Articles

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Human Genetic Technology, Eugenics, and Social Justice

W. Malcolm Byrnes

In this new post-genomic age of medicine and biomedical technology, there will be novel approaches to understanding disease, and to finding drugs and cures for diseases. Hundreds of new "disease genes" thought to be the causative agents of various genetic maladies will be identified and added to the list of hundreds of such genes already identified. Based on knowledge of these disease genes, many new genetic tests will be developed and used in genetic screening programs. Genetic screening is the foundation upon which reproductive technologies such as pre-natal diagnosis (PND) and preimplantation genetic diagnosis (PGD) are based. Genomic information arising from the human genome will also be essential for attempts to redesign the human genetic inheritance by engineering the human germline (germline engineering). In each of these technologies—PND, PGD, and germline engineering—there are serious ethical and social concerns. Moreover, all three are eugenic in nature because they strive to control which genes are passed down to future generations. The goals of this article are threefold: 1) to introduce the science behind the three technologies; 2) to give a brief overview of eugenics in the past century and show how these genetic technologies are eugenic; and 3) to present a view of social justice that rejects the deterministic view upon which eugenics is based and embraces a holistic, ecological view of nature and humanity.

Human Genetic Technologies

A normal human genome is made up of twenty-three pairs of chromosomes. The first twenty-two are the non-sex chromosomes, and the twenty-third is either XX (female) or XY (male). The human genome project thus has involved the sequencing of twenty-four chromosomes—the first twenty-two, plus X and Y. It is important to emphasize that recently published human genomic information—the identities of the thirty thousand or so genes and their locations on the twenty-four

chromosomes—is, in itself, a great good.[1] This information will revolutionize medicine in a very positive and powerful way.

The Field of Proteomics

Two examples from the field of proteomics, a spin-off from the human genome project (HGP), will illustrate this point. First, however, a couple of definitions are needed: The human proteome is defined as the full set of all of the proteins produced from the genes of the human genome. Proteomics is an area of biology that involves the high-throughput, rapid analysis of all the proteins expressed in a given tissue, organ or organism. The following techniques are involved in proteomics: separation of the many proteins of a cell or tissue, identification and quantification of the proteins that are present, and analysis and synthesis of all of the information generated.

The first example of a proteomics application is in the area of drug discovery and development. Through a technique called expression profiling, researchers will be able to identify and compare levels of proteins expressed in disease versus non-disease states.[2] By such a comparison, it will be possible to identify diagnostic markers for disease (specific cancer types, for example), gain knowledge of pathways affected by disease, and come up with possible drug targets. This same methodology can be turned around and used to screen newly-discovered drug candidates for their effectiveness and toxicity. Thus, expression profiling will be a powerful tool both for diagnosing disease and for coming up with safe and effective treatments for disease.

The second example is in pharmacogenetics, which studies how genetic variation affects the way people respond to drugs, and forms the basis of "personalized medicine."[3] Genetic variation, by controlling the properties of the receptors and enzymes that are produced, can affect how well a drug works and how toxic it is. Pharmacogenetics promises to be especially useful in oncology, where there are

[1]Two reports on a draft of the sequence of the human genome came out simultaneously in February 2001. One report was published on February 16, 2001, in the journal *Science*; it presented the results of an international collaborative effort led by J. Craig Venter of Celera Genomics, a company in Rockville, MD. The other report, published in the February 15, 2001, issue of the journal *Nature*, presented the results of a yet more extensive international collaboration, and was headed by Eric S. Lander of the MIT Whitehead Institute and Francis Collins of the NIH National Human Genome Research Institute. The entire contents of these two issues were taken up with primary and ancillary reports related to the human genome. The primary reports are: J. Craig Venter, et al., "The Sequence of the Human Genome," *Science* 291 (February 16, 2001): 1304; and Eric S. Lander et al., "Initial Sequencing and Analysis of the Human Genome," *Nature* 409 (February 15, 2001): 860.

[2]Stu Borman, "Genomics Advances," *Chemical and Engineering News* 79 (July 9, 2001): 44.

[3]Celia M. Henry, "Pharmacogenomics," *Chemical and Engineering News* 79 (August 13, 2001): 37. The words pharmacogenomics and pharmacogenetics often are used interchangeably, but pharmacogenetics "is more focused in scope and is viewed as a subset of pharmacogenomics, which encompasses factors beyond those that are inherited." Ibid., 38. See also the preceding article in this journal, Amalia M. Issa, "Clinical and Moral Challenges of Pharmacogenomics."

many drugs that are effective in only a small percentage of the population. For example, a given chemotherapeutic drug with many side effects might work in only thirty percent of the population, and have seventy percent nonresponders, i.e., people for whom the drug does not work.[4] It will be possible, by looking at which sets of proteins are expressed and not expressed in responders versus nonresponders, to predict ahead of time how likely it is that a cancer drug will be effective, or toxic. In this manner, pharmacogenetic information can be used to tailor treatment for a particular patient, boosting the likelihood of success and lowering the possibility of side effects.

Prenatal Diagnosis

In prenatal diagnosis (PND), a sample of a fetus's cells is obtained by means of amniocentesis or chorionic villus sampling, and the DNA extracted from the cells is subjected to a battery of genetic and chromosomal tests to see if genetic diseases or abnormalities are present. (In some cases, the mother's blood can be analyzed for the presence of chemicals or proteins that indicate disease; this is the case for alpha-fetoprotein associated with neural tube defects such as spina bifida). An abbreviated list of common genetic diseases for which tests are available is given on the Department of Energy website.[5] A test can be biochemical in nature, as is the case for

[4]Ibid., 41.

[5]The Department of Energy (DOE) was a major partner in the government-sponsored sequencing effort. The DOE website, available at: www.ornl/hgmis, gives information on the human genome project in general. Within the site is a subsite titled "Gene Testing," available at: www.ornl/hgmis/medicine/genetest.html. At this online location is a list of twenty-seven genetic diseases for which tests were available "as of 1998 from clinical genetics laboratories approved by the state of New York." In the list, presented below in its entirety, a description of the disease is in parentheses and asterisks indicate those tests that are considered "susceptibility tests" because they "provide only an estimated risk for developing the disorder": **Alpha-1-antitrypsin deficiency** (AAT; emphysema and liver disease); **Amyotrophic lateral sclerosis** (ALS; Lou Gehrig's Disease; progressive motor function loss leading to paralysis and death); **Alzheimer's disease*** (APOE; late-onset variety of senile dementia); **Ataxia telangiectasia** (AT; progressive brain disorder resulting in loss of muscle control and cancers); **Gaucher disease** (GD; enlarged liver and spleen, bone degeneration); **Inherited breast and ovarian cancer*** (BRCA 1 and 2; early-onset tumors of breasts and ovaries); **Hereditary nonpolyposis colon cancer*** (CA; early-onset tumors of colon and sometimes other organs); **Charcot-Marie-Tooth disease** (CMT; loss of feeling in ends of limbs); **Congenital adrenal hyperplasia** (CAH; hormone deficiency; ambiguous genitalia and male pseudohermaphroditism); **Cystic fibrosis** (CF; disease of lung and pancreas resulting in thick mucous accumulations and chronic infections); **Duchenne muscular dystrophy/Becker muscular dystrophy** (DMD; severe to mild muscle wasting, deterioration, weakness); **Dystonia** (DYT; muscle rigidity, repetitive twisting movements); **Fanconi anemia, group C** (FA; anemia, leukemia, skeletal deformities); **Factor V-Leiden** (FVL; blood-clotting disorder); **Fragile X syndrome** (FRAX; leading cause of inherited mental retardation); **Hemophilia A and B** (HEMA and HEMB; bleeding disorders); **Huntington's disease** (HD; usually midlife onset; progressive, lethal, degenerative neurological disease); **Myotonic dystrophy** (MD; progressive muscle weakness; most common form of adult muscular dystrophy); **Neurofibromatosis type 1** (NF1; multiple benign nervous system tumors

alpha-fetoprotein, or it can be genetic, as in the case for sickle cell anemia or phenylketonuria (PKU). These latter two diseases are examples of *monogenic* conditions, meaning that they are caused by a single defective gene. Other genetic diseases are *multifactorial* because they are caused by several or many genes acting in concert, and have a strong environmental component. Examples of multifactorial genetic diseases are the mental illnesses schizophrenia and bipolar disorder, as well as diabetes and most forms of cancer. In most cases of multifactorial disorders, the identities of the disease genes and the manner in which they interact with each other and the environment to cause illness are not known. A third type of genetic illness is caused by *chromosomal abnormalities*. These fall into two categories: 1) chromosomal rearrangement or fragmentation; and 2) the presence of additional or too few chromosomes. In this last category is Trisomy 21 (Down's syndrome), for which there is an extra chromosome 21; Turner's Syndrome, for which the person has a missing X chromosome (XO); and Kleinfelter's Syndrome, for which there is an extra X chromosome (XXY).

PND is not really a new technology. It has been available for a limited, but growing, number of genetic "defects" since the 1970s, when a maternal blood test for alpha-fetoprotein was introduced and amniocentesis became widely available.[6] Traditional chromosomal analysis (karyotyping), performed in order to determine the number and physical structure of the chromosomes, has been available since the late 1950s. The advent in the late 1980s of polymerase chain reaction (PCR), a technique in which segments of DNA are copied manyfold, revolutionized all of molecular biology, and made possible the rapid detection of genetic mutations. The subsequent development and perfection of fluorescence in situ hybridization (FISH), a technique by which sites on chromosomes can be visualized directly, made possible the very sensitive detection of chromosomal abnormalities. Adding to these technical innovations is the discovery of additional disease genes using the newly-published sequence of the human genome. This new information will have a tremendous im-

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that can be disfiguring; cancers); **Phenylketonuria** (PKU; progressive mental retardation due to missing enzyme; correctable by diet); **Adult Polycystic Kidney Disease** (APKD; kidney failure and liver disease); **Prader Willi/Angelman syndromes** (PW/A; decreased motor skills, cognitive impairment, early death); **Sickle cell disease** (SS; blood cell disorder; chronic pain and infections); **Spinocerebellar ataxia, type 1** (SCA1; involuntary muscle movements, reflex disorders, explosive speech); **Spinal muscular atrophy** (SMA; severe, usually lethal progressive muscle-wasting disorder in children); **Thalassemias** (THAL; anemias: reduced red blood cell levels); **Tay-Sachs Disease** (TS; fatal neurological disease of early childhood; seizures, paralysis). Since 1998, hundreds of new tests have become available, and the number is projected to expand greatly with the new information from the human genome project.

[6]David J. H. Brock and R. G. Sutcliffe, "Alpha-fetoprotein in the Antenatal Diagnosis of Anencephaly and Spina Bifida," *Lancet* 2 (1972): 197. Brock and Sutcliffe developed a test for alpha-fetoprotein in maternal blood that was used by the state of California in a mass screening program for neural tube defect that began in 1986 (Troy Duster, *Backdoor to Eugenics* [New York: Rutledge, 1990]: 120). Many additional states now require the test. Amniocentesis was developed in the early 1960s, but began to be used widely in the 1970s as a part of the procedure to test for Down's Syndrome.

pact on PND (and PGD) by causing a proliferation of the number of genetic tests available.[7] Emphasizing this point is the fact that thirty new disease-causing genes were discovered using publicly available genomic information even before the first draft of the genome was published in February, 2001.[8] Moreover, the availability of rapid methods for analyzing many genetic loci simultaneously using DNA chips will speed up the entire genetic screening process and make it economically more feasible.[9]

An important point to make about PND is that it does not necessarily result in abortion of the fetus found to be abnormal. Prenatal testing can be used to detect diseases that are treatable in utero or shortly after birth. Such is the case for Phenylketonuria, where early intervention and treatment prevent some of the worse effects of the disease. Indeed, Pope John Paul II, in *Evangelium vitae,* states that:

> When [prenatal diagnostic techniques] do not involve disproportionate risks to the child and the mother, and are meant to make possible early therapy or even to favor a serene and informed acceptance of the child not yet born, these techniques are morally licit.[10]

However, there currently is a very large gap in knowledge between disease genes and the therapies that are available. Until this gap closes, which seems unlikely given the direction things are going in, most prenatal testing will be done with the intention of having an abortion to prevent the birth of a "defective" child.

Preimplantation Genetic Diagnosis

Preimplantation Genetic Diagnosis (PGD) is similar to PND in the sense that both involve the testing of a prenatal human being for the presence or absence of one or more genetic diseases.[11] Some of the same techniques, namely PCR and FISH, are used in both. However, there are some differences: 1) PGD is performed on a single cell from an eight-cell stage embryo produced by in vitro fertilization (IVF), while PND is performed using cells derived from a fetus inside his or her mother's

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[7]Francis S. Collins writes: "Information gained from the human genome project will help us to develop diagnostic tools to detect whether a given person has a genetic predisposition for a particular disease. We already have tests for breast cancer, colon cancer and Alzheimer's disease. This list is going to grow quickly." Collins, "Reflections from the Director of the National Human Genome Research Institute," *Dignity: The Newsletter of the Center for Bioethics and Human Dignity* 7 (Summer 2001): 4.

[8]Lander, "Initial Sequencing and Analysis," 911.

[9]Wolfram Henn, "Genetic Screening with the DNA Chip," *Journal of Medical Ethics* 25 (April 1999): 200.

[10] Pope John Paul II, Enclyclical Letter, *Evangelium vitae: on the Value and Inviolability of Human Life* (March 25, 1995), available on the Vatican website at: www.vatican.va/holy_father/john_paul_ii/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae_en.html.

[11]Ricki Lewis has written a brief, informative article that discusses the history, technical aspects and ethical issues of PGD. Lewis, "Preimplantation Genetic Diagnosis: the Next Big Thing?" *The Scientist* 14 (November 13, 2000): 16, available at: www.the-scientist.com/yr2000/nov/research_001113.html.

womb; 2) the techniques used in PGD, such as PCR and FISH, must be exquisitely sensitive because, unlike PND, they are performed using a single cell extracted from the embryo; and 3) whereas, with PND, the typical treatment for the presence of a "defect" is abortion of the affected fetus, with PGD, the affected embryo is discarded and another, unaffected, embryo is chosen for implantation in the mother's womb. Typically, in a single IVF cycle, ten or more embryos are created using oocytes from the mother and sperm from the father. If all ten are tested for genetic defects, two or three of the unaffected or "healthy" embryos will typically be implanted. The remaining healthy ones will be frozen for later use, and any "defective" embryos will be discarded.[12] With PGD, then, the unpleasant physical, emotional and psychological effects of abortion are avoided.[13]

PGD involves biopsy of the eight-cell embryo in order to obtain one of its cells, called a blastomere, for molecular genetic diagnosis. The embryo is held into position using a holding pipette while a glass needle is used to drill a hole through the outer layer, or *zona pellucida*. The blastomere is removed by gentle suction; this single cell is used in the genetic analysis.[14] Apparently, removal of the one cell from the eight-cell embryo (leaving seven) does not adversely affect it and, after successful implantation, the embryo can develop into a normal baby.

One recent and somewhat controversial application of PGD was made in the case of parents who wanted to conceive (in vitro) and give birth to a child whose umbilical cord blood stem cells could be used as life-saving treatment for their other child who had Fanconi anemia (FA).[15] FA is an inherited illness that is characterized by congenital malformations and a tendency to develop leukemia. Persons who have FA are refractory to chemo- and radiation therapy because of impaired immune function; this necessitates the use of cord blood stem cells that are immuno-(HLA)-compatible. The controversial aspect of the case, aside from the fact that it, like every application of PGD, involves destruction of human embryos, is that the younger sibling was explicitly selected by PGD to be HLA-compatible with his or her sibling, and FA-free. This raises the issue of whether or not it is ethical for parents or doctors to choose offspring based on utilitarian arguments. It brings up the question: If we are selecting who is to be born based on a set of criteria, what will those criteria be and where will we stop?

There is little doubt that PGD will become a widely-used procedure in IVF clinics to weed out "defective" embryos and improve the chances of success. This will happen as a matter of course, without consultation with prospective parents. In

[12]Allen H. Handyside, "Pregnancy from Biopsied Human Preimplantation Embryos Sexed by Y-specific DNA Amplification," *Nature* 344 (1990): 768–770.

[13]Aniruddha Malpani and Anjali Malpani, "Preimplantation Genetic Diagnosis: The Newest ART [Advanced Reproductive Technology]," available at: www.fertilethoughts.net/malpani/new/chap26.htm.

[14]Handyside, "Pregnancy from Biopsied Embryos."

[15]Yury Velinsky, Svetlana Rechitsky, William Schoolcraft, Charles Strom, and Anver Kuliev, "Preimplantation Diagnosis for Fanconi Anemia Combined with HLA Matching," *JAMA* 285 (June 27, 2001): 3130–3133.

fact, the British Human Fertilization and Embryology Society, the body that regulates in vitro fertilization treatment in the United Kingdom, recently approved the routine use of PGD to screen for chromosomal abnormalities.[16] The justification given was that "screening for aneuploidy [a chromosomal abnormality] can benefit in particular those women who have suffered repeated miscarriage or IVF failure by identifying embryos that are most likely to successfully implant."[17] Thus, it will be a simple matter for IVF clinics to introduce broad embryo screening programs by arguing that it improves the chances of a successful outcome.

Germline Engineering

Human germline engineering (or "therapy") is different from both PND and PGD in that it involves the direct manipulation of the genetic material present in a person's germline (egg or sperm) cells. Whereas PND and PGD involve screening of embryos and fetuses for genetic defects followed by destruction of the defective ones, germline engineering involves insertion or deletion of genes in very early embryos that are subsequently implanted into a woman's uterus. The baby that is born will have, in all of the cells of his or her body, including germline cells, the altered genome. This altered genome, should the "engineered" person choose to procreate, will be passed on to future generations and become part of the collective genetic inheritance of the human species.

Germline engineering or therapy is different from somatic gene therapy, in which genes are inserted into the somatic (body) cells of the patient to cure disease. In somatic therapy, only the diseased, target tissue will take up the inserted DNA; the inserted genes will not be passed on to future generations because the patient's germline cells are not affected by the therapy. Somatic therapy has had a rocky road lately because of issues related to safety in clinical trials.[18] There have been some notable successes, however, in treating Severe Combined Immunodeficiency (SCID), also known as "Bubble Boy" disease, and hemophilia with somatic therapy.[19] It represents a valiant attempt on the part of modern medicine to ameliorate the effects of inherited genetic disorders, even in utero, and is not a subject of discussion here.

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[16]Annabel Ferriman, "UK Approves Preimplanation Genetic Screening Techniques," *British Medical Journal* 323 (July 21, 2001): 125.

[17]Ibid.

[18]Staff and wire reports, "FDA Suspends Trials at Gene Therapy Lab," *CNN.com* (January 22, 2001), available online at: www.cnn.com/2000/HEALTH/01/22/gene.therapy/. Gene therapy trials were halted at the University of Pennsylvania after the Food and Drug Administration discovered many research regulations violations in an investigation following the death of Jesse Gelsinger in September, 2000.

[19]Robin Eisner, "The Luster Might Be Returning to Gene Therapy Technology," *ABCnews.com* (April 27, 2001), available at: abcnews.go.com/sections/living/DailyNews/genetherapy000427.html. This news article reports the success of gene therapy in treating two French infants, aged eight and eleven months, who had Severe Combined Immunodeficiency (SCID) also known as Bubble Boy disease. The two infants had normal immune systems eleven months after gene therapy. In the procedure, some of their bone marrow stem cells were extracted, treated with the corrective gene, and then transplanted back into

There are currently two ways that germline engineering can be performed on early embryos: 1) by insertion of an artificial chromosome; or 2) by insertion of an individual gene by "gene targeting."[20] Artificial chromosomes would be used if one desired to insert several or many genes at once in order to introduce or correct complex traits. In this case, not only the genes of interest, but also their DNA regulatory elements would have to be included in a kind of "gene cassette."[21] There are some drawbacks to artificial chromosomes: 1) the defective genes that one would be trying to correct would still be present in one of the "natural" chromosomes, so the effect of the added genes might be diluted;[22] 2) the added chromosome could interact in unpredictable ways with genes on the other twenty-three chromosomes;[23] and 3) there would be a problem with passing the added chromosome on to progeny since, during fertilization, pairing of chromosomes occurs and there would be no pair from the engineered person's mate.[24] Since gene targeting does not have these difficulties, it seems likely that it will be the first method pursued. Indeed, it may become the method of choice to "treat" monogenic diseases such as sickle cell anemia and phenylketonuria.

Mario R. Capecchi, an expert in gene targeting in mice, has come up with a method for accomplishing germline gene replacement in people. The method, which involves the use of embryonic stem cells and nuclear transfer (cloning), is described below:

> In vitro fertilization using sperm and eggs donated by each set of parents would be used to generate one-cell embryos. In culture, the embryo would be permitted to progress to the four-cell stage. The embryo would then be separated into four cells; three of these cells would be frozen for later use. These are procedures routinely carried out in IVF clinics. Each of these four cells,

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the body. The term "Bubble Boy" refers to David Vetter, who died at age twelve in 1984. He had to live in a hygienically-sealed environment because of his severely compromised immune system as a result of having SCID. "Surprise Gene Therapy Success," *BBCnews* (March 2, 2000), available at: news.bbc.co.uk/hi/english/sci/tech/newsid_663000/663779.stm. This news story reports how two patients with Hemophilia B responded to gene therapy treatment, which involved delivery of the gene for clotting Factor IX via a viral vector. One patient had a fifty percent reduction in the need to administer Factor IX following therapy; the other had an eighty percent reduction.

[20]Mario R. Capecchi, "Targeted Gene Replacement," *Scientific American* 270 (March 1994): 52–59.

[21]John Campbell and Gregory Stock, "A Vision for Practical Human Germline Engineering," in *Engineering the Human Germline: An Exploration of the Science and Ethics of Altering the Genes We Pass on to Our Children*, ed. G. Stock and J. Campbell (New York: Oxford University Press, 2000): 10.

[22]From comments made by Daniel Koshland, Jr., during a panel discussion at the 1998 UCLA Symposium on germline engineering titled, "The Road Ahead," in *Stock and Campbell*, 83.

[23]Ibid.

[24]Mario R. Capecchi, "Human Germline Gene Therapy: How and Why," in *Stock and Campbell*, 37.

> frozen or unfrozen, would have an identical set of genes and would be capable of generating a normal child. The fourth cell would be allowed to divide in culture until a million cells were generated ... One million cells is an ample population size to permit the use of technologies, such as gene targeting, to introduce the desired genetic alteration into a subset of these cells. The subset of cells containing the desired genetic alteration would be isolated from the remaining cell population and carefully characterized to ensure that the genetic modification was accurate. At this point, the nucleus of one of the three frozen embryonic cells would be removed and replaced with a nucleus from the expanded pool of cells containing the prescribed genetic modification. In this cytoplasmic environment, the modified nucleus would receive instruction to commence making an embryo. The cells would be allowed to divide in culture once or twice, and then the embryo would be surgically transferred to the mother's womb to allow pregnancy to continue. A child produced in this way would contain the genetic modification, introduced in cell culture, in all of his or her cells, including the germ cells.[25]

Since it involves manipulation and destruction of human embryos as well as human cloning, germline engineering brings with it all of the ethical issues related to embryonic stem cells and cloning that have been so much in the news lately.

In 1998, W. French Anderson, a world leader in somatic therapy, stated that "we do not have the expertise to attempt germline therapy .... [W]e know so little about the human body and so little about living processes [that] we would be unwise to attempt genetic engineering to try to treat, much less 'improve,' the human zygote or embryo" (emphasis his).[26] Anderson also notes that "[in humans] the vast majority of attempts at germline transfer would result in deformed or dead embryos. It would be unethical, I believe, to attempt such a procedure in humans until the success rate in animals is significantly improved."[27] Thus, he urges caution but keeps open the possibility that germline engineering could be done in the future, saying: "what our society may want to do one hundred years from now is its business."[28] He does not believe that germline engineering is inherently unethical. But is it and, if so, why?

I will argue that all three of the genetic technologies outlined here, PND, PGD, and germline engineering, can be used for eugenic purposes. Of course, each of these technologies is different from the other. PND and PGD are alike in that they both involve screening of prenatal humans. PND is not inherently unethical, but it does tend to increase the likelihood of abortion of "defective" fetuses, and it does negatively affect the view that society has toward disabled persons. PGD is performed on very early embryos in an IVF setting. With PGD, there is certainly the expectation, stronger than for PND, that "defective" embryos will not be implanted. Thus, PGD taps into the "choosiness" of parents, and allows them to have a more active role in

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[25]Ibid., 35.

[26]W. French Anderson, "A New Front in the Battle Against Disease," in *Stock and Campbell*, 45 and 48.

[27]Ibid., 48.

[28]Ibid.

determining the characteristics of their children. As we will see, PND and PGD involve a kind of "laissez-faire" eugenics. Germline engineering is in a category by itself not only for the technical reasons stated by Anderson, but also because it involves the destruction of embryonic stem cells; it degrades and dehumanizes the person who is engineered and, indeed, the entire human family; and it has the potential to permanently alter the human gene pool in unpredictable and possibly devastating ways. It is overtly eugenic. But, before I discuss these issues in detail below, I will need to introduce eugenics and give a brief history of the modern eugenics movement.

Modern Eugenics

The term eugenics in Greek means "well-born." It was coined in the 1883 by Sir Francis Galton (1822–1911), the founder of the modern eugenics movement. Galton defined eugenics as "the science of improvement of the human race germ plasm though better breeding," or alternatively, as "that science that deals with all influences that improve the inborn qualities of a race; also with those [influences] that develop them to the utmost advantage."[29] Eugenics involves controlling which genetic traits are passed down to future generations by influencing or controlling the reproductive choices of people. Eugenics has had a profound effect on societies around the globe throughout the twentieth century. Examples include: the sterilization of the "feeble-minded and moron" in America just after the turn of the century, the euthanasia and genocide programs of Nazi Germany in the 1930s and 1940s, the post-World War II opinions on population control and on the relationship between race and IQ, the coercive sterilization and abortion policies of the People's Republic of China in the 1980s and 1990s, and today, the view that the lives of persons with disabilities are "not worth living" and should be eliminated.

An Abridged History of Eugenics

Sir Francis Galton, founder of the eugenics movement, was a cousin of Charles Darwin, the famous biologist who proposed the theory of evolution by natural selection. Galton took the ideas of Darwin and applied them to human society; he believed that, through evolution, mankind was gradually improving. Nevertheless, he felt that man should actively work with, not against, the natural force of evolution, and should use his reason to "accelerate the process of improvement and avoid any signs of decay in the human species."[30] Galton wrote in the introduction of his 1869 book, *Hereditary Genius*:

> I shall show that social agencies of an ordinary character, whose influences are little suspected, are at this moment working towards degradation of human nature, and that others are working towards its improvement. I conclude that each generation has enormous power over the natural gifts of those that fol-

[29]Francis Galton, *Inquiries into Human Faculty and Its Development* (London: MacMillan, 1883): 14. Francis Galton, "Eugenics: Its Definition, Scope, and Aims," *The American Journal of Sociology* X(1) (July 1904): 1–25.

[30]Bryan Appleyard, *Brave New Worlds: Staying Human in the Genetic Future* (New York: Viking, 1998): 54.

> low, and maintain that it is a duty we owe to humanity to investigate the range of that power, and to exercise it in a way that ... shall be most advantageous to future inhabitants of the earth.[31]

Bryan Appleyard, in his book *Brave New Worlds: Staying Human in the Genetic Future*, writes: "Galton was a statistician of genius, and his key insight was the way statistics could be used to arrive at generalizations about the human population."[32] Emphasizing that a statistical view of human population can alter our perception of the individual, Appleyard writes: "[With statistics] we cannot help but see the individual as part of something rather than the untouchable end point of a process. It is but a short step from here to seeing the aberrant or abnormal individual as an inconvenience, a blot on the picture."[33] For Galton and the early eugenicists, "[t]here were ... the masses and the elite. The elite tended to be a relatively small group who preferred to have fewer children. The masses were a vast group, which reproduced profusely ... [T]o the eugenicist, this lower-class fecundity was more than just an indication of social status; it was a threat to the future viability of mankind."[34]

This view that lower-class fecundity is a threat to the future of mankind is reflected in the writings of the American, Margaret Sanger, who in 1922 founded the Birth Control League (which was renamed the Planned Parenthood Federation of America, PPFA, in 1942). It comes as a surprise to many people that Sanger was an overt eugenicist. Her book, *The Pivot of Civilization*, which was recently placed in the public domain after the copyright held by PPFA finally expired, reveals an attitude full of contempt for "the feeble-minded, the moron and the imbecile" who exhibit a "high rate of fecundity."[35] Her thinking is clearly eugenic, as revealed in the following passage from Chapter Four of *The Pivot of Civilization*, which is entitled "The Fertility of the Feeble-Minded": "[T]he destiny and the progress of civilization and of human expression has been hindered and held back by this burden of the imbecile and the moron."[36] The full force of her feelings about "less desirable" members of society (defectives, morons, imbeciles, and the feeble-minded) along with her solution (segregation and sterilization) can be seen in the following excerpt, also from Chapter Four:

> Every feeble-minded girl or woman of the hereditary type, especially of the moron class, should be segregated during the reproductive period. Otherwise, she is almost certain to bear imbecile children, who in turn are just as certain to breed other defectives. The male defectives are no less dangerous. Segregation carried out for one or two generations would give us only partial con-

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[31]Francis Galton, *Hereditary Genius: An Inquiry into Its Laws and Consequences* (London: MacMillan, 1869).

[32]Appleyard, *Brave New World*, 54.

[33]Ibid., 56.

[34]Ibid., 58.

[35]Margaret Sanger, *The Pivot of Civilization* (New York: Bretano's, 1922), available at: www.pro-life.net/pivot_in.htm.

[36]Ibid.

> trol of the problem. Moreover, when we realize that each feeble-minded person is a potential source of endless progeny of defect, we prefer the policy of immediate sterilization, of making sure that parenthood is absolutely prohibited to the feeble-minded.[37]

The feminist journalist Julianne Malveaux, who is African-American, writes: "It is easy to see why there is some antipathy toward Sanger among people of color, considering that, given our nation's history, we are the people most frequently described as 'unfit' and 'feeble-minded.'"[38] This belief that the disabled and other "undesirable" people should be sterilized was not uncommon in American society at that time. It was taken up by the courts and, by 1931, twenty-seven of the forty-eight United States had enacted sterilization laws.[39] All-in-all, sixty thousand people were sterilized in the United States over the course of the next forty years.[40]

A well-known example of the application of a sterilization law occurred in the Supreme Court case *Buck* v. *Bell*.[41] Carrie Buck was a young woman who lived at the State Colony for Epileptics and the Feeble-Minded in Lynchburg, Virginia. The institution wanted to sterilize her in order to prevent her from producing more "imbeciles" (she had already had one child out of wedlock). The Supreme Court Justice who heard the case was Oliver Wendell Holmes. In his ruling in favor of sterilization, Holmes said about Carrie, her mother Emma and Carrie's daughter Vivian: "It is better for all the world if, instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind .... Three generations of imbeciles is enough!"[42]

The eugenics movement reached its horrific climax in the gas chambers and extermination camps of Nazi Germany where, in the 1930s and 1940s, six million Jewish people were brutally murdered in order to "purify the Aryan race." Less well known than the Jewish holocaust is the Aktion-T4 euthanasia program of Nazi Germany established in 1939, whose purpose was to get rid of "the severely retarded, the violently, chronically insane, and the desperately and painfully disabled."[43] It got its designation "T4" from the location of its headquarters at Tiergartenstrasse 4 in

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[37]Ibid.

[38]Julianne Malveaux, "Sanger's Legacy is Reproductive Freedom and Racism," *Women's eNews* (August 18, 2001), available at: www.womensenews.org/article.cfm/dyn/aid/618.

[39]From "Eugenics," available at: www.all.org/abac/eugen02.htm. This is within the website for the American Bioethics Advisory Commission, a division of the American Life League.

[40]Ibid.

[41]*Buck* v. *Bell*, 274 U.S. 200 (1927).

[42]Ibid.

[43]Hugh G. Gallagher, *By Trust Betrayed: Patients, Physicians, and the License to Kill in the Third Reich* (New York: Henry Holt and Co., 1990): 18.

Berlin, the site of the Fuhrer's Chancellory.[44] Hugh Gallagher, author of *By Trust Betrayed*, writes about the program:

> The idea was to put [the retarded, insane, and disabled] out of their misery in much the same way society shoots horses or puts down a suffering dog. There was a scientific rationale, of course: killing these people would somehow strengthen the genetic heritage of the body of the German people, the great mythic Volk—like removing a cancerous tumor from an individual body, perhaps. And, of course, there were the economic reasons—"useless eaters" were taking resources better used in the German war effort.[45]

Gallagher documents how the killings took place. Panels of physicians who acted as judges were set up to decide who would be euthanized. Those "patients" selected were loaded onto special buses with tinted windows and sent to one of several "killing centers" distributed around Germany. One such center was the Hadamar Psychiatric Institute near the town of Limburg on the Elbbach River in Essen. Upon arriving at Hadamar, the patients were checked-in and given food. Next, "the nurses would tell the patients they were to have a nice shower to rest and cleanse them after their journey. The unsuspecting patients would have no objection to such a suggestion."[46] Small groups of patients would then be led downstairs into the "showers." The door to the chamber then would be closed and locked and, at the touch of a button, carbon monoxide would flow out of the shower nozzles. After some minutes, the bodies were removed, brought to the crematorium, and burned. Phony death certificates were filled out and sent to relatives. The cause of death was carefully chosen to coincide with the medical history of the patient.[47] In this manner, more than two hundred thousand German citizens were killed by their physicians.

Gallagher writes:

> [T]he euthanasia program was carried out in the name of science. The physicians and the medical professors constantly assured each other and themselves that what they were doing was in the cause of the advancement of science, a refinement of the great traditions of medicine, and in the interests of their patients ....They congratulated each other on breaking loose from the foolish and unscientific sentiments of the past, which had served to weaken the family of man. Dr. Ernst Rubin, a professor of psychiatry at the universities of Munich and Basel, warned his colleagues to guard against the 'excessive compassion and love of one's neighbor characteristic of past centuries.' The physicians sought new "active therapies," efficient and scientific, commensurate with the new Germany.[48]

Following World War II and the discovery by allied forces of the eugenic and genocidal atrocities commited by the Nazis, the eugenics movement went underground. Eugenicists began to pursue a policy of "crypto-eugenics" in which eugenic

[44]Ibid., 57.

[45]Ibid., 18.

[46]Ibid., 14.

[47]Ibid., 12–16.

[48]Ibid., 201.

goals were pursued by less obvious means.[49] A dominant figure in the American eugenics movement at this time was Maj. Gen. Frederick Osborn, who is credited with reforming the eugenics movement after World War II by "purging it of racism."[50] It is interesting to note, however, that while Osborn was promoting reform, he was also an officer in a white-supremacist organization called the Pioneer Fund.[51] It is clear from this evidence that, instead of pursuing a real end to racism, Osborn instead was pursuing an end to the *appearance* of racism in order to advance eugenic goals.

In his 1956 Galton address to the Eugenics Society in London, Osborn noted that Galton's vision for mankind had not succeeded, that the movement was "reduced to a few small handsful of men in various countries ..." and that "the very word eugenics is in disrepute in some quarters."[52] He said that people "won't accept the idea that they are, in general, second-rate. We must rely on other motivation."[53] This other motivation was what Osborn called "voluntary unconscious selection."[54] How did it work?—by appealing to the idea of "wanted children." It is interesting that Planned Parenthood also has the slogan "every child a wanted child."[55] Both groups have ardently promoted worldwide population control measures.

Contemporary Eugenics

What about today; is eugenics being practiced now? The answer is a definite "yes." Eugenics is found around the globe. In some countries, such as the United States, it is practiced subtly; in others it is practiced overtly. Eugenics is present in Asian countries of the Pacific Rim such as Singapore, where the prime minister of the city-state enthusiastically has promoted it.[56] It is common in Northern India, where sex selection through abortion strongly favors the birth of boys.[57] And yet, no country can match the People's Republic of China, where overt, state-sponsored eugenics programs currently are in full operation.

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[49]Faith Schenk and A. S. Parkes, "The Activities of the Eugenics Society," *Eugenics Review* 60 (1968): 154–155.

[50]"Eugenics," available at www.all.org/abac/eugen02.htm.

[51]Ibid.

[52]Frederick Osborn, "Galton and Mid-Century Eugenics," *Eugenics Review* 48 (1) (April 1956).

[53]Ibid.

[54]Ibid.

[55]This currently is a slogan of the Planned Parenthood Federation of America.

[56]The Singapore prime minister promoted, in 1983, a policy to encourage female graduate students to marry and have children. At the same time, female high school dropouts were given financial incentives to be sterilized after their first or second child. C. K. Chan, "Eugenics on the Rise: A Report from Singapore," *International Journal of Health Service* 15(4) (1985): 707–712.

[57]R. Ramachandran, "In India, Sex Selection Gets Easier," available at: www.unesco.org/courier/1999_09/uk/dossier/txt06.htm.

Mainland China is known for its strict "one family-one child" laws that promote coercive abortion. Because of the value traditional Chinese families place on having a son, female babies are disproportionately affected. Perhaps less well known is that, in the 1980s and 1990s, China created a number of overtly eugenic laws. One such law, enacted in 1995, is described in an editorial in *The Lancet*:

> The new law makes compulsory for all a premarital medical examination for serious genetic diseases, some infectious diseases, and "relevant" mental disorders. If the disorder is serious enough, long-term contraception or tubal ligation will be used to enforce childlessness; otherwise, the couple will not be allowed to marry. During pregnancy, prenatal testing will also be compulsory, followed by termination if the fetus has a serious genetic or somatic disorder .... Voluntary termination remains an option, but compulsory termination will seemingly be at the discretion of the doctor.[58]

The thinking behind laws such as this is revealed in the following excerpt from a 1981 article titled "Popularizing the Knowledge of Eugenics and Advocating Optimal Births Vigorously," by Sun Don-Sheng of the Jinan Army Institute: "Only by promoting the births of better offspring can we improve the genetic quality of our population, reduce or eliminate a variety of genetic diseases, and thereby lessen the burdens imposed on both family and nation. Therefore, to promote eugenics is to secure immeasurable advantages with no harmful consequences."[59]

Human Genetic Technology and Eugenics

In anything, what the history of modern eugenics makes perfectly clear is that eugenic thinking has had and continues to have a significant impact on society: on the attitudes we have and the decisions we make. In this section, I first will argue that eugenic thinking, in the form of laissez-faire eugenics, informs the reproductive choices parents and doctors make in the genetic counseling setting. I will explore how the eugenic attitudes of society impact parents' reproductive decisions. Next, I will show how germline engineering is actively eugenic. Finally, I will argue that the eugenic mindset arises from a reductionist, genetic deterministic view of nature.

PND, PGD, and Laissez-faire Eugenics

David S. King and others present the argument that, with the ready availability of PND and the advent PGD, a new kind of eugenics called "laissez-faire"[60] or "backdoor"[61] eugenics is emerging in our society. In this kind of eugenics, market forces drive nominally-free reproductive decisions that have eugenic outcomes. There is no coercion by the state. Rather, eugenic decisions are made freely by individuals,

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[58]Editorial, "Western Eyes on China's Eugenics Law," *Lancet* 346 (July 15, 1995): 131.

[59]Sun Don-Sheng, "Popularizing the Knowledge of Eugenics and Advocating Optimal Births Vigorously," *Renkou Yanjiu* (Beijing) 4 (1981): 37–41. English translation available at: www.mankind.org/man22.htm.

[60]Philip Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (New York: Simon and Schuster, 1996).

[61]Duster, *Backdoor to Eugenics*, 127.

albeit with considerable pressure from society to make the "right" decision. King writes, in response to the mistaken notion that emerging genetic technologies are not eugenic because they are not state-imposed or coercive: "[F]rom the beginning, many eugenicists including the founder of the eugenics movement, Francis Galton, were opposed to coercion, believing that if people were properly informed, they would naturally make the 'right' reproductive choice."[62] It appears that Galton's assessment of society was right: we are now willingly placing the heavy burden of eugenics on our own shoulders.

Eugenics is all about controlling who is born so that the "best" genetic traits are passed on to future generations. But, who decides what are the best traits? In coercive eugenics, it is the state who decides; in laissez-faire eugenics, it is the parents, genetic counselors and doctors. Putting aside for the moment the ethical issues associated with decisions about who shall be allowed to live and who shall not, which are part and parcel to PND and PGD, there is the question of whether or not parents who make decisions to abort a fetus or destroy an embryo on the basis of a genetic test results really are making a free choice. Many convincingly argue that the opinions of genetic counselors, obstetricians and society profoundly skew the decisions parents make. Reflecting this view, David King argues that

> ...structural features of the prenatal testing situation militate against a genuinely free choice for patients.... [T]he dynamic of undergoing testing leads to a presumption of termination, should abnormality be found. Many women feel that once they have agreed to testing, they should opt for termination, since otherwise there was little point in undergoing testing."[63]

A 1993 survey of British obstetricians indicates that this sentiment is not unfounded. The survey revealed that a sizable fraction (thirty-four percent) of obstetricians required their patients to "agree to termination of affected pregnancies before they would proceed with amniocentesis;"[64] in other words, willingness to terminate was a prerequisite for prenatal diagnosis. Moreover, "[studies in which genetic counselors were videotaped] revealed a high level of directiveness [non-neutrality] by genetic counselors. Most disturbingly, the level was highest when clients were from lower socio-economic groups."[65] Thus, there is frequently considerable pressure on some parents to opt for termination if the fetus is found to be abnormal.

A key factor that affects the parents' decision of whether or not to abort a disabled fetus is how society views disability and the disabled. There are many kinds of disability, some of which result from infectious disease (poliomyelitis) or accident (spinal cord injury), others of which are from genetic lesions that might have been

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[62]David S. King, "Preimplantation Genetic Diagnosis and the 'New' Eugenics," *Journal of Medical Ethics* 25 (1999): 176–182.

[63]Ibid.

[64]Josephine M. Green, "Obstetricians' Views on Prenatal Diagnosis and Termination of Pregnancy: 1980 Compared with 1993," *British Journal of Obstetrics and Gynaecology* 102 (March 1995): 228–232.

[65]King, "Preimplantation Genetic Diagnosis."

incurred near the time of conception (Down's) or in utero due to environmental factors (fetal alcohol syndrome) or inherited from parents who may be carriers of a genetic disease (Huntington's, Sickle Cell, Tay Sachs). But, what all disabled persons have in common is that they are often viewed as "other" by the so-called "normal" members of society.

One could say that disabled people place burdens on, and are an inconvenience to, families and society. They often bring out fear in others. Henri Nouwen writes that Jean Vanier, founder of a global network of communities for the handicapped called L'Arche, discovered that "[handicapped people] evoke fear in the hearts of those who regard themselves as normal: the 'regulars,' the free, the healthy, the rich, and the successful. [Vanier] saw how they remind us of another reality to be avoided at all costs."[66] Confirming this view is Hugh Gallagher who writes:

> Undoubtedly, present-day feelings about the crippled and the insane are governed, tempered by human concern for their well-being and a sense of fair play. There is, however, an underside to these feelings; the chronically disabled are seen as "other"; as beyond the pale; as being, somehow, a threatening enemy. This is the dark side, which was laid bare by Nazi Germany.[67]

One recoils in horror upon reading about the Nazi extermination programs—the gas chambers, the ovens for burning bodies. What happened there, we think, could never happen here. Probably not.

And yet, what are we thinking when we choose to destroy or abort a nascent human being based on the results of a genetic test? What motivates us to do this? Fear is the most likely reason: fear of having our lifestyle altered by having to care for a disabled person, fear of social disapproval for bringing such a child into the world when it easily could be avoided, and fear of not having the financial resources or energy to provide for the special needs of a handicapped child. There is a kind of downward, back-and-forth interaction between the individual and society at work here. As more people buy into the idea that a disabled life is not worth living, and more parents choose in favor of PND/abortion or PGD, there is less social acceptance of disability, resources dry up, and it becomes increasingly difficult for parents to choose the "keep" the disabled embryo or fetus. Parental choices affect societal views, which affect parental choices. Moreover, people feel the need to justify their opinions about disability, and so turn against those who embody disability—the disabled themselves. Again, the inevitable result of all of this will be that social acceptance of disabled persons will decrease.

Nancy Wexler expresses the common view that it is better to be dead than disabled when, in defense of parents who choose to abort their genetically abnormal fetuses, she writes:

> Parents who use genetic services are not necessarily grocery store 'aficionados,' shopping for the perfect tomato. Rather, they are desperate to protect

[66]Henri J. M. Nouwen, *Lifesigns: Intimacy, Fecundity and Ecstasy in Christian Perspective* (New York: Doubleday, 1986): 32.

[67]Gallagher, *By Trust Betrayed*, 4.

> their children from harm; this may mean terminating a pregnancy before the fetus is viable to prevent later trauma for that child. Some would even argue that not terminating the pregnancy of a genetically impaired fetus, insisting knowingly that the child be born handicapped, is tantamount to child abuse.[68]

Here we find an interesting concept: not killing a person, albeit before he or she is born, might constitute child abuse. Conversely, killing an embryonic or fetal person constitutes protecting him or her from harm. This is a clear example of "mercy-killing" or euthanasia. It reflects the belief so prevalent in our "culture of death"[69] that says that a life of suffering is a life not worth living. Robert Brungs delivers a scathing assessment of this view that is right on the mark:

> In the abortion question, and especially in terms of some recent judicial decisions, we get the strange notion that the right to a quality of life is somehow a more fundamental right than the right to life itself. That the quality of life depends absolutely on the fact of life seems to have escaped notice. Of course, one interpretation of this whole question of the quality of life versus life is that my right to a certain quality of life supersedes someone else's right to life .... [This view] is no more and no less an ethic of profound selfishness.[70]

PGD and the "Culture of Choosiness"

In our consumeristic and competitive society that values "procreative rights," how will it be possible legally to deny parents the right to select, using PGD, whichever traits they wish to have in their children? As the *Roe* v. *Wade* decision that legalized abortion made patently clear, the human embryo or fetus has no legal rights whatsoever.[71] Regarding the impact that *Roe* v. *Wade* will have on emerging genetic technologies, Robert Brungs points out:

> [The Supreme Court, in *Roe* v. *Wade*] says, in effect, that you can be a living human being who is not a legal person, and has no protection under the law. This, equivalently, says that a human being has only that dignity that the State or a social consensus is willing to confer. Until this dignity is conferred, the individual can be treated (or disposed of) arbitrarily. This arbitrariness will be an essential attitude as we tinker with living human systems.[72]

Brungs goes on to say, "if the embryo (or fetus) in utero is not granted protection under the law, if its life is so erasable, why worry about embryos in vitro? And, indeed, without some reverse in the mischievous concepts underlying Roe v. Wade, this worry will decrease."[73] Eventually, we will end up choosing—and if the trend continues—designing our children through germline engineering.

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[68]Nancy S. Wexler, "The Oracle of DNA," in *Molecular Genetics of Neuromuscular Disease*, ed. L. P. Rowland (London: Oxford Univeristy Press, 1989), available at: www.hdfoundation.org/testread/oracle.html.

[69]John Paul II, *Evangelium vitae.*

[70]Robert Brungs, "Human Life vs. Human Personhood," in *What Is a Person*, ed. Michael F. Goodman (Clifton, NJ: Humana Press, 1988): 282.

[71]*Roe* v. *Wade*, 410 U.S. 113 (1973).

[72]Brungs, "Human Life vs. Personhood," 289.

[73]Ibid.

As mentioned earlier, one of the key differences between PGD and PND is that PGD "has no inbuilt brake on its application for the purposes of genetic selection, because it does not involve abortion, with all the physical and emotional trauma which that involves."[74] Furthermore, a likely consequence of the fact that so many embryos (a dozen or so) are available in each IVF cycle will be, as pointed out by David King, "the development of a culture of choosiness: since some embryos must be chosen above others [for implantation], it will appear common sense and 'in the best interest of the child' to pick embryos with the 'best' genetic profile."[75] Thus, eugenic choices on the part of parents will become an order of magnitude easier with PGD compared to PND. And, this "choosiness" will fit in well with our consumeristic mindset.

Germline Engineering is Dangerous and Overtly Eugenic

What sets germline engineering apart from the other two genetic technologies discussed here (PND and PGD) is that it has the power to permanently alter the biological human species. Scientists cite the potential of germline "therapy" for treatment of disease but, as German scientist Stefan F. Winter and others point out, "there is almost no medical need for germline gene 'therapy.'"[76] Why is there no need? Preimplantation genetic diagnosis already is available to screen embryos and select those without "defects," so there is no need to go in and change the gene directly. So, the real application of germline engineering will be for enhancement or improvement of a child's genetic endowment.[77] Germline engineering is more proactive than PGD because it involves parents "designing" their children. It is the ultimate form of eugenics because it gives parents and their doctors the potential literally to shape the future of mankind. This impending ability of people to control the genetic makeup of their descendents brings to mind images of the "Brave New World" described by Aldous Huxley. Drawing on this theme, the biologist Lee M. Silver has predicted that, should germline engineering become more commonplace, there may come a day when the human species becomes divided into two separate species, the GenRich-humans and the Natural-humans, who would have "as much romantic interest in each other as a current human would have for a chimpanzee."[78]

Are we treading on dangerous ground here? Will we be playing God if we attempt germline engineering? The concern about eugenic outcomes with PND and PGD, which are merely selective, is amplified one-thousand fold with germline engineering, which involves direct alteration of the genome in order to "improve" the quality of one's offspring. The concerns are many:

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[74]King, "Preimplantation Genetic Diagnosis."

[75]Ibid.

[76]Stefan F. Winter, "Our Societal Obligation for Keeping Human Nature Untouched," in *Stock and Campbell*, 114.

[77]Ibid.

[78]Lee M. Silver, *Remaking Eden: Cloning and Beyond in a Brave New World* (New York: Avon Books, 1997): 241.

1) Scientific experimentation is based to a certain extent on trial and error. Many "failures" will be required to perfect the germline engineering technology. What will be done with these failures, i.e., the defective embryos to which W. French Anderson referred earlier?[79] Furthermore, a defect does not have to be obvious to be present and to exert a deleterious effect on the health of the "engineered" person. How will the more subtle, but potentially harmful, defects be detected?

2) Related to this is the fact that we do not know how all of our genes are turned on and off in various tissues during different stages of development. We also do not know how all of the proteins produced from these genes interact. It is true that, as high-throughput analysis of proteins and as the discipline of "systems biology"[80] grows, we will have a better understanding of how cellular components all interact. But the picture will never be complete because "the whole is greater than the sum of the parts." There are levels of complexity we will never fully understand. Given that we will never be able to predict with certainty what the outcome of a genetic alteration will be, is it ever okay to play with a person's genetic makeup in this way?

3) What effect will manipulation of the "collective" human genome have on the health and survivability of future generations? The effects of PND and PGD in lowering genetic diversity are discussed below. With germline engineering, the effects will be more dramatic. What if there are unintended consequences of the genetic alteration down the road in future generations? Do we really want to tamper with the integrity of the human genome? We humans are the products of billions of years of evolution, from the time that life first arose on the planet until now. Our genome came to be what it is through intimate contact and dynamic interaction with the web of life on earth. Do we really want to intervene in this process?

4) If germline engineering does manage to succeed without damaging us biologically, what spiritual and psychological effects will it have on us? How will our children feel about being products of our manufacture? How will they feel about being our commodities? It will be *dehumanizing* for them. With regard to this last point, Leon R. Kass, in "The Moral Meaning of Genetic Technology," writes:

> Make no mistake: the price to be paid for producing optimum or even only genetically sound babies will be the transfer of procreation from the home to the laboratory. Increasing control over the product can only be purchased by the increasing depersonalization of the whole process and its coincident transformation into manufacture. Such an arrangement will be profoundly dehumanizing, no matter how genetically good or healthy the resultant children.[81]

C. S. Lewis in *The Abolition of Man* describes what will happen to us if our technological conquest of nature continues unabated and enters the realm of "Man" himself:

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[79]Anderson, "A New Front," 45 and 48.

[80]Leroy Hood, "The Human Genome Project: Launch Pad for Human Genetic Engineering," in *Stock and Campbell*, 19.

[81]Leon R. Kass, "The Moral Meaning of Genetic Technology," *Commentary* 108 (September 1999): 32–38.

> The final stage is come when Man by eugenics, by pre-natal conditioning, and by education and propaganda based on a perfect applied psychology, has obtained full control over himself. *Human* nature will be the last part of Nature to surrender to man. The battle will then be won. We will...be henceforth free to make our species whatever we wish it to be. The battle will indeed be won. But, who, precisely, will have won it? For the power of man to make himself what he pleases means, as we have seen, the power of some men to make other men what *they* please.[82]

Germline engineering, then, is not only overtly eugenic, it is a kind of tyranny inflicted upon future generations. It sets up an inequality between parents, who are the creators, and their "engineered" children, who are the created. It is profoundly immoral and dehumanizing. It could have irreversible and damaging effects on the health of our children. For all of these reasons, I would argue strongly that germline engineering should not be attempted.

Personhood

The issue of whether, and at what stage, a human embryo or fetus is a person is pertinent to the discussion here because, for all three technologies (PND/abortion, PGD, and germline engineering), human embryos or fetuses are destroyed. This issue has been the subject of intense debate for decades. I will not attempt to address it with any rigor here, except to say that the science of human embryology makes it clear that a unique human life begins when an oocyte is fertilized by a sperm to become a human zygote.[83] There is no reason to presume that a human zygote is *not* a person. All arguments that stipulate that a zygote or embryo is not a person are given to justify doing with it (him or her) what one wants. Once personhood is denied a zygote, it is no longer clear where along the process of human development the boundary between non-personhood and personhood should be placed. It becomes arbitrary and according to the interests of the person making the decision. Some will place the boundary at fourteen days post-conception, when the embryonic "primitive streak" is formed and "twinning" is no longer possible. Others will place it at forty days when "quickening" is estimated to occur, or at twenty-one weeks when the fetus is viable outside the womb (this point is constantly being pushed back as neonatal medicine develops), or at birth, or even some time after birth.[84] One can place the boundary here or there, and move it around, depending on what one wants

[82]C. S. Lewis, *The Abolition of Man* (New York: HarperCollins, 1974): 59.

[83]Renée Mirkes gives an excellent and up-to-date discussion of the personhood of the embryo, especially as it relates to the recent debate on embryonic stem cells. (Mirkes, "NBAC and Embryo Ethics," *National Catholic Bioethics Quarterly* 1(2) (Summer 2001): 163–187.) It is generally accepted in human embryology that human life begins at conception. An example of this viewpoint is found in: Jan Langman, *Medical Embryology*, 3rd ed. (Baltimore: Williams and Wilkins, 1975): 3. Langman writes, "[T]he development of a human being begins with fertilization, a process by which two highly specialized cells, the spermatozoon from the male and the oocyte from the female, unite to give rise to a new organism, the zygote."

[84]Peter Singer, in his book, *Writings on an Ethical Life* (New York: HarperCollins, 2000): 162–163, argues that: "If a right to life must be based on the capacity to want to go

to do with the embryo (get stem cells from it) or fetus (obtain fetal tissue). In this way, human beings become commodities for our use.

A unique and refreshing view of personhood comes from the African ethicist Godfrey Tangwa. He discusses the beliefs of his native Nso people of Africa regarding neonatal personhood:

> In Lamnso', there is a saying 'wan dze wan a dze lim Nyuy,' [which means] 'a baby/child is a baby/child, a handiwork of God.' The saying signifies the unconditional acceptance of a neonate, irrespective of how it comes about, no matter how it is, no matter what its particularizing and individuating physical and mental attributes."[85]

He goes on to state, in response to the definition of a person given by Tristram Englehardt as "[an] entity who is self-conscious, rational, free to choose, and in possession of a moral character":[86]

> The morality of an action or procedure is to be determined from the standpoint of the agent rather than that of the patient (the recipient of the action). In other words, a moral agent can do moral good or evil, irrespective of whether the patient of his or her action (or lack thereof) is a person, a non-human animal, a plant, or even an inanimate thing .... Human persons are not morally special, they are morally liable."[87]

This view turns the tables on the usual (Western) approach to the issue of how one should treat others. The usual approach is first to set out to establish the personhood of the recipient of action, then treat him or her accordingly.

Tangwa's way of answering the question "who is a person?" is reminiscent of the way Jesus answers the legal scholar's question "Who is my neighbor?" in the gospel of Luke.[88] Jesus tells the parable of the Good Samaritan, in which it is the Samaritan traveler (not the priest or the Levite) who goes out of his way to care for the man who was robbed, beaten, and left to die on the roadside. After telling the parable, Jesus asks the scholar: "Which of these three, in your opinion, was neighbor to the robbers' victim?" The man answers, "the one who treated him with mercy." Jesus then says to him: "Go and do likewise."

Jesus turns the tables on the question, "Who is my neighbor?" He knows that the legal scholar is asking this question in order to justify excluding certain people

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on living, or on the ability to see oneself as a continuing mental subject [criteria for personhood according to some ethicists], a newborn baby cannot have a right to life .... [A] newborn is not an autonomous being, capable of making choices, and so to kill a newborn baby cannot violate the respect for autonomy .... [T]here should be at least some circumstances in which a full legal right to life comes into force not at birth, but only a short time after birth—perhaps a month."

[85]Godfrey B. Tangwa, "The Traditional African Perspective of a Person: Some Implications for Bioethics," *The Hastings Center Report* 30 (September 2000): 39.

[86]Tristram Englehardt, *The Foundations of Bioethics* (New York: Oxford University Press, 1996): 16.

[87]Tangwa, "The Traditional African Perspective."

[88]Luke 10: 25–37.

whom society considers outcasts or undesirables (Samaritans, prostitutes, the disabled, lepers). He focuses attention on what it means to *be* a neighbor to someone rather than who *is* a neighbor. As Tangwa would say, he takes moral responsibility away from the recipient of action and places it squarely on the agent of action. And, to make his point crystal clear, he chooses a Samaritan, one despised by the Jews, as a model of compassion. The message is clear: we are all equal in God's eyes, everyone is our neighbor, and we are to be neighbor to everyone.

In the parable of the Good Samaritan, the Samaritan "approaches the victim" lying in the ditch on the side of the road. It is when we "approach" or "go over" to people different from ourselves and connect with them on a human level that we are able to respond with compassion to them. When we do this, something miraculous happens: divisions fall and the "other" becomes "one of us." Gail H. Landsman, in chronicling the stories of mothers of disabled children, found that: "Unifying the apparently conflicting stories of sorrow and hope, of pain and enrichment, is the acquired knowledge that humanity is found in forms different from those that might once have seemed acceptable or bearable."[89] Landsman further writes: "Who is to judge the real value of a person? Her retarded child, [the mother of a profoundly retarded boy] speculates, was sent to her to remind her of what really matters in life, and through him she sees ... others in a new light."[90]

These mothers and their handicapped children have much to teach us about what really matters in life. Landsman says: "it is the child's ability to give and receive love that appears most often in [the mothers'] narratives as a defining feature of his or her humanity."[91] Thus, it is not the presence of the right or a perfect genetic makeup that qualifies us for membership in the human family; it is the capacity to give and receive love, a capacity we all have. Besides, each of us is a whole person in possession of a human genome—this should be qualification enough.

Reductionism, Organicism, and Human Genetic Diversity

It is a belief in reductionism, which postulates that an object can be understood by analyzing the sum total of its components, that is behind the genetic deterministic notion that genes determine our behavior and are the carriers of our destiny. According to reductionism, "as soon as one has completed the inventory of these components [molecules, genes, whatever] and has determined the function of each of them, it should be an easy task to explain also everything observed at the higher levels of organization."[92] The problem with this belief, says biologist Ernst Mayr, is that: "Living organisms form a hierarchy of ever more complex systems, from molecules, cells and tissues through the whole organism, populations and species. In each higher

[89]Gail H. Landsman, "Reconstructing Motherhood in the Age of 'Perfect' Babies: Mothers of Infants and Toddlers with Disabilities," *Signs* 24(1) Autumn 1998): 69.

[90]Ibid.

[91]Ibid.

[92]Ernst Mayr, *This is Biology: The Science of the Living World* (Cambridge, MA: Harvard Univesity Press, 1997): 17.

system, characteristics emerge that could not have been predicted from knowledge of the components."[93] Thus, reductionism is inadequate to explain living systems.

A competing paradigm for the understanding of living organisms is *organicism*, which holds that "[every] system, every integron loses some of its characteristics when taken apart, and many of the important interactions of the components of an organism do not occur at the physiological level but at a higher level of integration."[94] Thus, a multiplicity of perspectives is needed to begin to understand the nature of a complex organism such as a human being.

As a species, humans have evolved by means of natural selection acting on spontaneous mutations that arise in the genome. Some genetic mutations are deleterious in the sense that they cause expression of defective versions of proteins. This can cause disease. An example is sickle cell anemia caused by a defective version of the oxygen-binding protein hemoglobin. In this case, and in the cases of other monogenic diseases such as cystic fibrosis, Tay Sachs, and Phenylketonuria, to name a few, the origin of the disease in a particular genetic mutation is irrefutable. Putting aside the issue of the personhood of the embryo, it might seem from a public health point of view that it is a good thing, therefore, to rid the human population of genetic mutations known to cause disease, especially those for which a cause and effect relationship is clear. But, we have to ask: Is it wise for us to tamper with the collective genetic inheritance of our species? One could argue that this is a legitimate concern, that it is unwise for us to tamper with our collective genetic inheritance, whether directly through germline engineering or indirectly by using PND and PGD. Indeed, Alison Morse argues that, "eugenic choices affect the pool of diversity on which a healthy species depends. Excluding certain traits from the human population not only raises ethical issues for the individual, but also can affect a baseline of genetic diversity in the human species."[95]

With respect to protecting human genetic diversity, two points are in order. First, the definition of "good" and "bad" traits is tied to a particular culture, and culture is dependent on its environment. The sickle cell trait may be "bad" in our society in which malaria is currently uncommon. But, in Central and Western Africa, having the sickle-cell trait in heterozygous form, i.e., being a carrier, is definitely "good" because it provides immunity to malaria. Moreover, if northern-latitude climates were to change and become more tropical, as well could happen if global warming continues unabated, this very trait we seek to eliminate could prove to be advantageous. The point is that it is impossible to gaze into the evolutionary future and see which traits will be "good" and which will be "bad."[96] The second point is that mutations do not arise in a vacuum. Other genetic traits that are correlated with a so-called disease gene may prove to advantageous for our species, either now or in

[93]Ibid., xii.

[94]Ibid., 20.

[95]Allison Morse, "Searching for the Holy Grail: The Human Genome Project and Its Implications," *Journal of Law and Health* 13(2) (Summer 1998): 219.

[96]Ibid.

the future. This point highlights again the problem associated with a reductionist view of human biology, which is that the whole is greater than the sum of its parts. We do not know how this particular gene interacts with that inside the human body. Thus, from a biological and population genetic point of view, eugenics is unwise.[97]

There is an emerging system of thought in environmental science that says that natural disasters happen when ecological balance is upset, when natural laws are broken by human technological interference.[98] This system of thought can be applied to human populations as well. Just as we must be careful to protect the environment and preserve biodiversity for present and future robust health of our living planet, so also we must protect our collective genetic inheritance and preserve human genetic diversity by avoiding eugenic interference. This thinking represents a kind of eugenics in reverse. It recognizes the vital importance of genes for the future of mankind, but rather than seeking to eliminate "defective" genes as does eugenics, it seeks to preserve the genetic diversity that arises naturally.

Eugenics and Social Justice

The link between human beings and the natural world is not just metaphorical—it is actual. The human species, and with us, our genome, is the product of millions of years of complex and intimate interaction with the natural world around us. How can we begin to understand the complexity of this interaction and, by extension, our own complexity? That which affects our natural world affects us. The same natural laws apply to all of creation. There is a profound interdependency among all living things, including ourselves. We are all part of the same organic fabric of life. Michael W. Fox writes about the sanctity of nature and our connection with the earth:

> To be human means to be part of the whole, part holy, part humus. We cease to be well and to be human when we wantonly destroy the whole and when our chauvinism defiles all that is holy, including our own humanity. So to be human means to realize the divinity of nature and self, and to be mindful of the God in all, as we are all in God.[99]

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[97]Purging the sickle cell trait from the human population is unwise from a human genetic diversity point of view. However, this does not imply that treatments for sickle cell anemia should not be vigorously sought. On the contrary, this is where medical attention should be focused. It is also worthwhile to reiterate that there is no way to purge humanity of the sickle cell trait without destroying the persons, as embryos or fetuses, who carry it.

[98]This hypothesis is being advanced, in part, by Alan Wexelblat, an MIT-trained computer engineer who analyzes the interaction between human technology and nature. "Wexelblat's Law" is explained as follows by Wexelblat himself: "You build a technological system, then overexploit natural conditions, and Mother Nature takes revenge." (Joel Garreau, "Nature's Revenge," *The Washington Post,* September 2, 2001.)

[99]Michael W. Fox, *Beyond Evolution: The Genetically Altered Future of Plants, Animals, the Earth and Humans* (New York: The Lyons Press, 1999): 218–219.

In this same vein, the "land ethic" of Aldo Leopold reflects a reverence for the natural world and a deep appreciation of the interconnectedness of all creatures that depend on the land:

> Each species, including ourselves, is a link in many [food] chains. The deer eats a hundred plants other than oak, and the cow a hundred plants other than corn. Both, then, are links in a hundred chains. The pyramid [of life] is a tangle of chains so complex as to seem disorderly, yet the stability of the system proves it to be a highly organized structure. Its functioning depends on the cooperation and competition of its diverse parts.[100]

This same appreciation of the deep interdependence and interconnectedness among all living creatures is expressed by Leonardo Boff in his book *Ecology and Liberation: A New Paradigm*:

> Ecology reaffirms the interdependence of beings, interprets all hierarchies as a matter of function, and repudiates the so-called right of the strongest. All creatures manifest and possess their own relative autonomy; nothing is superfluous or marginal. All being constitutes a link in the vast cosmic chain. As Christians, we may say that it comes from God and returns to God.[101]

What we find in the "land ethic" and "deep ecology" branches of environmental ethics is a profound respect for nature in all of its diversity. All are valued; nothing is "superfluous or marginal." It is this profound respect for diversity and the value placed on the individual that we must borrow from environmental ethics in order to understand how to respond to those among us who are disabled, whom some seek to destroy when they are embryos or fetuses. Using the body as an analogy, St. Paul, in one of his letters to the Corinthians, writes about how each person is important:

> [A]s it is, God placed the parts, each one of them, in the body as he intended. If they were all one part, where would the body be? But as it is, there are many parts, yet one body. The eye cannot say the hand, "I do not need you," nor again the head to the feet, "I do not need you." Indeed, the parts of the body that seem to be weaker are all the more necessary ... God has so constructed the body as to give greater honor to a part that is without it, so that there may be no division in the body, but that the parts may have the same concern for one another. If [one] part suffers, all the parts suffer with it; if one part is honored, all the parts share its joy.[102]

It is St. Francis of Assisi who, like no other, appreciated the sanctity of nature. He reverenced all natural things, animate and inanimate. He spoke of Brother Fire and Sister Water, and wrote the beautiful Canticle of Brother Sun (Canticle of Creatures). On one occasion, he preached to a flock of birds, and there are many stories of his friendships with all sorts of animals: a rabbit, a kingfisher, a fish, a pheasant, a

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[100]Aldo Leopold, *The Sand County Almanac* (New York: Ballantine Books, 1970): 252–253.

[101]Leonardo Boff, *Ecology and Liberation: a New Paradigm* (Maryknoll, NY: Orbis, 1995): 7.

[102]1 Corinthians 12: 12–25.

cicada, a sheep and a wolf, to name a few.[103] Such a deep and personal relationship with nature, and more particularly, with each living thing and natural object (rocks, water), is something that is beyond our comprehension. Omer Englebert writes:

> Because everything comes from the same source, Francis sensed the kinship which exists between men, animals, plants, the sea and the stars....Did not Christ Himself speak of the goodness of the Heavenly Father who gives the sparrow its food and the lily of the fields its brilliant garb? ... [N]o one in the West ever experienced or expressed as did St. Francis such a feeling of the universal brotherhood of all creation."[104]

It goes without saying that the deep respect and reverence that St. Francis had for all living creatures and natural objects extended to people as well.

G. K. Chesterton writes of St. Francis:

> He honored all men; that is, he not only loved but respected them all. What gave him his extraordinary personal power was this; that from the Pope to the beggar, from the sultan of Syria in his pavilion to the ragged robbers crawling out of the wood, there was never a man who looked into those brown burning eyes without being certain that Francis Bernardone was really interested in *him*; in his own inner individual life from the cradle to the grave; that he himself was being valued and taken seriously ...[105]

This is the example we are called to follow; this is how we must act toward each individual member of the human family.

Each person is unique and indispensable in the complex web of human society. Every person's life is worth living. We must reject a reductionist view of humanity which says that our genes determine what we do and who we are. Likewise, we must reject eugenics, which says that our worth is genetically determined. Instead, we must embrace a holistic, ecological view of humanity, which says that all of our lives are interdependent and valuable, and proclaims that every person has the right to exist and to live. Made "in the image of God"[106] and born of the earth, mysteriously both spiritual and natural, each of us is "wonderfully made."[107] God created our world out of Love; it is the law of Love that rules all of creation. This law of Nature, the law of Love, is "written upon our hearts."[108] Following our hearts, we must, like the Good Samaritan, put aside our fear and find the courage to "go over" to those who are different—the disabled, the marginalized, the poor. For, this really is what it means to be human.

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[103]Omer Englebert, *St. Francis of Assisi: A Biography* (Ann Arbor: Servant Books, 1979): 135.

[104]Ibid., 133.

[105]G. K. Chesterton, *Saint Francis of Assisi* (New York: Image Books, 1990): 96–97.

[106]Genesis 1: 26–27.

[107]Psalms 139: 13–16.

[108]Jeremiah 31: 33.