

Future Perfect: Dealing with Imperfections in Decisions About Genetics

Future Perfect: Confronting Decisions about Genetics, Lori B. Andrews. New York: Columbia University Press, 2001. pp. 264.

This book examines a number of conceptual models for looking at developments in genetics and genetic technologies. It explores the implications of using three frameworks for regulating health services in the United States: the medical, public health, and fundamental rights models. Andrews searches for an overall conceptual framework for genetics regulation and suggests that the empirical data on the impact of genetic testing provides the basis for such a framework. The choice of a framework, according to the author, will help policy-makers avoid the “Band-aid” regulation that has characterized the U.S. government’s response to developments in genetic services.

Andrews favors the fundamental rights model because it “would require a careful consideration of the appropriate measures for ensuring voluntariness, adequate information, and quality assurance [and] existing legal doctrines would support many of these measures” (p. 161). Under this model, the right to extensive information about potential genetic services would be guaranteed. This would force physicians to learn more about genetics. At the same time, the model would give people control over their genetic information, as manifested already in guidelines prohibiting physicians from giving genetic information routinely to employers. There would also be protection for the ability of individuals to refuse services.

Andrews considers the medical model untenable because she finds physicians, as gatekeepers, quite directive in presenting options. This can be problematic considering that “physicians may not be adequately trained or motivated to understand the nature of certain genetic diseases or the medical and psychological implications of testing” (p. 108). Moreover, “medical malpractice suits are seen as the way to enhance the quality of care” (p. 152).

The public health model has been invoked to prevent hazards to the population at large but Andrews finds no clear justification for using it to support mandated genetic services. Prevention does not make sense for many genetic conditions.

Quality assurance also suffers because it is affected by the political uncertainties that surround budget setting.

Future Perfect begins by describing how genetic discoveries are catching people unprepared and keeping them wondering where the technologies are headed. It shows how the rapid integration of genetics into clinical practice has paved the way for commercialism, given rise to genetic tests that do not always have a therapeutic counterpart, and cultivated exaggerated faith in genetic technology.

Recalling how people reacted to early developments in the field of genetics, Andrews observes that the same policy questions that face decision-makers at present have previously shown the ineptitude of policy-makers to address systematically the significance of new technologies.

To deal with genetic discrimination, Andrews points out “three levels of protection” to (1) ensure that people have control over the genetic information that is generated about them, (2) give them control of who has access to that information, and (3) prevent discrimination based on genetic information (p. 150).

By marking off different conceptual models for examining genetics issues, Andrews is able to point out major presuppositions that may otherwise not be readily apparent. She goes over the many issues that arise in the development and provision of genetic services in a manner that avoids directing the reader towards an emotional response to problems or controversies. Along the way, she brings to the surface the varying conceptual models for sifting through the maze and arriving at some conclusions or recommendations. The process requires much documentation and the author does come up with plenty of citations and references that provide a broad picture of the contemporary scene involving genetics research and services.

Adding to the book’s virtues is its ability to present the range of options that emerge from the advances in genetic technology without being over-optimistic or unnecessarily alarming. The extensive documentation cuts across varying perspectives. The balanced presentation augurs very well for an objective examination of conceptual models that *Future Perfect* sets out to do. It is limited only by a hint that the models are incompatible with one another, thus creating the impression that one must only choose the best fit to the exclusion of the others. The incompatibility does not have to be accepted because the models,

while highlighting certain features, are not mutually exclusive. They can be more suitably presented as intermingling approaches that are representative of competing but concurrently legitimate perspectives, all deserving of in society's attention and reflection.

One may also question the assumption that the formulation of a sensible public response requires the adoption of a single framework that can put problems and issues of genetics in their "proper" conceptual basket. In a particular situation, there may be one model that best brings to light a fitting solution to a problem or issue. Thus, from the perspective of formulating legal policy, the fundamental rights approach may have its own appeal. After all, the language of rights is a fundamental component of legal discourse. The assertion of rights and the struggle against rights violations fall naturally into place in a legal context. However, this would not necessarily indicate the fittingness of the rights model for genetics in general. A different model may be seen to have the edge in looking at other situations and problems. The medical model and the public health model represent important perspectives that cannot merely be subsumed under a single overarching framework without sacrificing novel and important ideas that come inevitably with new discoveries, such as those that abound in genetics.

A single conceptual framework may seem like a necessity from the point of view of uniform policy regulations regarding genetics but it can be argued that uniformity is not a virtue in the context of rapidly developing technology. Novel or even revolutionary developments have to be met not only with caution, but also with a readiness to understand and accommodate. An open framework may give rise to a measure of inconsistency in policy formulation. However, such inconsistencies may be a small price to pay for the benefits of the genetic revolution.

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