HOW REPROGENETICS WILL TRANSFORM THE AMERICAN FAMILY

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INTRODUCTION

Incredible advances in reproductive technology continue to offer people new options for having babies that were inconceivable just a few short years ago.[1] Men once classified as sterile because they were unable to produce sperm can now become biological fathers with the use of nuclear injection into the unfertilized eggs of their partners.[2] Postmenopausal women of any age, unable to produce their own eggs, can use donor eggs and hormone treatment to become pregnant and give birth.[3]

Even more exotic possibilities for reproduction have already been demonstrated in other mammalian species and will soon be applied to humans as well. These include protocols that allow two women to have a baby together by embryo fusion,[4] and somatic cell nuclear transfer techniques that will allow infertile couples and individuals to have monoparental biological children.[5] Indeed, our current understanding and technological prowess over the process of human reproduction is so extensive that it will soon be possible for any one or two people, of any sex or age, to have monoparental or biparental children. For reasons to be discussed below, these expanding reproductive horizons are scaring the daylights out of some people.

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1. *See generally* LEE M. SILVER, REMAKING EDEN: HOW GENETIC ENGINEERING AND CLONING WILL TRANSFORM THE AMERICAN FAMILY (1998) (discussing genetic and physiologic technologies in regard to human reproduction).

2. *See id.* at 160.

3. *See id.* at 225-26.

4. *See id.* at 206-22.

5. *See id.* at 137-41.

At the same time, as reproductive horizons are expanding, there has been an explosion in the area of genetic research and technology. The Human Genome Project, with its goal of identifying each and every human gene, has been pried from the nonprofit government agencies, the National Institutes of Health and the Department of Energy, and sucked into the private sector where biotech companies are already in hot competition to profit handsomely from controlling this goldmine of information.[6] Identifying all 100,000 or so human genes, which is set to be accomplished by the year 2003, is actually only the first step in this massive effort. The second step, which is just as important, is to identify all of the major ways in which people differ at each of these genes, and how these genetic differences correlate with differences in critical personal characteristics, like resistance or susceptibility to every known infectious and inherited disease, and the efficacy of specific drugs or medical protocols in counteracting these diseases.[7] It is only a matter of time before connections are also made between genetic profiles and physical or mental attributes that we commonly refer to as innate talents.

Most scientists and other scholars are willing to accept the fact that genes influence complex physical and mental attributes, but many believe that the pathways from genes to expressed traits are so complex that we will never be able to figure them out. The conclusion these people seem to draw is that misdiagnosis and the manipulation of complex genetic traits will always be beyond our reach.[8]

For better *and* worse, this conclusion is no longer valid. Advanced genetic technologies merged with computer technology to yield new tools for analysis like deoxyribonucleic acid ("DNA") chips, which will make it possible to scan a person's entire genome cheaply and rapidly.[9] Companies will surely use this powerful tool to conduct large population studies. The results will allow correlations to be made between specific genetic profiles and the expression of specific complex traits, even as the path from gene to trait remains hidden within a black box. We do not have to understand how a gene works to know its ultimate

6. *See* J. Craig Venter et al., *Shotgun Sequencing of the Human Genome*, 280 SCI. 1540, 1540-41 (1998).

7. *See* Leonid Kruglyak, *The Use of a Genetic Map of Biallelic Markers in Linkage Studies*, 17 NATURE GENETICS 21, 21-23 (1997).

8. *See* DEAN HAMER & PETER COPELAND, LIVING WITH OUR GENES: WHY THEY MATTER MORE THAN YOU THINK 307-09 (1998); *see also* Richard J. Tasca & Michael E. McClure, *The Emerging Technology and Application of Preimplantation Genetic Diagnosis*, 26 J.L. MED. & ETHICS 7, 11-14 (1998) (discussing the technical and inherent risks attributable to misdiagnosis).

9. *See* HAMER & COPELAND, *supra* note 8, at 302-03.

impact on a human life.

I. REPROGENETICS AND EUGENICS

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 children,[10] and whether to add in genes they do not even carry in order to provide them with increased chances for health, longevity, happiness, and success.[11]

Again, there are those who believe that it will not be possible to manipulate complex human attributes in the embryo.[12] However, if a complex disease like diabetes can be controlled with the use of a single molecule (insulin) after birth, it and many other similarly complex traits will certainly be amenable to significant manipulation with the use of single, well-placed genes before pregnancy even begins. As another example, consider height—this complex trait is probably influenced by hundreds of genes, and yet, we already know that a single gene addition (growth hormone) could easily change this trait in a way that is desired.

When reproductive and genetic technologies are combined in this way, both their design and purpose are so different from that of either technology alone that the combination is deserving of a new appellation: reprogenetics. Reprogenetics is the use of genetic technologies in the course of reproduction to ensure or prevent the inheritance of particular genes in the child.[13]

To a limited degree, reprogenetics is already practiced and accepted by a major portion of society. Each time a woman decides to abort a fetus based on the results of amniocentesis, she is choosing against the presence of certain genes in her children. And each time an abortion is chosen because the resulting child would have been mentally retarded (without other medical problems), reprogenetics is being practiced for the sole purpose of increasing the intelligence of the child that is ultimately born as a result of a later pregnancy.

Why is there such a reluctance on the part of many in society to call a spade a spade in this context? One part of the answer is that the

10. *See* SILVER, *supra* note 1, at 233-47.

11. *See id.* at 269-73.

12. *See* HAMER & COPELAND, *supra* note 8, at 307-09.

13. *See* John A. Robertson, *Oocyte Cytoplasm Transfers and the Ethics of Germ-Line Intervention*, 26 J.L. MED. & ETHICS 211, 211 (1998).

practice of reprogenetics sounds suspiciously like the discredited social theory of eugenics. Indeed, many social commentators confuse the two even though they are fundamentally different in both purveyors and goals.[14]

The stated purpose of eugenics was the improvement of the so-called "gene pool" of a society by state control over the breeding practices of its citizens.[15] In America, early twentieth century attempts to put this idea into practice brought about the forced sterilization of people deemed genetically inferior because of supposed reduced intelligence, minor physical disabilities, or possession of a supposed criminal character.[16] Further "protection of the American gene pool" was endeavored by congressional enactment of harsh immigration policies aimed at restricting the influx of people from Eastern and Southern Europe, which were seen as regions harboring populations with undesirable genes.[17] Two decades later, Nazi Germany used an even more drastic approach. It attempted to eliminate, in a single generation, those who carried undesirable genes.[18] In the aftermath of World War II, all of these misguided attempts to practice eugenics were rightly repudiated as discriminatory, murderous, and infringing upon the natural right of human beings to reproductive liberty.[19]

While eugenics is practiced at the level of a state, reprogenetics will be practiced at the level of individuals and couples. And while eugenics is concerned with the vague notion of a gene pool,[20] reprogenetics is concerned with the very real, but narrow, question of what genes a single child will receive. While the enaction of eugenics would

14. *See* SILVER, *supra* note 1, at 185-90 (discussing the policies and background of eugenics).

15. *See id.* at 254.

16. *See* PHILIP R. REILLY, THE SURGICAL SOLUTION: A HISTORY OF INVOLUNTARY STERILIZATION IN THE UNITED STATES 41 (1991). Between 1907 and 1963, more than 60,000 people were involuntarily sterilized. *See id.* at 94.

17. *See id.* at 22-24. All four of the Author's grandparents were from these regions.

18. *See id.* at 105-10. It has been reported that under the German sterilization program, the Nazis sterilized 3,500,000 people between 1933 and 1945, thereby far eclipsing similar American activities. *See id.* at 109-10.

19. *See generally* STEFAN KÜHL, THE NAZI CONNECTION: EUGENICS, AMERICAN RACISM, AND GERMAN NATIONAL SOCIALISM 100 (1994) ("After World War II, members of the American Eugenics Society sought to distance themselves from their former support for Nazi race policies. The elimination of millions of Jews, Gypsies, and handicapped people had completely discredited Nazi race policies."); Elizabeth S. Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 DUKE L.J. 806, 811 ("By the 1960's, involuntary sterilization was frequently characterized as an unjustified intrusion by the state on individual liberty and privacy.").

20. *See* SILVER, *supra* note 1, at 258-59.

lead to a restriction of reproductive freedom or worse, reprogenetics will do exactly the opposite. It will give people the opportunity to have children who will be healthy, happy, and loved.

If reprogenetics is used to increase happiness for all those involved in its practice and outcome, what could possibly be wrong with it? Plenty, according to some people. But before discussing the fears it engenders, it is important to first build the case for why I am convinced this technology will actually be used.

II. GENETIC ENGINEERING

Over the last eighteen years, the technology of germline genetic engineering was used with increasing efficiency to alter in very specific ways the embryonic genomes of a variety of mammalian species, including mice, pigs, and sheep.[21] Until recently, however, the possibility that this technology might be applied to human embryos was not given serious consideration by most scientists. There were three levels of technical problems that seemed insurmountable. First, the technology was extremely inefficient, with success rates typically less than fifty percent (in terms of the fraction of animals born with the intended modification).[22] Second, the application of the technology was associated with a high risk of newly induced mutations.[23] Finally, there was, and still is, a general sense that genetic engineering can never be performed on people because of the possibility that a particular modification might have unanticipated negative side effects. The existence of any one of these problems alone would be sufficient to categorize human germline genetic engineering as unethical and unallowable.

As we approach the new millennium, the technological landscape changed and it seems likely that all three of these technical problems could be overcome. With the application of both cloning and new DNA screening technologies at the embryonic level, it becomes possible to pre-select only those genetically engineered embryos in which the desired genetic change is implemented, without any damage to the pre-existing genome. This technical advance would eliminate the first and second problems associated with genetic engineering. But what about the question of unintended side effects from the added genetic material?

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21. *See* BRIGID HOGAN ET AL., MANIPULATING THE MOUSE EMBRYO: A LABORATORY MANUAL at v (2d ed. 1994).

22. *See* Sharon Begley, *Little Lamb, Who Made Thee?*, NEWSWEEK, Mar. 10, 1997, at 53, 56.

23. *See id.* at 59.

The issue of unintended side effects can be eliminated if genetic engineering is applied specifically to provide children with genes that other members of the population receive naturally. As an example, approximately one percent of people with a Western European ancestry carry a gene that provides complete resistance to infection by HIV, the AIDS-causing virus.[24] The absence of any deleterious side effects of this specific gene on human beings can be demonstrated by examining large numbers of people who already carry it naturally. In a situation of this type, we must ask whether any rationale exists for a state authority to stop parents from using genetic engineering to place an AIDS resistance gene in their child. Is there any moral difference between a genetic vaccine given to an embryo and a protein-based polio vaccine given to an infant?

One difference is that the polio vaccine is made available to all children in our society, irrespective of the affluence of their parents. Unfortunately, it seems unlikely to me that genetic engineering will ever be available in such an egalitarian fashion. Some might argue that this is the difference that is ethically significant.[25] But, if we look at the world population as a whole, there are places where vaccines against deadly diseases are not available to children who grow up with a real risk of dying from the disease. At this level of analysis, afterbirth vaccines given today are no different ethically from future genetic vaccines. In both cases, there are lines drawn between individuals or populations who are affluent enough to receive the vaccine and those who are not.

But beyond vaccines against disease, parents of the future will be able to provide their children with many other genes that enhance physical or mental characteristics which other children inherit naturally. The first class of genes that comes to mind are ones that increase life span.[26] Beyond that will be genes that provide talents, like perfect musical pitch,[27] genes that attenuate personalities against both shyness and hyper-aggression,[28] and genes that provide particular mental skills, like

24. *See* Rong Liu et al., *Homozygous Defect in HIV-1 Coreceptor Accounts for Resistance of Some Multiply-Exposed Individuals to HIV-1 Infection*, 86 CELL 367, 373 (1996); *see also* Caroline Quillent et al., *HIV-1-Resistance Phenotype Conferred by Combination of Two Separate Inherited Mutations of CCR5 Gene*, 351 LANCET 14, 14 (1998) (describing CCR5, a gene that is associated with resistance to HIV-1 infection).

25. *See* Jeremy Rifkin, *Who Will Decide Between Defect and Perfect?*, WASH. POST, Apr. 19, 1998, at C4.

26. *See* Dan Seligman, *Outlawing DNA*, FORBES, July 6, 1998, at 110, 110.

27. *See* Joseph Profita & T. George Bidder, *Perfect Pitch*, 29 AM. J. MED. GENETICS 763, 766-69 (1988).

28. *See* Seligman, *supra* note 26, at 110.

an increased ability to learn multiple languages.[29]

Again, I want to emphasize that to avoid unintended consequences, it is likely that in the near future, all of these so-called enhancements will be based on genes that occur naturally in a proportion of the population. In the long run, however, our knowledge of the human genome and the way in which it works is sure to advance to the point where enhancements beyond those present in any person alive today will become safe and efficient.

III. THE MEDICAL MODEL VERSUS THE MARKET MODEL

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.[30] 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.[31] 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 order" 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 leaders who think 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 babymaking. Governments do not make babies, people do. It is individuals and couples—not governments—who want to reproduce themselves biologically in their

29. *See* HAMER & COPELAND, *supra* note 8, at 231-34.

30. *See* LEON R. KASS & JAMES Q. WILSON, THE ETHICS OF HUMAN CLONING 38-39 (1998).

31. *See* Lawrence Wu, Note, *Family Planning Through Human Cloning: Is There a Fundamental Right?*, 98 COLUM. L. REV. 1461, 1511 (1998).

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 is the way it has 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 reprogenetic 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 cannot 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 is 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 are willing to spend thousands of dollars in attempts to have a baby with the use of in vitro fertilization,[32] or the services of a surrogate mother. 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.

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

32. *See* Peter J. Neumann et al., *The Cost of a Successful Delivery with In Vitro Fertilization*, 331 NEW ENG. J. MED. 239, 239-42 (1994).

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 do not have the right to control the characteristics of their children-to-be in the way described above.[33] 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 able to give their children very real advantages in life that less affluent parents are unable to afford. In American society, children of the affluent receive 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.

In a society that places a high value on individual freedom, like that found in the United States, it is hard to find any legitimate basis for restricting the use of reprogenetics. Each individual use of the technology can be viewed in the light of personal reproductive choice with no ability to change society at large. But when taken together over many individuals and many generations, these new technologies could drastically affect the nature of human society. The ultimate, and perhaps inevitable outcome of a libertarian market-based society could be a genetic gap between classes, the GenRich and the Naturals,[34] that becomes

33. *See* KASS & WILSON, *supra* note 30, at 42.

34. *See* SILVER, *supra* note 1, at 4.

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 genetics confronts us with future prospects of being able to change the nature of our species is a fact that seldom appears to be addressed in depth. Scientific knowledge may not yet permit detailed understanding, but the possibilities are clear enough. . . . [In the end] the agenda is set by mankind as a whole, not [simply] by the subset involved in the science.[35]

Unfortunately, I disagree with the editors of *Nature*. Scientists will not be able to control the agenda even if they wanted to. They are simply not the ones with power in a market-based society. But, it is utterly naive to think that mankind as a whole, unable to reach consensus on so many other critical societal issues, will have any effect whatsoever. Instead, I believe that power will lie in the marketplace, and that the agenda will be set by individuals and couples who will act on behalf of themselves and their children. And my fear is that the marketplace could very well determine the evolution of humankind.

Is there an alternative? So long as sovereign states prevail, international borders can do nothing to halt the passage of cells and genes lying deep within a woman's body. Only a single world state could control the use of reprogenetics, providing it in measured amounts to all its citizens. From our vantage point at the beginning of the third millennium, such a Huxley-like world seems much more securely in the realm of fiction than even the most fantastical scenarios imagined in this book. Nevertheless, the future of humankind is a thousand times longer than its past and is impossible to foresee.

I have no doubt that the growing use of reprogenetics is inevitable. For better *and* worse, a new age is upon us—an age in which we as humans will gain the ability *to change the nature of our species.*

35. John Maddox, *Exploring Life as We Don't Yet Know It*, 380 NATURE 89, 89 (1996).