

Jahrbuch für Recht und Ethik

Annual Review of Law and Ethics

Band 10 (2002)

Herausgegeben von

B. Sharon Byrd
Joachim Hruschka
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Guidelines for Genetics

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Vorwort

Dieser Band des *Jahrbuchs* faßt die Beiträge zu einem Symposium zusammen, das die Herausgeber im Rahmen der Begleitforschung zu den rechtlichen, ethischen und gesellschaftlichen Implikationen des Deutschen Humangenomprojekts (DHGP) in der Zeit vom 26. bis zum 30. Oktober 2000 in der Leucorea in Wittenberg zu dem Thema „Internationale Richtlinien für die Genetik“ veranstaltet haben. An dem Symposium haben teilgenommen: *Erwin Bernat* (Graz), *Gunther Biewald* (Erlangen), *B. Sharon Byrd* (Jena), *Ellen Wright Clayton* (Nashville), *Lloyd R. Cohen* (Arlington), *Roger B. Dworkin* (Bloomington), *Bernard Gert* (Hanover, New Hampshire), *David Heyd* (Jerusalem), *Joachim Hruschka* (Erlangen), *Jan C. Joerden* (Frankfurt [Oder]), *Matthias Kaufmann* (Halle), *Eike-Henner W. Kluge* (Victoria), *Diane Longley* (Sheffield), *Thomas Nenon* (Memphis, Tennessee), *Melanie Ranft* (Halle), *Irina von Schilling* (Erlangen), *Jan C. Schuhr* (Erlangen), *Peter Südbeck* (Bonn), *Arnd Wasserloos* (Frankfurt [Oder]) und *William J. Winslade* (Galveston). Die Veranstalter danken dem Bundesministerium für Bildung und Forschung (BMBF) und dem Deutschen Zentrum für Luft- und Raumfahrt (DLR) als Projektträger des Ministeriums für die Finanzierung des Symposiums. Für ihre Hilfe bei der Vorbereitung des Symposiums und der Drucklegung dieses Bandes des *Jahrbuchs* danken die Herausgeber insbesondere Frau *Anette Hübner* im Interdisziplinären Zentrum für Ethik in Frankfurt (Oder) und Frau *Ayke Darius* im Institut für Strafrecht und Rechtsphilosophie in Erlangen. Herrn *Lars Hartmann* im Verlag Duncker & Humblot in Berlin ist für die verlagsmäßige Betreuung der Publikation zu danken. Die diesem Band angefügten Verzeichnisse hat Frau *Cornelia Winter* (Frankfurt [Oder]) erstellt, der die Herausgeber dafür zu Dank verpflichtet sind.

Das *Jahrbuch für Recht und Ethik* stellt im übrigen auf seiner Internetseite

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im Hinblick auf die schon erschienenen Bände weitere Informationen zur Verfügung, insbesondere auch englische und deutsche Zusammenfassungen der Artikel sowie Bestellinformationen.

Die Herausgeber

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**Regulierung oder Deregulierung? –
Regulation or Deregulation?**

Hopeless Philosophical Reflections on the Senselessness of Regulation in Genetics

David Heyd

The title of this article calls for an explanation. Our concern here is with philosophical reflections on the issue of regulation of genetic research and practice. Why is such regulation senseless, and in what sense are these reflections hopeless? The problem that I would like to raise lies at the crossroads of theory and practice, of abstract thinking and social policy. It highlights the difficulty in bioethics in general, indeed in all applied ethics: to what extent is philosophical argument relevant to actual social and legal decisions.

The following arguments are based on a combination of abstract argument and personal experience. I was invited as a philosopher to take part in various multidisciplinary fora that were given the task of suggesting guidelines for genetic research and practice in Israel. This experience sharpened my awareness of the tension between two irreconcilable points of view – that of pure reflection and that of social responsibility, a tension which itself deserves philosophical attention. Unlike philosophy students, who are willing to follow the logic of an argument to its ultimate conclusion, committee members lacking philosophical inclination often react with a blend of wonder and hostility to abstract theorizing, especially when it leads to perplexing conclusions.

The gap between moral philosophy and social practice has always cast doubt both on the “relevance” of moral philosophy, on the one hand, and on the abstract justification of social practices, on the other. Philosophical ethics has traditionally considered itself as “practical”, that is both pertinent and applicable to everyday decision making; but it never achieved a particularly good record in making direct impact on social institutions and norms. Social planners and politicians have often pretended that the policies they promoted were informed by ethical principles; but we all know that in most cases these policies were the product of power relations, economic interests, popular pressures and irrational motives of both public officials and the public. The recent emergence of the field of “applied ethics” marks the contemporary effort to bridge this gap, primarily in medical ethics. Applied ethics has become a meeting point of philosophers and public officials (legislators, practitioners, religious leaders). Practitioners are eager to obtain philosophical input before making decisions and philosophers acknowledge the legitimacy of principled reflection on actual moral dilemmas raised by new technologies. This effort

to bridge the traditional gap has both theoretical aspects (the rise of the discipline of applied ethics) and an institutional dimension (the invitation of philosophers to take part in social decision making processes).

I. Regulation

Let us start with the theoretical discussion of the problems of regulation in general. Regulation means subjecting behaviour to rules. This is apparently a typically rational enterprise, which has two aspects – formal and substantive. Formally speaking regulation is the means for shaping human behaviour so as to be coordinated, predictable and governed by principles and aims which are not merely subjective or haphazard. But regulation also attempts to guide human conduct to substantive goals considered desirable or valuable (and even more so, to prevent undesirable and wrong behaviour). Legislation, the most typical kind of regulation, is – both in its substantive and formal functions – the hallmark of rationality in the political sphere. As has been noted by theorists of norms, some parts of the legal system, those concerned with conventions, are typically of a coordinative nature, while other parts, related to social ideals and values, prescribe desirable goals and proscribe harmful behaviour. The regulation of genetic practice belongs primarily to the second category: it is less concerned with the creation of coordinated forms of behaviour on which there is wide consensus. Unlike traffic rules, which are typically conventional, the regulation of genetic practice aims at much more than coordination. It is concerned with the direction of scientific and medical practice to morally acceptable paths.

Regulation is particularly called for in new practices. Due to their novelty, new practices lack the social coordination associated with tradition and are often motivated by goals which are not accepted by society for a variety of reasons, often related to conservative inertia. Genetic technologies are a typical case of a radically new, unprecedented kind of practice. They have rapidly developed in various countries and research centers with no systematic coordination, often under circumstances of competition and secrecy. These technologies have also been developed using methods and aiming at goals which are highly controversial within public circles. Thus, their novelty calls for formal coordination of activity, both on national and international levels, and for the formulation of morally accepted substantive goals to which these technologies must be subjected. Genetic regulation attempts to implement both the formal and the substantive functions of regulation.

Thus far we have assumed that regulation as such is rational and one could conclude that it is, at least *prima facie*, desirable and good. However, regulation is often criticized for being a form of social despotism, the violation of individual rights, the suffocation of private initiative and inventiveness. The liberal tradition is prominent in the skeptical attitude towards regulation in general and many of its proponents are willing to pay the price of lesser coordination and even of “undesir-

able” activity so as to preserve individual autonomy, social heterogeneity and freedom of creativity. Like in the economic sphere, regulation is considered as having a stifling effect. Conservatives, on their part, support regulation, since it is a typical means of preserving traditional norms and forms of behaviour. Ideologies which are committed to particular social purposes also appeal to regulation as their preferred social strategy. Regulation thus serves as the litmus test for one’s social-philosophical views: liberal-oriented people struggle to minimize it, while central planners in the economy, socialists, religious fundamentalists and many others support regulation as a primary means for enhancing their respective values.

We do not wish to enter into this deep debate, but only to point out that genetic practice is a particularly striking example of the problem of regulation since it raises strong arguments both for and against social control. On the one hand, genetics is a science in which the amazing progress in discovery and application is due to the free exercise of intellectual imagination, personal creativity, bold hypotheses, and courageous willingness to overcome traditional well-entrenched metaphysical and scientific views. In that sense, one can easily imagine how regulation of genetic research could have stifled the rapid development of the field since Crick’s and Watson’s discovery of the double helix. Regulation is a traditional enemy of academic freedom and the spirit of inventiveness. One may add the more recent translation of theoretical progress in genetics into marketable goods in the pharmaceutical sphere as a process which is based on entrepreneurship, economic initiative, financial risk – all of which can flourish only in a relatively unregulated world. On the other hand, it is undeniable that genetics is a risky business, that it touches upon very deep interests and values of human beings, that it has potentially far-reaching social consequences and that it may cause misery, injustice and exploitation. Considered from this point of view, genetic practice definitely calls for some measure of social control, for normative regulation of some sort. Genetics is an interesting case since it combines opposite driving forces. On the one hand, it stands in the forefront of scientific research these days and is the realm in which the borders of our scientific, medical and social imagination are stretched to their extreme limits. On the other hand, it raises our deepest fears and sharpens our commitment to traditional values of the integrity of human nature and the right of persons to their human identity. Accordingly it calls for revolutionary changes in our world view but at the same time promotes a particularly conservative adherence to old practices and systems of beliefs.

What sort of regulation is fitting to the new field of genetic research, diagnosis and therapy? There are different *levels* of regulation, which can be ordered on a hierarchical scale, each appropriate to different purposes. This order also roughly reflects the history of regulation of genetic research. On the lowest level we find the institutional attempt of universities and research institutes to guide academic activity according to ethical principles. Then there is the governmental level, in which ad hoc ministerial regulations are issued, often as a response to urgent needs and public outcries. Then comes legislative intervention, that is parliaments enact-