Justice in Genetics: Intellectual Property and Human Rights
from a Cosmopolitan Liberal Perspective

By: Louise Bernier

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Summary: Louise Bernier provides a fresh perspective on how best to tackle the problem of global access to healthcare in Justice in Genetics: Intellectual Property and Human Rights from a Cosmopolitan Liberal Perspective. The author develops a theory that relies heavily upon a cosmopolitan liberal perspective where finite healthcare resources are more equitably distributed throughout the world. Bernier analyzes how this theory could be applied to the current healthcare environment including the obstacles to implementation. She also touches on the intersection of intellectual property, international human rights, and genetics and how these systems interact with Bernier’s theory of distributive justice.

About the Author: Louise Bernier is Professor and Head of the Law and Life Sciences Program at the University of Sherbrooke, Quebec, Canada.

493 Daniel M. Austin, Book Note, SYRACUSE SCIENCE & TECHNOLOGY LAW REPORTER (2011) (reviewing LOUISE BERNIER, JUSTICE IN GENETICS (2010)).
494 LOUISE BERNIER, JUSTICE IN GENETICS: INTELLECTUAL PROPERTY AND HUMAN RIGHTS FROM A COSMOPOLITAN LIBERAL PERSPECTIVE (Edward Elgar ed., 2010).
495 Id.
**Introduction**

In this book, the author analyzes the interplay between intellectual property rights and human rights and how these forces act upon the distribution of medicine and humanitarian aid. Instead of seeing intellectual property and human rights as forces at odds with one and other, the author believes that they are interconnected. The author argues that both sets of rights draw their power from the same source, the fundamental ideals of justice.

This analysis begins with an assessment of the present challenges to the distribution of healthcare in the developing world. Then the analysis shifts to focus on the political, legal, and economic forces that surround the problems of medicine distribution. The author examines this issue from a global perspective, analyzing the statements and actions of several international organizations including the G8, the World Health Organization, and the World Trade Organization.

Ms. Bernier then starts to develop her own theories as to how intellectual property and human rights are both served by justice and how these two forces can be harnessed to help provide a equitable distribution of healthcare that will lead to better health outcomes in the developing world. The author believes in a cosmopolitan theory of justice where respect for both intellectual property rights and human rights can lead to better relations between the developed world and the developing world. Moreover, the

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496 BERNIER, supra note 2, at xii.
497 Id.
498 Id. at 2.
499 Id. at xii.
The author believes that this theory of justice can help countries in the developing world gain better access to medicine and more advance healthcare services.\footnote{Id. at 3.}

Finally, the author lays out several possible roadmaps or actions that could be taken to further her cosmopolitan theory justice through the continued respect for both human rights and intellectual property.

**Part I: A Theoretical Framework for Healthcare Distribution:**

The positive benefits that result from advancements in science such as genetics should be shared with people around the globe. This is the basic theory of distributive justice.\footnote{Bernier, supra note 2, at 19.} The theoretical basis for the equitable distribution of healthcare resources is based on the fundamental belief of fairness and equality.\footnote{Id.} This theoretical basis is necessary because it provides the foundation for a common vision by declaring that all individuals should have a right to basic needs such as food, water, shelter, clothing and adequate medical care.\footnote{Id.} It is from this basic idea of equality and fairness and the belief that each individual matters, regardless of whether they come from a rich developed country or a poor undeveloped country. Access to healthcare includes the use of modern medical technologies including the most recent developments in science and in particular, genetic research. This bedrock principle is what forms the basis for distributive justice in healthcare distribution.\footnote{Id.}

\footnote{Id. at 3.}\footnote{Bernier, supra note 2, at 19.}\footnote{Id.}\footnote{Id.}\footnote{Id.}
Section 1: Global Application of Distributive Justice: A Cosmopolitan Approach

When applying a cosmopolitan approach to the distribution of healthcare discoveries and advancements, one of the main tenets is that each individual on the globe counts as a single unit. Each individual, regardless of what nation they come from, or their socio-economic status is important and should have an equal share of the benefits from genetic research and medical technology advances.505 Along with the idea of who gets to benefit from these advancements in healthcare, the notion of who gets to profit from their application is another important question.506

It is likely that advances in genetics and other scientific technologies will initially only benefit those members in wealth societies.507 The problem with this type of distribution is it will help to increase the healthcare inequality gap between those individuals who can pay for cutting-edge breakthroughs and those who cannot.508 The former will prosper while the latter will struggle because they have been shutout from these advancements in medicine and the healthcare inequality gap will continue to widen.509

Section 1.1: Distributive Justice

In order to apply a cosmopolitan theory of distributive justice to international healthcare, it is essential that the theory allows for the international distribution of genetic research. The author believes that the advances in scientific technology and especially

505 Bernier, supra note 2, at 20.
506 Id. at 21.
507 Id.
508 Id.
509 Id.
genetics should not be limited by market forces, but should be applied equally on a global scale to those who are most in need of this technology.\textsuperscript{510} Several theories exist with the goal of redistribution of property including medical and healthcare technology.\textsuperscript{511} Some of the theories discussed by the author are liberalism, distributive justice, and social cooperation.\textsuperscript{512}

The essence of distributive justice was articulated nearly 50 years ago by John Rawls in \textit{A Theory of Justice}.\textsuperscript{513} In his book, Rawls describes distributive justice as a phenomenon where individuals have “rights that cannot be sacrificed simply to create more benefits for others.”\textsuperscript{514} What flows from this theory is that social primary goods such as “liberty, opportunity, income, and wealth are to be distributed equally unless an unequal distribution will advantage the least well-off”.\textsuperscript{515} Distributive justice is different from many other types of social justice because it takes into account the most vulnerable in a given population based on the ideals of fairness.\textsuperscript{516} Furthermore, although distributive justice is normally applied to one society, an international form of distributive justice is necessary when dealing with international healthcare issues such as genetic and genomic research because it application, and potential benefits are global.\textsuperscript{517}

\textit{Section 1.2 Cosmopolitanism: A Way of Envisioning Global Justice}

\begin{flushleft}
\textsuperscript{510} BERNIER, supra note 2, at 22.
\textsuperscript{511} Id. at 22.
\textsuperscript{512} Id. at 22-23.
\textsuperscript{513} Id. at 23.
\textsuperscript{514} Id. at 24-25.
\textsuperscript{515} BERNIER, supra note 2, at 23.
\textsuperscript{516} Id. at 23.
\textsuperscript{517} Id. at 24.
\end{flushleft}
The ideas of cosmopolitanism can be captured in two categories: Institutional and Moral cosmopolitanism.\textsuperscript{518} First, institutional cosmopolitanism is an idea that deals with political systems.\textsuperscript{519} Specifically, institutional cosmopolitanism regards the world as a single nation with a single super government and discards the notion of individual nations.\textsuperscript{520} Furthermore, moral cosmopolitanism deals with the “theoretical basis for the justification of institutions, practices, and interpersonal relationship”.\textsuperscript{521} Moral cosmopolitanism views individuals as humans, and does not categorize people based on ethnicity, culture, country of origin or other indicators.\textsuperscript{522}

The theory of cosmopolitanism fits well with genetic research because people throughout the world share many of the same genes.\textsuperscript{523} With such commonality, genetic research and gene treatment regiments have world-wide application.\textsuperscript{524} A distributive framework of global justice initiatives requires not a local mindset but an international.\textsuperscript{525}

\textbf{Section 2: An Argument for Global Distribution in Health}

The basis for a global distribution in health means that each individual will have the same access to healthcare services and resources as any other.\textsuperscript{526} First, this section deals with a theoretical basis, an ideal situation where the theory of distributive justice

\begin{itemize}
\item \textsuperscript{518} \textit{Id.}
\item \textsuperscript{519} BERNIER, supra note 2, at 24.
\item \textsuperscript{520} \textit{Id.}
\item \textsuperscript{521} \textit{Id.}
\item \textsuperscript{522} \textit{Id.} at 25.
\item \textsuperscript{523} See \textit{Id.}
\item \textsuperscript{524} BERNIER, supra note 2, at 24.
\item \textsuperscript{525} \textit{Id.} at 28-29.
\item \textsuperscript{526} \textit{Id.} at 47.
\end{itemize}
would work in an optimum environment. Furthermore, the author describes the benefits and consequences of having an ideal global distribution in health.\textsuperscript{527}

The second half of this section deals with a more pragmatic approach to the distribution of healthcare resources as the world stands today.\textsuperscript{528} This approach is more practical and tries to apply a cosmopolitan theory of distributive justice to a world that is less inviting.\textsuperscript{529} Although health and healthcare inequality exists in the world, the author argues that healthcare is important to all people and if a cosmopolitan approach to healthcare distribution was applied to the current environment, compensation would need to be paid to those individuals who are not provided with an equivalent distribution of healthcare resources.\textsuperscript{530} Moreover, the author argues that along with compensation, the international healthcare system should adapt and change to bring those individuals who are disadvantaged into alignment with the healthcare resources of the more fortunate.\textsuperscript{531}

\textit{Section 2.1: Conception of Health Justice}

In deciding what the ideal concept of health justice constitutes, it is important to determine first how health is defined.\textsuperscript{532} The term health or healthy has a number of definitions and ranges from meaning freedom from disease or infirmity to a more inclusive definition which includes not only the absence of disease but also the freedom from “disabilities, loss of abilities due to trauma and environmental harms, as well as

\begin{thebibliography}{99}
\bibitem{527} \textit{Id.}
\bibitem{528} \textit{Id.}
\bibitem{529} BERNIER, \textit{supra} note 2, at 47.
\bibitem{530} BERNIER, \textit{supra} note 2, at 47.
\bibitem{531} \textit{Id.}
\bibitem{532} \textit{Id.} at 48.
\end{thebibliography}
other functional deficits.” 533 The author supports a more broad definition of health and believes an ideal definition of health means that an individual can function normally. 534

Applying this broad definition of what health or healthy means, the author believes that upcoming advances in healthcare generally, and genetics research in particular, should be shared equally and applied to individuals regardless of income, citizenship, or any other factor. 535 The requirement for utilization of these modern treatments should be based on need; if someone is unhealthy, or falls below the standard of normal functioning then that individual should have access to the most modern healthcare technology. 536 The goal of this ideal conception is that each person is treated as an individual and should be allowed to obtain healthcare services that will ensure a healthy life regardless of where they come from and there background. 537

Section 2.2: Normative Grounds to Operate Distribution and Premises upon which to Claim Health Equity and Fairness

In this section the author stresses a concept of global equality of opportunity that provides a basis for distributive justice. 538 This concept is applied to the distribution of healthcare services and resources in the current global environment. The author lays out a framework on how to reach global equality of opportunity including the use of rights and duties based theories along with applying the Rawl’s difference principle. 539

533 Id.
534 BERNIER, supra note 2, at 48.
535 Id. at 49.
536 BERNIER, supra note 2, at 51.
537 Id. at 51.
538 Id. at 63.
539 BERNIER, supra note 2, at 63.
One piece required in a global concept of justice requires that all individuals have the right to equality of opportunity.\(^{540}\) In this particular instance, the right described is the right to healthcare and specifically, the right of all individuals to have access to genetic technology.\(^{541}\) The concern with defining a right to healthcare is that defining the right requires specificity. For example, to ensure equality of opportunity, the right to healthcare must be allowed at any time, not just in emergency cases.\(^{542}\) In order for equality to exist, people must have the same right at the same time, or to have the same rights all the time.\(^{543}\)

Along with defining the rights of an individual, an institution must exist to ensure that an individual’s rights are protected. Specifically, this global institution must ensure that “rights must be adequately protected by required duties and obligations to refrain from harm, defend the interest of the right-holders, and facilitate the enforcement of their rights against particular agents.”\(^{544}\) Included in this analysis is who should act? Should it be states? Or international organizations like the United Nations? The author stresses that the organization that takes up this task should be well coordinated in order to ensure adequate protection of these important rights.\(^{545}\) An alternative to having a centralized body who would coordinate and ensure rights, is to have the more wealthy states redistribute their healthcare and genetic resources to those states that do not have the same level of resources.\(^{546}\) Although the author realizes the current inequality that exists

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\(^{540}\) Id.
\(^{541}\) Id. at 65.
\(^{542}\) Id.
\(^{543}\) Id.
\(^{544}\) BERNIER, supra note 2, at 68.
\(^{545}\) Id. at 73.
\(^{546}\) Id. at 74.
in the world, it is possible to change the focus of governments and allow equality and justice to play a larger role. 547

One example the author noted was an effort to have rich nations provide the United Nations with 0.75% of their GDP for development projects in parts of the world that were less fortunate. 548 Although this particular project was unsuccessful, the global structure is still relatively new and the author believes there are numerous opportunities that can be utilized to change the inequality that currently exists in the distribution of healthcare and genetic resources. 549

**Part II: Normative Tools for Distribution in Health:**

The first section of this analysis focused on theoretical issues surrounding distributive justice of healthcare and genetic resources. 550 The second section focuses on two areas of law that are critical to the development of genetic science: intellectual property law and human rights law. 551 These two areas of law play a critical role in dealing with issues of access and fairness. 552

**Section 3: International Intellectual Property Law: A First Tool?**

In this section, the author addresses whether international intellectual property law as it is currently stands is either helpful or a hindrance to the distributive justice of

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547 *Id.* at 81.
548 *Id.* at 82.
549 BERNIER, *supra* note 2, at 83.
550 BERNIER, *supra* note 2, at 85.
551 *Id.*
552 *Id.*
healthcare and genetic resources.\textsuperscript{553} Included in this analysis is a brief description of intellectual property rights, the patent system, and its relevance to genetic science.\textsuperscript{554}

\textit{Section 3.1: The Patent System}

In describing the current state of the patent system, the author highlights the use of patents in the area of genetic research.\textsuperscript{555} In order for an invention to be eligible for a patent, the invention must be new, involve an inventive or new step in a process, and it must be useful – meaning that it has some commercial application.\textsuperscript{556}

Applied to genetic material, the question of whether genes or genetic material is patentable has been plaguing lawmakers for over twenty years.\textsuperscript{557} Current international law allows for “isolated genetic material” to be patentable.\textsuperscript{558} The ethical debate between whether genetic material should be patentable plays on a tension between the individual inventor’s rights and the rights of the community to use the invention to help as many people as possible.\textsuperscript{559}

\textit{Section 3.2 Some Theoretical Justifications for the Institutions of Patents}

The author in this section discusses several theories have been put forth to justify the need for patents. Included in these theories, the author highlights the arguments made by Locke’s Labour theory and the Utilitarian Theory of Property.\textsuperscript{560}

\textit{Section 3.3 Global Distribution, Justice, and the Patent System: An Assessment}

\textsuperscript{553}\textit{Id.} at 87.
\textsuperscript{554}BERNIER, supra note 2, at 87.
\textsuperscript{555}\textit{Id.} at 90.
\textsuperscript{556}\textit{Id.}
\textsuperscript{557}BERNIER, supra note 2, at 91.
\textsuperscript{558}\textit{Id.} at 91-92.
\textsuperscript{559}\textit{Id.} 92.
\textsuperscript{560}\textit{Id.} at 100, 103.
In this section, the author describes, under a global distributive justice theory framework, what the ideal tension should or could be between patent law, research and development of genetic materials, and knowledge.\textsuperscript{561} The author argues that although the patent system was designed to allow the patent holder to recoup financial and personal investment, a secondary goal of the patent system is to ensure society greater knowledge for the common good.\textsuperscript{562} Although these two goals were the driving force behind the patent system, it appears that the former and not the latter has come to fruition. The author argues that the benefit to society has not been fulfilled while the individual benefits the patent holder possesses have taken over the patent system.\textsuperscript{563}

The author concludes her analysis of intellectual property law by claiming that IP is driven not by the common good for society but by market forces and the use of finite supply to drive up the cost of patented products, including products that are used in healthcare and genetics research.\textsuperscript{564}

\textit{Section 4: International Human Rights Law: A Second Tool?}

The focus of this chapter relates to the use of international human rights legal system and whether the current system helps or hinders the move towards a global distributive justice system in healthcare.\textsuperscript{565}

\textit{Section 4.1: The field of International Human Rights Law}

The current system of international human rights took hold after the Second World War.\textsuperscript{566} Although human rights issues have been debated for centuries, after World

\begin{footnotesize}
\textsuperscript{561} \textit{Id.} at 116.
\textsuperscript{562} BERNIER, supra note 2, at 116.
\textsuperscript{563} BERNIER, supra note 2, at 116
\textsuperscript{564} \textit{Id.} at 143
\textsuperscript{565} \textit{Id.} at 146.
\end{footnotesize}
War II, there was a resurgence in human rights issues.567 There have been several organizations created to deal with international human rights and an international bill of rights was created in the 1960’s.568 The recognition of human rights was simply based on an individual as a human being.569 The author then goes on two discuss the two types of human rights; first, “civil and political rights” and “economic, social, and cultural rights.”570

Section 4.2: Distribution, Access, Justice and the International Human Rights Systems: An Assessment:

In this section the author compares an ideal system of cosmopolitan theory of distributive justice relating to human rights and the reality of how the international community actually deals with international human right issues.571 In making this comparison, the author believes that the most important metric is whether there is universal access to healthcare and genetic technology.572

To help show the different models that are applied to the issue of international human rights and access to healthcare, several types of universalism are compared.573 Included in the comparison is universalism as it relates to relativism, individualism and westernalization.574

566 Id. at 147.
567 Id.
568 BERNIER, supra note 2, at 147-78.
569 Id. at 148
570 BERNIER, supra note 2, at 148.
571 Id. at 157.
572 Id.
573 Id.
574 Id.
**Section 4.3: The conceptualization of Human Rights within the Reality of the Market**

In this final section the author discusses the interplay between the concept of international human rights and the reality of what is actually taking place in the marketplace. The author asserts that there is an international consensus about basic human rights, but this ideology is not practically applied to political and economic forces affecting the world marketplace. The author recognizes this distinction and argues that many of the reasons the current system is not changing is because there are economic and political powers that are profiting from the current system and enjoying incredible benefits. Socio-economic rights including the right of equal access to opportunity for healthcare and genetic services and technologies are being protected by powerful interests and these individuals do not want to see a change in the distributive framework that would bring about more equality and fairness.

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575 Id. at 182.
576 Id.
577 Id. at 192.
578 Id. at 191-92.