Science + Hope ⟷ Technology + Fear:

Suffering, the EVANHOE PROCESS, and Genetic Reproductive Technology in American Family Culture

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EVANHOE PROCESS

Charles Alfred + Barbara Jean → Laurelin + Richard Paul + Rebecca

No genetic reproductive technology was used in the making of this family.

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The conception of family changes across cultures and across time. Contrast the Western idea of family as mother-father-children Unit with the more village-oriented Hispanic tradition, or with the ideal family of China, which includes several generations. Changing, too, is the traditional American ideal of the nuclear family (ENTER aproned Mother bearing ham to feed a modest number of scrubbed, smiling kiddies while Dad stands proudly), which is being replaced with acceptance that healthy families can include divorced parents, single mothers, or same-sex partners.

The American idea of family is changing again. This new family is one made possible – or possibly just better – by genetic reproductive technology. These technologies include methods for identifying genes in fetuses that are linked to disease and analyzing the DNA of parents to assess the risk of passing on a genetic condition to a child. One of the more controversial methods is used in tandem with *in vitro* fertilization to screen fertilized eggs for various risky traits and choosing the best "candidates" before the eggs are implanted into a potential mother. These technologies have been in practice for the past three decades to help families. However, the technologies have limits. Genetic reproductive technologies cannot determine if a child will actually develop a disease; they can only identify genetic predispositions to diseases. They produce statistics, quantifications of what *might* happen. These genetic reproductive technologies continue to advance, and there is high potential for further understanding and manipulation of genes. For example, aside from disease-related testing, in the

future it may be possible to test for genes that influence behavior, personality, and intelligence[1].

The ways in which the continual introduction of these technologies affects the family dynamic are sweeping and complex. First, let's glance at the problem on an interdisciplinary scale. According to the Genetics and Public Policy Center's 2004 report, *Issues and Options for Policymakers*, genetic reproductive testing will raise "scientific, legal, regulatory, ethical, moral, and societal issues." The modern outlook on genetic research and technology is an amalgamation of views. The general public is interested in the possibilities – and possibilities for freaks – stemming from genetic research. In science articles published worldwide, one finds the buzz words "stem cell," "genetic engineering," "Human Genome Project." From a governmental perspective, the Bush administration takes a cautious approach toward genetic and stem cell research, a closely related area whose primary goals are to aid reproduction and cure diseases. Opposing the government's conservative view are agencies like the Union of Concerned Scientists, who maintain that the scientific community is strongly in favor of genetic research.

Behind the scientific-political front, the constant debate of family planning and reproductive rights runs like continual background noise. In general, the noise boils down to a societal consciousness of the intimate connection between the rights of a mother and child – although feminists and pro-life Christians argue for the rights of opposite parties. On a personal level, modern genetic reproductive technologies raise emotions in individuals: namely, fear and hope. These individuals compose families whose socio-economic backgrounds, beliefs, and reproductive situations are markedly unique. Although American families are so different, most Americans agree that there are appropriate uses of reproductive genetic technology. In a 2001 study, the Genetics and Public Policy Center (GPPC) polled 6,000 Americans on their views on genetic reproductive testing. Americans answered with conviction (70% approved) that appropriate uses of genetic reproductive technologies include testing for fatal childhood diseases, compatibility of tissue or blood with a living sibling, and the likelihood of developing adult-onset cancer. In other words, Americans approve of using genetic technology to alleviate suffering in future generations.

[1] This paper makes use throughout of two booklets, *Issues and Options for Policymakers*, and *What American Thinks*, published in November, 2004 by the Genetics and Public Policy Center (abbreviated GPPC). The Genetics and Public Policy Center, based in Washington, D.C., is part of the Phoebe R. Berman Bioethics Institute and is funded by the Pew Charitable Trusts.

The GPPC asked another survey question that seems to draw a parallel between the modern situation and ancient Eastern philosophy. The question was, Agree or Disagree: Suffering is a part of life. This idea is thousands of years old; the first noble truth of Buddhism is just that fact. *Life is suffering.* According to Buddhist philosophy, to have been born is to exist in a world where all experience suffering. And, the American people agree. Within every demographic, when comparing sex, age, ethnicity, religion, income, education, or political affiliation, the percentage of those who agree was consistent. Roughly 80% of those surveyed believe that suffering is an integral part of human life.

This dichotomy – that the American people believe suffering is inherent to life, and that they want to eliminate what is inevitable – is indicative of human nature. It is perhaps the societal expression of a simple sentiment shared by all parents: All parents want to protect their children from suffering, but yet all parents experience the agony of the inevitable failure to protect.

Suppose we allow reproductive genetic technologies in our culture for the approved means – that is, to prevent or reduce suffering. Even so, in the face of emerging genetic technologies, in the face of shifting societal paradigms, in the face of transforming family dynamics, the only truly change will be the process.

The experiences of a family – positive or negative – are not mandated strictly by the genome. In the same way that we view children as more than random combinations of parental genetic code, we can view experiences as more than the sum of the DNA of its members. For example, from the course of 20+ years of the EVANHOE PROCESS, the following facts emerge:

- Richard Paul wrapped Rebecca up in toilet paper and blew flour all over her with a fan.
- Barbara Jean once told Rebecca, “I love you, even when I’m mad at you.”
- Rebecca worships Laurelin for her beauty, intelligence, kindness, and good humor.
- Laurelin pretended to be possessed by a demon for the purpose of terrifying Rebecca.
- Charles Alfred forgot Richard Paul at the grocery store. Charles still can’t talk about it without getting upset.

The occurrence of these events cannot be attributed to explanations of DNA alone. Scientists knows every genome that constitutes a member of the human species, parts of brains

that light up when we are angry or pleased, hormones that influence behavior. Yet it cannot account for the depth of love and misery that humans experience in a lifetime. Human does not equal simple DNA; human life involves biology plus experience.

Try, then, to explain the classic interaction of Nature and Nurture using the EVANHOE PROCESS as the primary example:

DNA * experience → Human

Since families are made up of many individuals,

DNA * experiences of individual members → Family

Since the individual members add up to the EVANHOE PROCESS,

DNA * EVANHOE PROCESS → Family

What, then, is the reason that family yields suffering? Buddhism can offer insight as to why. The second noble truth states: *The origin of suffering is attachment*. Our very nature is to become intimately connected to our families. We share, first and foremost, living tissue and scraps of DNA. We develop, from a sphere of cells to a functioning being, not *next to*, but *within* a mother. We learn lifelong habits from the guidance and control our parents impart on us. Ideally, family life has its rewards; families provide support and affirmation, families celebrate birthdays and accomplishments, families care deeply and express that caring daily.

But ultimately, family members watch one another age and die. Family is impermanent. Because of this attachment – call it love, even – to something that will inevitably vanish, the fleeting nature of human life will yield pain.

Given the convictions of Buddhism and the American people, suffering doesn't come from DNA. It is a byproduct of life itself. Suffering manifests itself as *the* incurable disease. Despite the fact that genetic reproductive technologies are designed to eradicate suffering, they are aimed at the wrong component of the equation.

While suffering cannot be eliminated, perhaps it can be reduced. Given that suffering is engrained in family life, would a family such as the EVANHOE PROCESS escape *some* of these negative emotional manifestations in the presence of genetic manipulation?

DNA * EVANHOE PROCESS → family

DNA * EVANHOE PROCESS $\xrightarrow{\text{GENETIC REPRODUCTIVE TECHNOLOGY}}$ happier family?

The application of genetic reproductive technologies that Americans can accept is that genetic technology can at least reduce suffering. This idea was introduced into our culture with the arrival of the first "test-tube" baby in 1978, giving couples the opportunity to have children who otherwise would not have been able[2]. The new control over our genetic reproduction makes Americans question the role of humans in evolution. Some Americans view genetic manipulation as an extension of evolution, although self-performed; we can improve the quality of life by adapting around disease. When asked by the GPPC whether they agreed with the statement "Reproductive genetic technology is potentially the next step in human evolution," the American public answered in an inconclusive but remarkably consistent way. Again, despite comparisons of sex, age, ethnicity, religion, income, education, or political affiliation, the split is close to 50/50. Depending on the survey group, between 40% and 60 % of Americans agree that the Darwinian application of technology is the next step in human evolution[3].

Because many Americans hold the (slight misconstrued) view that natural selection "improves" a species, they accept genetic technology because of a tendency of human nature: humans hope. The unavoidable attachment that chains us to our families makes us want the very best for them. We want to help them adapt to be better equipped to have happy and successful lives. But along with this desire is the fear that the situation will result in negative or even malevolent consequences. According to the Genetics and Public Policy Center survey, among the top concerns of the public are discrimination against the disabled, loss of diversity, and treating children like products. Outlining these fears may offer insight into their ability to lessen suffering in family life.

GATTACA Effect

The public fears what I'll call the GATTACA effect – genetic discrimination, a sort of imposed caste system based on genetic 'superiority'. The film GATTACA portrays a society that operates within one such caste system, and raises the question of when an individual can

[2] "History of Human Genetic and Reproductive Technologies." Center for Genetics and Society. http://www.genetics-and-society.org/technologies/history.html.

[3] Charles Darwin never implied that evolution is proactive – in other words, that species consciously do it to themselves. This American outlook is clearly a manipulation of his initial intent. Rather, Darwin's concept of evolution is not personified, and has no end goal. The American view is more akin to the views of "social Darwinist" Herbert Spencer. Spencer argues that "survival of the fittest" occurs on an individual level, so by promoting the best and brightest individuals in our species, everyone benefits.

overcome genetic predisposition with willpower. Additional concerns are that, if we lessen the occurrence of disabilities, will we eventually develop less tolerance for individuals with them? In addition, many fear that since this technology is available and beneficial, it will pressure parents to opt for the technology. So, with the mentality that "truly caring parents 'fix' their children," we will come to judge not only those with disabilities, but also entire their parents.

Monoculture

Biologically and socially, diversity is a concern. In a Darwinian sense, a healthy species is one able to adapt. Clearly, by eliminating disease, the species is adapting to overcome a negative condition. However, a big factor in adaptability is genetic diversity. A diverse species stands a far better chance of overcoming an obstacle than a monocultured species would. So the challenge arises from maintaining a balance between genetic 'superiority' and genetic diversity.

Financial discrimination is an additional concern; since insurance coverage for this kind of therapy is rare, only those with lots of money can afford to make better children. In the United States, these tend to be upper-class white persons, a fairly homogenous group whose replication will not lend itself to diversity.

Children®©™

To the American public, one of the scariest potential results is that genetic reproductive technology will lead to treating children as products. Here is one fear that right-wing conservatives and left-wing conspiracy theorists share: BABY FACTORIES in the literal and literary, Huxleyan sense, where mini-humans are bottled and "decanted," as in the novel Brave New World. Presumably, the initial intent of genetic technologies is to eliminate disease. Once we begin testing future fetuses for genetic conditions, even if for noble Darwinian reasons, this quickly becomes a slippery-slope argument. First we test for disease, then for strong immune systems and bones, then muscular strength, then intelligence and personality, then eventually aesthetic, physical traits such as hair color, eye color, leg length, absence of moles. The parallels to Nazi Germany, its master-race goals, and its childbirth program surface often. This kind of aesthetic manipulation opens the door for racism, an ugly, hateful mindset that the United States still struggles to eradicate. Beyond aesthetics, if children are treated in such a material fashion, it seems a small step before we create them in labs and plant them into artificial uteruses.

Where would this desire come from? Despite popular misconception, it likely will not manifest from some evil government plan to make clones, or from a twisted group of scientists out to develop the ultimate species. If this Children®©™ phenomenon comes to be, it will result from the wishes and hopes of parents. Parents often have the idealistic dream that their children will be "more than they were" – that their successors will have greater talent, greater intelligence, greater success, greater happiness – the American dream. According to two Sacramento town hall participants in the Genetics and Public Policy Center study, "We always want the best for our children. But we always want the best children, too." Armed with reproductive genetic technology, parents can strive to create the 'best' children, based on their own standards.

Given these three fears, it seems genetic reproductive technologies may in fact induce more family baggage, rather than reduce it. True, these fears are purely speculative, based on slippery slope predictions which hold little factual basis. The result *may* be a race marching toward some arbitrary perfection, wherein humans are bred as race horses; a species that, by following the natural course of intellectual evolution, now takes natural selection into its own hands to produce clone after clone; a society where disease is shoved under the rug, ignored, if it can't be done away with all together.

If one of these scenarios becomes real, then family dynamics will suffer. If the family dynamic remains the same, then suffering will continue to exist as it does now. Whether any of the scenarios come to fruition, or whether they do not and family dynamics remain largely the same, it's clear that genetic reproductive technologies cannot and will not eliminate suffering.

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Despite the fact that eliminating suffering from family structures is a contradictory – or even impossible – task, and the fact that the public fears the manipulation of genetic technology for racist or material ends, Americans still express hope for genetic reproductive technologies. There may be realistic ways for society to use genetic reproductive technologies. The most reliable way that genetic reproductive technologies could reduce suffering is through knowledge – statistics – that may ease a family decision. Knowing the facts of science and the genuine

repercussions is essential for a family to make a choice. To have a fighting chance at using genetic reproductive technologies to lessen suffering, the government must allow for the unrestricted quest for and distribution of knowledge of reproductive genetic technologies.

Note the crucial difference between *knowledge* and *use*. This theoretical separation of knowledge and use can disconnect science and technology for an improved progression of genetic research. **Science** in its purest form can simply be defined as *knowledge gained through experience*. A more technical definition of science is *the observation, identification, description, experimental investigation, and theoretical explanation of phenomena; a methodological activity or study.* Science's closely associated neighbor is **technology**: *the scientific method and material used to achieve a commercial or industrial objective*, or simply *the practical application of science*. Technology, then, is the second part of the quest – "how can we use this for general improvements?"

Society may perceive that the birth of a new discovery is inevitably followed with the afterbirth of technology. However, the connection is relatively new, born to the Western world in the 17th century. The connection was made formally by Sir Francis Bacon, whose writings outlined a vision for knowledge of nature to be sought after not for its own sake but for utilitarian applications. The idea that science and technology can reinforce one another became more accepted as a natural progression – *Step 1: Gain knowledge, Step 2: Use knowledge* – and was made increasingly intentional throughout the 20th century. This connection has muddled the goals of the two. The evidence can be seen in all fields of science – particularly ones involving human health, like the industries of medicine and pharmacy, and genetic reproductive technology, where research and development are one and the same.

In the face of the changing production of family, by adopting a separation science can return to a pure process of acquiring knowledge. However, the current government makes no such distinctions between science and technology, limiting the acquisition of knowledge. The government has exerted forceful restrictions on genetic stem cell research. The strongest expression of government control has been through the 2001 limits placed on federal funding so that government dollars could only be spent on research using existing stem cell lines[4]. The

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[4] Fact Sheet: Embryonic Stem Cell Research. Aug. 9, 2001. http://www.whitehouse.gov/news/releases/2001/08/20010809-1.html

action specifically restricted “the cloning of human embryos for any purpose,” and mandated that genetic stem cell research be used for therapeutic, not reproductive, purposes. Although this action sparked a strong disapproving reaction from the scientific community, lobbying groups continue to challenge the United States government to take a more active role in the regulation of genetic science and technology. This desire for government control over knowledge comes from societal fear of “cloning,” “playing god,” or “perverting nature” – from the idea of genetic technology being manipulated toward evil purposes.

However, any form of government control imparted over research will seriously damage freedom of knowledge. The government’s current limitations on stem cell genetic research are too restrictive. By controlling research, the government restricts knowledge that may promise to relieve suffering. In addition, many genetic reproductive technologies are reapplied in a scientific-minded way, and seek only to obtain information on which a parent may act. If the government were to limit the rights of parents to use reproductive technology to *gain information* about the future genetic conditions of a child, that also would be an unethical restriction of knowledge.

Suppose science is armed with knowledge. The knowledge then can be distributed to the American public. Or, theoretically it should be. However, there is clearly a need for better genetic education of the public. Misconceptions and ignorance are rampant. From the Genetics and Public Policy Center survey, at least 90% of Americans had heard of sensationalist and science fictionesque cloning, while only about 35% had heard of Prenatal Genetic Diagnosis, a far more useful and realistic application. Only 22% of Americans could answer correctly that currently, genetic technologies cannot test for traits such as intelligence (in other words, 52% believed that it can test for intelligence, and 26% flat-out didn’t know.) Even if the knowledge exists, the public clearly is not getting the right education.

The government must also help with the distribution of accurate knowledge. However, the Bush administration is not fulfilling this role, either. It was accused by the Union of Concerned Scientists of actively manipulating and suppressing scientific knowledge. As stated in a July 8th, 2001 article by the Union of Concerned Scientists, Dr. Janet Rowley, member of the President’s Advisory Council on Bioethics said, “I have seen first hand through the President’s Council that this administration distorts scientific knowledge on stem cell research, which makes it increasingly difficult to have an honest debate in a field that holds promise for treatment of

many serious diseases like Parkinson's and juvenile diabetes.[5]" The public cannot be expected to make informed decisions when first, potential knowledge obtained through research is denied, and second, the knowledge which exists is misconstrued.

Once the government avoids restricting knowledge, science yields knowledge, and the public has access to accurate versions of that knowledge, families can act. But it is here, with the stage direction ENTER TECHNOLOGY, that manipulation occurs. Enter discrimination, fear, guilt, falsely fed hopes. To rely on the individual family to decide is to re-introduce the aforementioned problems. First, the enormous variance of the "American family" and its unique values. Second, the paradoxical desire to end suffering beside the knowledge that it is inherent to life. And third, the American family's adherence and subjugation to emotion. True, knowledge is essential to a government's decision-making process, and to a family's. But a critical difference arises: when a family acts on the decision to use genetic technology, whether to improve the chances of having a healthy child or to determine whether to continue a pregnancy, families do not philosophize far beyond the basic understandings of self and situation. They do not think about the fate of the species, or the preservation of democracy. They think about family, and they think about loving a child, and they think about giving the child the best possible chances in suffering world. A clear view of personal morals, a firm understanding of the kind of statistics that genetic reproductive technologies produce, and conviction to do the best thing, the right thing – parents use these tools as best they can. But to echo a previous point, parents want the best for their children … and also, the best children. If parents were given the *option* of specifying sex, height, or hair color, most would consider it briefly, if even for a moment. This is where the highest potential for corruption occurs.

This is where government influence can provide protection. Society can benefit from restricted use of genetic technologies to prevent major fears from coming true, phenomena like Monoculture, the GATTACA effect, Children®©™. But instead, the government actually has placed restrictions only on research and has left the technological applications up to medical practitioners. Currently, there is little government oversight on the field of genetic reproductive technology. Medical practitioners decide which services to offer, insurance companies elect how

[5]"New Cases of Scientific Abuse by Administration Emerge: Thousands More Scientists Join Protest." Union of Concerned Scientists. July 8, 2004. http://www.ucsusa.org/news/press_release.cfm?newsID=405.

much coverage to offer, and individual parents choose which services to employ and what to do with that information.

However, the balance between restricting technology to avoid wide-spread harm and societal damage and preserving the rights of individuals is a delicate one. The role of the United States government is to protect the freedoms and rights of its people. A major component of the government's current inability to act on family planning and pro-choice issues is the absolute and literal lifeline between mother and child. To ensure the rights of one is to restrict the rights of the other. Also problematic are the links of these issues to religion, morality, and ethics, which are highly individualized and varied across the population. As the Bill of Rights specifically allows that Congress avoid laws restricting such beliefs, to establish any laws pertaining to such heavily valued rights would be extremely difficult.

The government must protect science and the knowledge it produces, and allow all families the right to access accurate knowledge. The only control the government may employ – with public input – is over which options for genetic reproductive technology to make widely available. But by merit of freedom, the burden of decision falls on the family. Parents must be ensured the right to act on genetic information to choose whether to employ these technologies as they wish. As the Genetics and Public Policy Center iterates, "in a democratic system of government, the voice of the public is critical in making sound public policy decisions." And America has spoken. According to a survey by the same organization, 67% of Americans surveyed believe that people should decide how to use genetic technologies for themselves because the consequences are so personal. Still, these decisions are firmly rooted in the personal beliefs of a couple or individual. Families, flawed and varied as they are, make the final call.

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As American family culture faces a changing paradigm, the original question is extremely important.

DNA * EVANHOE PROCESS $\xrightarrow{\text{GENETIC REPRODUCTIVE TECHNOLOGY}}$ happier family?

The hope to end suffering could drive a family like the EVANHOE PROCESS to accept and employ the service of genetic reproductive technology, despite fears.

Fear + Hope $\xrightarrow{\text{EVANHOE PROCESS}}$ Acceptance & Use of Genetic Reproductive Technology

However, the above equation without scientific knowledge and information is a dangerous scenario. From uneducated decisions come a greater possibility for manipulative scenarios like a monocultured species, genetic discrimination, or treating children as products. By learning more through research and using it to provide information to families, knowledge is the only way genetic reproductive technology can promise to relieve suffering. Proper government support of science, the unrestricted distribution of information, and responsible individual use of technology will help families make decisions and improve individual lives as they run their courses. But because each unique family has the right to act for itself on its own values and beliefs, the burden of decision must be localized.

Research → Knowledge

Knowledge + Education $\xrightarrow{\text{EVANHOE PROCESS}}$ Informed Decision

Informed Decision $\xrightarrow{\text{GENETIC REPRODUCTIVE TECHNOLOGY}}$ Responsible Use

But where is the part of the equation that shows suffering can be eliminated or reduced from the technology? A family may use knowledge to feel more at east with a family decision. But there is no concrete evidence that in all of this:

Science + technology
Hope + Fear $\xrightarrow{\text{EVANHOE PROCESS}}$ Reduction of Suffering?
Knowledge + Education
Rights to Decide and Use

The sorrow wrung from the family dynamic cannot be alleviated by genetic reproductive technology. Suffering sources primarily from the EVANHOE PROCESS itself – from family.

EVANHOE PROCESS ↔ suffering.