral, political, and legal importance of human rights to the improvement of global health. Since making these improvements in health, in particular for those who are worst off, is a pressing and perhaps defining ethical issue for contemporary bioethics, human rights are a critical tool in the bioethicist's toolbox. But the limitations of the human rights framework must be recognized alongside its legal and political power. In response to shameful resource shortages in maternity care in developing countries, Paul Farmer has asked, "Should there be a right to sutures? To sterile drapes? To anesthesia?" (Farmer 2008: 9). When the lack of these resources leads directly to high rates of maternal mortality, it is reasonable to try to locate such rights in the law, but fixing global health problems is not as simple as defining ever more specific human rights. As Venkatapuram et al. argue, the human rights framework is not capable of doing all of the work we want it to do; it is "only one of many instruments of advancing health and health equity" (Venkatapuram et al. 2010: 12). In arguing that it is unacceptable *both* to ignore the social causes of morbidity and mortality simply because they are not "explicitly identified in existing law" *and* to "opportunistically stretch the meaning of rights so much that the term 'human rights' risks becoming an empty concept,"

these authors identify precisely the balance that bioethics ought to seek between endorsement of and skepticism about the human rights framework.

### Related Topics

Chapter 1, “The Right to Health Care,” John D. Arras

Chapter 2, “Social Determinants of Health and Health Inequalities,” Sridhar Venkatapuram and Michael Marmot

### Note

- 1 This chapter was written by Elizabeth Fenton in her private capacity. No official support or endorsement by the Presidential Commission for the Study of Bioethical Issues or the Department of Health and Human Services is intended, nor should be inferred.

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### Further Reading

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