

Jahrbuch für Recht und Ethik

Annual Review of Law and Ethics

Band 7 (1999)

Herausgegeben von

B. Sharon Byrd
Joachim Hruschka
Jan C. Joerden



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Themenschwerpunkt:

Der analysierte Mensch
The Human Analyzed

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Vorwort

Im Rahmen der Begleitforschung zu den ethischen, rechtlichen und gesellschaftlichen Implikationen des Deutschen Humangenomprojekts (DHGP) haben die Herausgeber in der Zeit vom 2. – 10. 8. 1998 an der Europa-Universität Viadrina in Frankfurt (Oder) ein Symposium zu dem Thema „Der analysierte Mensch – The Human Analyzed“ veranstaltet.

Dieser Band des *Jahrbuchs* faßt die Beiträge zu diesem Symposium zusammen, an dem Humangenetiker, Philosophen, Ethiker, Kultur-, Rechts- und Wirtschaftswissenschaftler aus Großbritannien, Israel, Kanada, Österreich, den U.S.A. und Deutschland teilgenommen haben, und zwar: *B. Sharon Byrd* (Jena), *Lloyd R. Cohen* (Arlington), *Thomas Crofts* (Frankfurt [Oder]), *Andreas Drechsler* (Bonn), *Roger B. Dworkin* (Bloomington), *Jörg M. Fegert* (Rostock), *Lawrence A. Frolik* (Pittsburgh, Pennsylvania), *Bernhard Gert* (Hanover, New Hampshire), *Jan C. Heller* (Atlanta), *David Heyd* (Jerusalem), *Eric Hilgendorf* (Konstanz), *Jochen Hoffmann* (Erlangen), *Joachim Hruschka* (Erlangen), *Jan C. Joerden* (Frankfurt [Oder]), *Matthias Kettner* (Essen), *Martina Keilbarth* (Heidelberg), *Eike-Henner W. Kluge* (Victoria), *Peter Koller* (Graz), *Wolfgang Kuhlmann* (Aachen), *Henk van Liempt* (Bonn), *Joan Loughrey* (Preston), *Thomas Nenon* (Memphis, Tennessee), *Jan C. Schuhr* (Erlangen), *Lorenz Schulz* (Frankfurt a. M.), *Lee M. Silver* (Princeton), *Albrecht E. Sippel* (Freiburg i. Br.), *Peter Stanglow* (Frankfurt [Oder]), *Marc Stauch* (Nottingham), *S. Edward Stevens, Jr.* (Memphis, Tennessee), *Gregory Stock* (Los Angeles), *Irina von Schilling* (Erlangen), *Arnd Wasserloos* (Frankfurt [Oder]), *Arnulf Zweig* (Eugene / New York).

Die Veranstalter danken dem Bundesministerium für Bildung, Wissenschaft, Forschung und Technologie (BMBF) und dem deutschen Zentrum für Luft- und Raumfahrt (DLR) als Projektträger des Ministeriums für die Finanzierung dieses Symposiums. Für die Unterstützung bei der Drucklegung dieses Bandes des *Jahrbuchs* und bei der Organisation des Symposiums danken die Herausgeber insbesondere Frau *Ayke Darius* im Institut für Strafrecht und Rechtsphilosophie in Erlangen, Frau *Anette Hübner* im Interdisziplinären Zentrum für Ethik in Frankfurt (Oder) und Frau *Susen Pönitzsch* am Lehrstuhl für Strafrecht und Rechtsphilosophie in Frankfurt (Oder). Frau *Heike Frank* im Verlag Duncker & Humblot in Berlin gebührt Dank für die verlagsmäßige Betreuung der Publikation. Die diesem Band angefügten Verzeichnisse wurden von Herrn *Peter Stanglow* erstellt, dem die Herausgeber dafür zu Dank verpflichtet sind.

In seinem achten Band (2000) wird sich das *Jahrbuch für Recht und Ethik* schwerpunktmäßig dem Thema „Die Entstehung und Entwicklung der Moralwis-

senschaften im 17. und 18. Jahrhundert“ widmen. Das *Jahrbuch für Recht und Ethik* stellt im übrigen auf seiner Internet-Seite

<http://www.uni-erlangen.de/JRE>

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

Die Herausgeber

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**Genetische Grundlagen –
Genetic Basis**

Reprogenetic Technologies and the Forces that Will Drive Their Use

Lee M. Silver

Overview of the Issues

Incredible advances in reproductive technology continue to offer people new options for having babies that were inconceivable just a few short years ago.¹ At the same time, genetic technology has merged with computer technology to yield new tools for analysis like DNA chips, which can be used to obtain rapid and complete genetic profiles of individual people and cells. The new genetic technologies have implications for the practice of all forms of medicine, but when they are combined with reproductive technologies – in the form of reprogenetics – the implications are staggering. Prospective parents will soon be able to choose which of their genes to give to their children², and whether to add in genes they don't even carry³, in order to provide them with increased chances for health, longevity, happiness, and success.

Some bioethicists are concerned that reprogenetic technologies will cater only to “the basest drives of humanity,” or that they will objectify human beings and place them on par with products to be modified and manipulated at will. There is often the stated notion that these technologies will be used by unscrupulous governments or groups aiming to produce people for their special needs. Many of these scenarios take their cue from Huxley's influential novel “*Brave New World*,” which describes a world in which the state exerts complete control over human reproduction and human nature as well. In this brave new world, the state uses fetal hatcheries to breed each child into a predetermined intellectual class that ranges from alpha at the top to epsilon at the bottom.

While Huxley guessed right about the power we would gain over the process of reproduction, I think he was dead wrong when it came to predicting *who* would use the power and for what purposes. These technologies will be of no use to governments for the simple reason that they will not allow the birth of babies “to or-

¹ *Silver, L. M.*, *Remaking Eden: Cloning and Beyond in a Brave New World*, New York: Avon Books, 1997.

² *Ibid*, p. 233 - 265.

³ *Ibid*, p. 266 - 280.

der” because human beings are much more than their genes. (Indeed, we are more than our genes and our environment combined. Alone among all species, human beings can consciously choose to go against genetically programmed instincts. And they can choose to go against cultural dictates as well. Thus any leader who thinks they can create human beings predetermined to behave in a specified way will be greatly disappointed.)

More importantly, however, what Huxley failed to understand, or refused to accept, was the driving force behind baby-making. Governments don't make babies, women do. It is individuals and couples – not governments – who want to reproduce themselves biologically in their own images. It is individuals and couples who want their children to be happy and successful. And it is individuals and couples who will seize control of these new technologies to reach otherwise unattainable reproductive goals, and to help their children achieve health, happiness, and success. That's the way it's always been since humans first walked the face of the earth.

I claim here that most people do not wish to overcome these powerful instinctive forces. It is the desire to have biological children, and the desire to provide one's children with all possible advantages in life that will drive the use of reproductive technologies.

The desire to have and raise a child is such a powerful instinctive force that many people who experience it have a hard time explaining where it comes from. The reason we can't figure it out is because we have little control over it. It is programmed into our genes, and is second in power – in most people – only to the drive for self-preservation.

Not surprisingly, infertility can have a devastating effect on people. Many say it's equivalent to the death of a loved one. It can cause serious depression and lead to the breakup of marriages. This is why many couples – even those of modest means – are willing to spend \$30,000 or more in attempts to have a baby with the use of In Vitro Fertilization (or IVF), or the services of a surrogate mother⁴. Of course, when parents do adopt children, they discover that they love them as much as any parent could love a child (because of a further instinct that we have for taking care of “children we find in our nest”).

The second driving force – the desire to provide our children with all possible chances for happiness and success in life – is universally expected in normal parents. Indeed, many normal parents do not simply want normal children, they want their children to be *better* than normal in some way. The drive to protect and advantage children extends across many other species besides human beings, including most mammals and birds.

⁴ Neumann, P. J., et al. “The cost of a successful delivery with in vitro fertilisation”, New Eng. J. Med. 331 (1994), 239 - 243.

I argue here that reproductive and reprogenetic technologies will be used exclusively by individuals and couples who are driven by these two primary forces. Advanced reproductive technologies will be used to provide infertile couples and individuals with the opportunity to have biological children in the context of loving families. Reprogenetic technologies will be used to provide children with increased chances of physical and mental health and increased longevity. If standard medical practice is followed, no technology will be applied until its safety and efficacy is demonstrated to the greatest degree possible in both non-human model organisms and natural human populations. If standard medical practice is followed, the benefits will outweigh the risks.

There are those who will argue that parents don't have the right to control the characteristics of their children-to-be in the way I describe. But American society, in particular, accepts the rights of parents to *attempt* to control every other aspect of their children's lives from the time they are born until they reach adulthood. If one accepts the parental prerogative after birth, it is hard to argue against it before birth, if the intention and expectation is to increase health and happiness.

Indeed, the problem with reprogenetic technologies is not that they are inherently bad, or that people will use them for harmful reasons. The problem, I believe, is that they are too good. The power of reprogenetics is so great that those families and groups *not* able to afford its use could become severely disadvantaged. Thus, I believe the real ethical concern with reprogenetics is one of fairness and equality of access, not harm.

This ethical problem is not a new one (expect perhaps in degree). It is inherently unfair for some people to have access to technologies that can provide advantages while others, less well-off, are forced to depend on chance alone. But in every democratic society, affluent parents are allowed to give their children very real advantages in life that less affluent parents are unable to afford.

In American society, children of the affluent get better health care and better education, and they are often raised in an environment that is more conducive to developing strategies for future success. If one accepts the right of affluent parents to provide their children with an expensive private school education, it becomes difficult to use 'unfairness' as a reason for rejecting the use of reprogenetic technologies intended to accomplish the same goal of increasing chances for success and happiness.

And therein lies the real ethical dilemma that will emerge from reprogenetics. For while each individual attempt to provide a child with resistance to disease may be viewed as entirely acceptable, the ultimate, and perhaps inevitable, outcome of a market-based approach to the technology could be a gap between classes – both individuals and societal groups – that becomes wider and wider with each generation.

On March 14, 1996, John Maddox, the editor of the British journal *Nature* wrote an impassioned editorial saying in part: "That the growing power of molecular ge-