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The Sophistication of Ellis Island in Prenatal Diagnosis with Subsequent "Selective Termination" of Babies with Disabilities

by

Mr. Adam J. Hildebrand

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"Give me your tired, your poor, your huddled masses yearning to breathe free..." - Emma Lazarus

Those words, inscribed in the base of the Statue of Liberty, have caused many hearts to swell with feelings of dignity and hope. The concept of America as a "melting pot" suggests that all people are welcome, all people have inherent value and worth as human beings. The most memorable words of our Declaration of Independence state that *all* people have the "right to life, liberty, and the pursuit of happiness." During the founding of our country, people fled the tyranny and poverty of their homelands to find their destiny – a better life. Indeed, millions of people *did* find a better life for themselves in a democratic, free society.

Between 1900 and 1914, the vast majority of immigrants to the United States came through Ellis Island, a processing center through which millions of immigrants passed before stepping onto American shores. Yet for some people, what they experienced at Ellis Island was bitter

disappointment and rejection. Some people were not permitted on our shores, and were deported to an unknown fate. The numbers of people refused entry at Ellis Island, roughly categorized as "undesirables," varied greatly during the first thirty years of the twentieth century. These included people with "communicable diseases, anarchists, criminals, lunatics, people with mental problems, the mentally deficient, the lame, and cripples." In one year, 1907, more than a million immigrants were "processed" at Ellis Island. Of this number, approximately 9,600 were turned back. While this is a small percentage, less than one percent, numbers alone do not tell the whole story. As one author, Bill Severn, noted, "statistics are a bloodless thing." He explains:

To find the human side of immigration, you had to climb the steps of the Great Hall (at Ellis Island) to talk to one of the "undesirables." Many had saved a few pennies a day and gone without meals to pay the steerage ticket. One such story involved a sixteen-year-old Russian boy – a cripple who could not earn a living in the fields at home. He was sent to the United States by an uncle with a letter attached explaining his situation. When he was interviewed, he made the following statement:

I stood on the front of the ship with several of my fellow-countrymen who like me were bound for America. As we came closer to the shore my joy knew no bounds. I was soon to be in a land where my race in not persecuted. I heard of this gold that could be had for the asking, and I longed to gather some of it and return to my old parents in Russia. Now they tell me I must return home, for they cannot find my uncle, and furthermore, cripples like me are not wanted here.⁵

On hearing this, the immigrant inspector said, "Hunchy (referring to the crippled boy) is clean loco."

The focus of this article is not to argue the merits or demerits of immigration policies, but to suggest that human societies have historically excluded certain people from participation or even membership based on the presence of disability. One of the major reasons for such exclusion is that people with disabilities are very often viewed as people who, for one reason or another, might become (or become perceived as) an "economic burden" to the state. Coupled with Darwin's concept of "survival of the fittest," it is the "unfit" who are most likely to be excluded from participation or even presence in society.

In modern society, we have much more sophisticated methods for screening out and rejecting the "unfit." Modern science has developed methods of eliminating the "unfit" before they are even born, through the prenatal diagnosis of congenital abnormalities with the intention of "selective termination" (abortion) of unborn babies with disabilities. In this paper, I will demonstrate that the practice of aborting "unfit" babies has its roots in eugenic thought, and I will discuss how we have deceived ourselves through unconsciousness, subtle dynamics that demonstrate a disregard for the inherent dignity of every human life. I will also discuss how we use language to detoxify and obscure the reality of aborting babies with disabilities. I will examine these topics in light of Catholic moral teaching on the dignity of the human person, and the inestimable value and sanctity of human life.

The Purposes of Prenatal Diagnosis

Prenatal diagnosis is the examination and analysis of the status of an unborn baby, with the purpose of monitoring human embryonic development, and of detecting virtually thousands of abnormalities in utero.⁸ Currently the major methods of prenatal diagnosis include:⁹

- 1. Amniocentesis, which involves the withdrawal of amniotic fluid from the amniotic sac for analysis. Usually performed around 15 to 16 weeks gestation, amniocentesis is routinely performed on older pregnant women (over 35) who may have greater risks to "genetic defects."
- 2. Chorionic villus sampling (CVS), the biopsy or sampling of the developing placenta (chorion) in which 10-25 mg. of fetal chorionic villi are aspirated transcervically or transabdominally.
- 3. *Ultrasound diagnosis*, a method of visualizing the placenta, embryonic membranes, and the embryo or fetus using high resolution machines.
- 4. Fetal tissue sampling, the removal of a small sample of fetal tissue to detect a variety of anomalies or pathologies.
- 5. Maternal Serum Alpha-Fetoprotein Screening (MSAFP), an analysis of amniotic fluid used to detect neural tube defects, such as spina bifida and meroanencephaly.
- 6. *Maternal blood sampling*, the analysis of a pregnant woman's blood to detect genetic defects and metabolic abnormalities of the unborn child.

Also, there are a relatively small number of therapeutic procedures

currently being developed for treating anomalies in utero, including medical therapy, fetal surgery, dietary supplements, and gene therapy. 10, 11

There are valid, moral, and good purposes for prenatal diagnosis. The Congregation for the Doctrine of the Faith of the Roman Catholic Church (1987) addressed this issue: "Is prenatal diagnosis morally licit? If prenatal diagnosis respects the life and integrity of the embryo and the human fetus and is directed towards its safeguarding or healing as an individual, then the answer is affirmative." The morality of prenatal diagnosis, then, depends on the intention and purpose of the procedures employed and whether or not disproportionate risks are involved.

Catholic moral teaching recognizes that there are legitimate purposes for prenatal diagnosis. The Instruction cited above further states: "Prenatal diagnosis makes it possible to know the condition of the embryo and of the fetus when still in the mother's womb. It permits, or makes possible to anticipate earlier and more effectively, certain therapeutic, medical, or moral procedures." Alfred Cioffi outlined the valid and moral purposes of prenatal diagnosis as follows:

If the diagnosis is a true positive one, it may also be instrumental in providing for a better pregnancy management in several ways. First, depending on the type and degree of the anomaly, it helps the physician to enter into dialogue with the parents (the mother), and if an adequate cure is presently available, either eliminate the defect entirely, or to diminish it significantly. Second, it allows the physician to determine whether or not an early delivery is advantageous...Third, it can help the parents in planning for the eventual delivery of a child with some birth defect. ¹⁴

By "eliminate the defect," Cioffi is not suggesting that the defect be "eliminated" by eliminating the baby. One does not cure a disease by killing the patient. Cioffi's principle thesis is that the unborn baby who has a genetic defect is a *patient* (the title of his book is *The Fetus as Medical Patient*, see reference 8).

Rejection of the "Unfit"

While there are valid purposes for prenatal diagnosis, the Congregation for the Doctrine of the Faith Instruction (1987) further states: "[prenatal diagnosis] is gravely opposed to the moral law when it is done with the thought of possibly inducing an abortion depending on the results." Pope John Paul II (1995), in his encyclical *Evangelium Vitae* (The Gospel of Life), clearly summarized the issues of prenatal diagnosis and "selective termination":

Special attention must be given to evaluating the morality of prenatal diagnostic techniques which enable the early detection of possible anomalies in the unborn child. In view of the complexity of these techniques, an accurate and systematic moral judgment is necessary. When they do not involve disproportionate risks for 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, 16 these techniques are morally licit. But since the possibilities of prenatal therapy are today still limited, it not infrequently happens that these techniques are used with a eugenic [my emphasis] intention which accepts selective abortion in order to prevent the birth of children affected by various types Such an attitude is shameful and utterly of anomalies. reprehensible, since it presumes to measure the value of a human life within the parameters of "normality" and physical well-being, thus opening up the way to legitimizing infanticide and euthanasia as well 17

When the intention of prenatal diagnosis is to identify and destroy unborn babies with disabilities, we as a society and as individuals are succumbing to eugenic thinking with a disregard for human life. The "selection" and subsequent "termination" of an unborn baby with disabilities, at least in some respects, is a modern, sophisticated version of the rejection of the "undesirables" at Ellis Island, all in the name of choice and liberty.

In order to compare the screening and deportation of immigrants with the prenatal diagnosis and "selective termination" of unborn babies with disabilities, let us examine what happened at Ellis Island. One of the very functions of Ellis Island was to screen certain individuals from admittance. Barbara Benton described this screening process as follows:

Special effort was made to detect idiots, imbeciles, epileptics, the feeble-minded, the senile, and the insane - all excludable by law. During inspection "inattentive" or "stupid-looking" persons would be asked in various languages to state age, destination, and nationality or to do simple sums or multiplication. Failure to answer correctly was sufficient to have an immigrant marked "X" (with a chalk mark) and detained for mental examination. The *medical inspectors* [my emphasis] at Ellis bore an overwhelming responsibility in determining the state of health of as many as 5,000 immigrants daily, and their opinions led to a great many deportations.¹⁸

There are a number of parallels between the screening and deportation of immigrants at Ellis Island and prenatal diagnosis with subsequent

"selective termination" of people with disabilities:

- 1. The deportation of "undesirables" and the "selective termination" of unborn babies with disabilities both entail rejection based upon the presence of a devalued characteristic of the person.
- 2. Both entail methods of "screening."
- 3. In both instances, there is a "marking" of persons, one with chalk, the other with high technology and sophisticated language.
- 4. There is a "barring of admittance" in both actions.
- 5. The nature of the decision to deport or "terminate" are both grave decisions, in that they are either life-defining (as it defines where one will live) or life-denying (whether one will live at all).
- 6. Members of the medical profession helped select people to deport, and now help select people for "selective termination."
- 7. Eugenic thinking has a significant (though usually unconscious) influence in both actions.
- 8. The notion of "economic burden" is a powerful dynamic in both situations.
- 9. The government directly operated Ellis Island, and governments of some nations are becoming increasingly involved in funding genetics services which provide prenatal diagnoses.
- 10. In both instances, the perceived value of persons is diminished.

Some aspects of the dynamics above in and of themselves may not necessarily be immoral. For instance, some forms of "screening" may have legitimate puposes in other contexts. However, when these dynamics combine and interact, the devaluation of human life is at work. Even so, the Ellis Island metaphor, like all metaphors, is limited. People at Ellis Island were deported rather than killed. The screening of people at Ellis Island also involved "born" persons, while prenatal diagnosis obviously involves unborn persons – though Catholic moral teaching is clear that unborn babies *are* persons (more on this later). Another difference is that at least at present, the screening at Ellis Island involved a wider variety of

"anomalies" than the genetic "defects" in "selective termination." However, there is potential for knowledge gained through the Human Genome Project¹⁹ to yield information that could indicate other "reasons" for "selective termination." Indeed, "sex selection" through prenatal diagnosis, while currently outside of the current secular "moral consensus" in western societies, may be a precursor of things to come. Dorothy C. Wertz and John C. Fletcher have pointed out that:

Examining the ethical arguments on sex selection through prenatal diagnosis and their implications for social policy is now an urgent task for three reasons: (1) Recent data suggests that physicians in the U.S. and some other nations may comply with prenatal requests for sex selection. (2) advances in genetic knowledge, such as international projects to map the human genome, beg a question whether sex selection is a precendent for direct genetic "tinkering" having little or nothing to do with disease.²⁰

Perhaps the clearest parallel between Ellis Island and "selective termination" is the perception of people with disabilities as "burdens." The primary conscious rationale for barring admittance to "mental defectives" was economic. As Benton observed, "the central issue was whether or not a person was likely to become a public charge. If detained for medical reasons, the question was whether or not the immigrant could be expected to recover sufficiently from the disability in order to avoid becoming a charity case." ²¹

The rejection of people with disabilities who would or might become "burdens" to the state stems from a utilitarian world view. In this view, the value of persons is measured by their productivity or "usefulness" to society. People with disabilities who may need additional support from society thus become perceived as a "drain" on the resources of the state. This perception still exists, in that the societal benefits of prenatal diagnosis with subsequent "selective termination" can be construed as relieving the economic "burden" of caring for babies with disabilities. Kenneth L. Garver and Bettylee Garver have expressed concern that clinical genetics is being subjected to pressures to become "cost-effective" by decreasing the numbers of people born with disabilities. They state:

Another concern is the increased pressure to make clinical genetics and genetic counseling cost-effective. There have been demands in Great Britain to audit genetics services; it has been suggested that for a genetics clinic to be funded, it should demonstrate that the birth prevalence of a particular disease or

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malformation is declining and the termination of pregnancies, because of that disease, is increasing in the population.²²

Xin Mao, in a recent article that discusses ethical issues in genetic services, has observed:

In the Netherlands seven regional clinical genetics centers involved in pre- and postnatal chromosome analysis, biochemical and DNA diagnosis, and genetic counseling supported by the national health insurers cost (approximately) \$50 million per year. As a result of their combined activities, the birth of 600 to 1600 severely handicapped children is avoided every year. The costs of their medical and psychosocial care would have been \$500 million to \$1 billion during an average life span of 10 years.²³

The economic burden image appears over and over again in human history, and had a major role in justifying the early German euthanasia program. In the treatise *The Release of the Destruction of Life Devoid of Value*, Professors Karl Binding and Alfred Hoche made the following statements in 1920:

Concerning the economy, those full idiots are imposing the greatest burden on the environment and society while at the same time they are serviced by persons who are able to live a normal life...I have found that the average expenditure per idiot person for a year is 1,300 marks. If we add up all of the idiots, they number 20,000 to 30,000. If we take an average life span of 60 years, we can calculate how much capital in the form of food, clothing, energy and national resources is deducted for an unproductive purpose...The question of whether we should spend all of this money an *ballast type persons* [my emphasis] of no value was not important in previous years because the state had sufficient money.²⁴

Lest we think that this rather crude analysis is something of the past, in its *Guide to Clinical Preventive Services: Screening for Down's Syndrome*, the U.S. Preventive Services Task Force of the National Institute of Health (NIH) makes the following statement (in 1997) under a section entitled "Burden of Suffering": "Based on 1988 cross-sectional data, the lifetime economic costs of Down's syndrome have been estimated at \$410,000 per case." While the NIH does not explicitly promote "selective termination" of babies with Down syndrome, the evaluation of their lives in dollars and cents, coupled with a "burden of suffering" image,

suggests that it is undesirable and much too costly to raise a child with Down syndrome.

Binding and Hoche helped pave the way for the elimination of "undesirables" in pre-Nazi Germany, as in their minds, the interest of the state versus the interests of the individual were explicitly at stake:

We have neglected to see the state as an organism with its laws and rules, in a manner similar to the way we look at a human organism. We doctors know that in the interest of the whole human organism, single, less valuable members have to be abandoned and pushed out.²⁶

Kenneth L. Garver has commented on Michael R. LaChat's article (published in 1975 in *The Linacre Quarterly*) in which LaChat described "how the German physicians changed from being physicians to the people in the early twentieth century, until, by 1930, they became physicians of the state. In other words, their concerns focused on the worth of individuals to the State."^{27, 28} In a more recent article in *Ethics and Medics*, Edward J. Furton raises serious questions and concerns regarding the future role of government and the "elimination of genetic defects":

Should governments approach the elimination of genetic defects as they have the elimination of infectious diseases?...Will parents who refuse to have an abortion to eliminate their "defective" children be denied health insurance in the future? More broadly, will government impose penalties on those who refuse to participate in the elimination of defective genes from the gene pool?²⁹

The interests of the state must not categorically override the interests of the individual. A society that does not respect the interests of individuals is in danger of tyranny. One of the primary functions of society is to enable individuals to pursue their rights to life, liberty, and the pursuit of happiness. The Congregation for the Doctrine of the Faith recognized the danger of placing the interests of the state over and above the interests of the individual when it concluded:

In conclusion, any directive or programme of the civil or health authorities or of scientific organizations which in any way were to favour a link between prenatal diagnosis and abortion, or which were to go as far as directly to induce expectant mothers to submit to prenatal diagnosis planned for the purpose of eliminating fetuses which are affected by malformations or which are carriers of hereditary illness, is to be condemned as a

violation of the child's right to life and as an abuse of the prior rights and duties of the spouses.³⁰

Again, sometimes there are good reasons for prenatal diagnosis. When the intention is to defend and preserve life, prenatal diagnosis can not only be helpful, but may at times be essential to protecting vulnerable human beings. However, given the legal status and broad acceptance of abortion, prenatal diagnosis is commonly employed with a "search and destroy" motivation. After all, screening is screening – some people pass through the "screen," others do not.³¹ The nature of the screen, and the methods of screening for anomalies among unborn babies, have become clothed in medical jargon and high technology. Whether one is rejected after traversing the "watery womb" of the high seas in hopes of a better life, or if one is an unborn child in its mother's watery womb, awaiting life itself, the defining issue is the same: people with disabilities are not seen as having the same value as other persons.

The predominant theme in contemporary medical ethics is that the prenatal diagnosis of abnormalities with the *intention* of offering "selective termination" as an alternative to bearing a "defective" child is becoming increasingly acceptable. Indeed, some people consider such "intervention" advisable. Dorothy Wertz has noted that:

...philosopher Dan Brock of the Bioethics Department of Brown University, Providence, RI, believes that under some circumstances a woman has a moral duty to have prenatal diagnosis and abort the fetus. Such cases would presumably be limited, according to Brock, to cases where the child would have a poor quality of life and die very early, as in anencephaly, Trisomy 13, and Tay-Sachs disease. Brock says that in these cases "the disease or condition is so harmful and irremediable that it makes the child's life not worth living." 32

A review of the literature shows that the vast majority of people decide to "selectively terminate" their unborn children once there is a determination of fetal abnormality through prenatal diagnosis:

- 1. Thomasa (1996) in *Medical Ethics*: "In spite of promising developments, in the overwhelming majority of cases of fetal abnormality, virtually the only significant medical intervention is abortion." ³³
- 2. Elizabeth Kristol (1993) in *First Things*: "In England, the journal *Prenatal Diagnosis* reported one regional study in which abortions after a diagnosis of neural-tube defects led to an 86 percent reduction in the birth

of individuals with these disorders. The authors concluded that 'the success of the program in medical terms is apparent'."³⁴

- 3. Simpson and Elias (1993), authors of the text, *Prenatal Diagnosis*: "Prenatal diagnosis of genetic disease with selective termination of affected pregnancies is the accepted preventive medical application of contemporary medical genetics." ³⁵
- 4. Furton (1998) notes that Christine Eng, M.D., Assistant Professor at the Mt. Sinai School of Medicine, reported on the large-scale willingness of Ashkenazi Jews (84%) to use abortion to eliminate children who are discovered in utero to have a genetic disease.³⁶
- 5. Cioffi (1995) in *The Fetus as Medical Patient*: "Of the expectant mothers who are informed of carrying a child with some birth defect, over 90% have an abortion."³⁷
- 6. Since 1984, screening for Down syndrome has become routine for pregnant women over age 35. The screening has been so "effective" that more recently, a study in 1992 found that 80% of children with Down syndrome are now born in women less than 35 years of age. The study noted that "effective prenatal screening for women in this low-risk group would be highly desirable." 38

Unconscious Assumptions

Why do so many people decide to abort their babies with disabilities? The dynamics that lead to the abortion of unborn babies with disabilities can be very subtle, and stem from unconscious motivations. Usually such decisions are made without full explication of the reasons behind the decision. Sigmund Freud, in his seminal work on the concepts of repression and unconsciousness, stated that:

The essence of the process of repression lies, not in abrogating the ideational presentation of an instinct, but in withholding it from becoming conscious. We then say of the idea that it is in a state of unconsciousness, of being not apprehended by the conscious mind, and we can produce convincing proofs to show that unconsciously it can also produce effects, even of a kind that finally penetrate to consciousness.³⁹

Sometimes unconscious assumptions conflict with what people think they

believe. When people harbor negative feelings and assumptions deep within their hearts about a person or group, and when their conscious minds aspire to nobler values, there is a conflict between what the mind thinks and what the heart feels. Wolf Wolfensberger has observed that negative sentiments and assumptions about people with disabilities are often driven into the unconscious. For example, one might *think* of persons with disabilities as having inherent value and are fully human just like everyone else. Yet, in one's heart of hearts, there may be unspoken or unconscious sentiments that make one "feel" that a person with a disability would be better off dead, and perhaps should never have been, or should never be, born.

When such powerful conflicts exist, words may not express what is really meant. The mind may not fully register what the "heart" feels. In the words of Jesus, "the things that come out of the mouth come from the heart, and they defile. For from the heart come evil thoughts..." Mt. 15:18-19. Unconscious assumptions often find expression in words and actions that convey meanings that are very subtle, yet powerful. When people hold deeply negative assumptions about the value and worth of people with disabilities, their words (and even their thoughts) may only partly convey the true meaning of what is intended, or what is true. These subtle or partial messages can cloud the mind and allow people to use words that are very harmful, and sometimes, deadly. For example, if certain groups of people are "felt" to be less worthy, inconvenient, burdensome, and subhuman, while it may not consciously be acknowledged, people may in their hearts question whether such persons would be better off dead.

Because such negative assumptions are usually unconscious, a doctor may not stand in the hospital corridor or examination room and consciously think, "People with disabilities have no value and therefore should be killed," or "A deformed child is not a human being and does not deserve to live." These assumptions, usually suppressed and repressed into the unconscious, can express themselves through more subtle feelings deep within the human "heart", within the soul's consciousness, if you will. These deeply embedded negative values can be understood as "killing thoughts." From a spiritual perspective, "killing thoughts" derive from an evil domain, a domain in which demonic forces seek out and perpetrate the destruction of life, the confusion of minds, and the darkness of souls.

Evil Thoughts Lead to Evil Words; Evil Words Lead to Evil Actions

When people describe other people about whom they hold unconscious assumptions, they often "detoxify" certain words. That is,

they deceive themselves into thinking that those words have innocuous or benign meaning, and thus the real meaning is obscured. Words can therefore disguise reality and allow people to think that what is happening is not really happening. Words like "selective termination", "prevention of disease", "terminating a pregnancy", "removing tissue", "evacuating the uterus", and the like hide the reality that aborting a baby with disabilities, or any baby, is a killing act.

Sometimes it is helpful to use words that may not have common usage, but which help clarify reality. I propose that the word "obfuscation" captures the essence of the dynamics described above. Webster's New World Dictionary defines "obfuscate" as: "1) to cloud over, obscure, make dark or unclear; 2) to muddle, confuse, bewilder." The Random House Dictionary of the English Language (unabridged) defines "obfuscate" as: "1) to confuse, bewilder, stupefy; 2) to make obscure; 3) to darken."

The noun "obfuscation" means the *process* of making a reality unclear, muddled, and dark. One might say that confusion and deception are the hallmarks of obfuscation. It is a process of distorting reality and hiding the truth. In the spiritual domain, obfuscation that leads to deception, destruction of life, and other harmful dynamics is a function of evil. Obfuscation, then, is the opposite of clarification – a more widely used and more understandable word, which means to clarify, to make clear, to make easier to understand. Margot Hentoff applied the concept of obfuscation to abortion in an article written in 1975 entitled "Let's Stop Deceiving Ourselves About Abortion." In the article, Hentoff stated:

Here we have one of the problems created by the liberal community's *obfuscation* [my emphasis] of language in refusing to speak plainly about what abortion is. They have held on to the illogical concept that the fetus is not a human being, that no killing is involved, and that the abortion is merely an operative procedure on a woman who has the right to decide what she wants to do with her body and the products thereof.⁴³

Human beings have become very sophisticated in the use of language. However, through "sophistication" it is possible to lose contact with reality. The reality behind some of the words often used to describe abortion and "selective termination of genetic defects," shows that words can conceal, rather than reveal, the truth (see Table page 60).

Where has our sophisticated use of language taken us? Interestingly, the root meaning of the word "sophistication" is derived from the Sophists who were a class of teachers and orators in Greece around 500 B.C. James Evans described the Sophists as follows (*please see p. 59*):

The Words

The Definitions

The Reality

CHOICE

"1) The act of choosing; selection; 2) the right, power, or chance to choose; option; 4) the best or most preferable part." 44

The "choice" that a pregnant woman is presented with is a decision to kill her child. This decision is not a "choice" for the baby, but a death sentence.

BEING PREGNANT

"The condition or quality or period of being pregnant." Pregnant" is defined as "1) having (an) offspring developing in the uterus; 2) with young or with child." 45 Being pregnant does not mean that a woman is going to have a baby. The state of "being pregnant" means that a woman already has a baby - at an earlier stage of development.

TERMINATE A PREGNANCY

"Terminate" means:
"1) to bring an end in space or time; 2) the end or conclusion of; 3) limit, bound, finish, or conclude."46

To "terminate" a pregnancy means having a baby killed by injecting a saline solution that causes severe chemical burns, and/or tearing the baby's body apart limb from limb.

GENETIC DEFECT

"Genetic" is defined as "of the genesis or origin of something." "Defect" is defined as "1) lack of something necessary for completeness: deficiency. shortcoming; 2) an imperfection or weakness: fault. flaw. blemish" "Defective" is defined as "1) having a defect or defects; faulty, imperfect: 2) having a physical or mental defect; subnormal: 3) with a physical or mental defect.47

An unborn baby who has a disability is not a "genetic defect," but a human being who may have a genetic defect. There is no such thing as a "perfect baby"; all human beings are imperfect.

Originally a term for a man of wisdom and skill, it quickly came to be particularly identified with a group of people who practiced a new trade or profession: the tutors or teachers who moved from city to city, practicing their trade for a fee. At least two predilections bound this disparate group together: they shared an interest in analyzing language and logic, and they tended toward tough-minded skepticism...By the age of the Roman Empire, the term "sophist" had come to be synonymous with a teacher of rhetoric. 48

Will Durant pointed out that Protagoras, the most renowned of the Sophists, may well have been among the first to articulate principles that would later become the essential elements of secular humanism and relativism:

No absolute truth can be found, said Protagoras, but only such truths as hold for given men under given conditions; contradictory assertions can be equally true for different persons or at different times. All truth, goodness, and beauty are relative and subjective; "man is the measure of all things..." To the historical eye a whole world begins to tremble when Protagoras announces this simple principle of humanism and relativity; all established truths and sacred principles crack; individualism has found a voice and a philosophy; and the supernatural bases of social order threaten to melt away. 49

The connection between "Sophist-ication" and rhetoric, then, is telling. Words can be used to depart from essential truths, such as the absolute and inherent value of human life. Human wisdom, combined with advanced technology made by human hands, has brought us very sophisticated means of marking an "X" on unborn babies with very fancy chalk, using very fancy words. But the meaning and intention is the same: to reject, and now destroy, the "unfit." One could argue that the rejection of the "unfit" at Ellis Island was more honest. At least it was clear what was happening, and people were deported rather than killed. Rather than deport people with disabilities or hide them away in institutions, unborn children with disabilities are now killed before they see the light of day.

Eugenic Aspects of Prenatal Diagnosis and "Selective Termination"

Given that "killing thoughts" may be driven into our unconscious minds, and given that sophisticated words can obscure rather than clarify, it may be helpful to examine the history of "weeding out the unfit" in order to

explicate (and hopefully extricate!) deeply-held assumptions. If one examines the eugenics movement in the late 1800s and early 1900s, one can see that the relationship between eugenic thought and the "selective termination" of unborn babies with disabilities is striking.

The word "eugenics" was coined in 1883 by the English scientist Francis Galton, a cousin of Charles Darwin. Galton took the word from a Greek root meaning "good in birth" or "noble in heredity" or "well born." He intended the term to denote the "science" of improving human stock by giving "more suitable races or strains of blood a better chance of prevailing speedily over the less suitable." ^{50,51}

The eugenics movement of the late 1800s and early 1900s was an attempt to improve society by eliminating those elements of the population who were preceived as the cause of many social ills. It is difficult to imagine, but at one time, the presence of "unfit undesirables" was thought to be *the* major social threat to the well-being of society – perhaps as great as the nuclear threat in our own time.

The elimination of the "unfit" found expression in a number of social movements, most dramatically in the German euthanasia program, which began with the "mercy killing" of people with mental or physical disabilities. In a relatively short time, the euthanasia program quickly expanded to include millions of people who were deemed a threat to the "purity" of the Aryan race. The elimination of "unfit" persons was also a hallmark of the birth control movement beginning in the 1920s. Margaret Sanger, the founder of Planned Parenthood and the champion of birth control (and a member of the American Eugenics Society), made the following statements:

Every single case of inherited defect, every malformed child, every congenitally tainted human being brought into this world is of infinite importance to that poor individual; but it is of scarcely less importance to the rest of us and to all of our children who must pay in one way or another for these biological and racial mistakes ⁵²

and

No more children should be born when the parents, though healthy themselves, find that their children are physically or mentally defective. 53

and

Birth control is nothing more or less than the facilitation of the

process of weeding out the unfit, of preventing the birth of defectives or of those who will become defectives.⁵⁴

Preventing people with disabilities from being born is eugenics revisited, a process of "weeding out the unfit."

The Dignity of the Human Person

People with disabilities commonly find themselves discriminated against, excluded, and isolated. Why is it that people with disabilities are so often set apart? In order to understand the reasons, one needs to examine the norms and values of our culture. In a culture that places such high value on health, wealth, productivity, achievement, beauty, intelligence, etc., those people who are perceived as lacking these qualities – people who are "sick, poor, unproductive, unsuccessful, ugly, stupid," tend to be devalued, or seen as having less value, perhaps even as less than human. The root cause of these harmful judgments is that persons with disabilities are so often not really viewed as *persons*.

The dignity and value of a human person rests in the very identity of the human being. Being human is something that a person *is*, not something that a person *does*. Being human is not what we *become*; it is what we *are*. From the very beginning, when the sperm and egg combine to create a unique human being, complete with its own set of chromosomes and a singular DNA code, the new entity is a human being at its earliest stage of development. The fertilized egg, once the unique chromosomal pattern is formed, is a new human being (what else could it be?) made in the image of God, who, given the proper nourishment and care, will realize his or her endowed potential as a human person.

There is legitimate argument among scientists and theologians as to exactly when a human being becomes an individual – a human person. It is debatable whether the developing human being at its earliest stage can truly be an "individual" when there is potential for recombination (when the fertilized egg "recombines" to form a new individual), or twinning (when the fertilized egg divides to form more than one individual). However, whether or not the first few hours or days of life involve the life of an *individual* person, or a human entity (a human "being") that has the potential to develop into *more than one* person, there is no doubt that the fertilized egg *is* alive, *is* human, and thus *is* human life. Therefore, *every* human life, because it is human, has inherent dignity and value. The inherent, absolute value of the life of a human being is an endowment, not an achievement. Alfred Cioffi summarized Catholic thinking on the dignity of the human as follows:

The intrinsic dignity (of the human being) is not dependent on either a particular achievement by any given individual, or on a bestowal or recognition by society at large. Rather, it is seen as an endowment from God. It is from here that its moral worth emerges: all human beings are beings of moral worth by virtue of being human. ⁵⁶

Pope John Paul II has emphatically underscored the dignity of the human person in *Veritatis Splendor*:

The "second tablet" of the Decalogue, (is) the summary (cf. Rom 13:8-10) and foundation of which is the commandment of love of neighbor: "You shall love your neighbor as yourself" (Mt 19:19, cf. Mk 12:31). In this commandment we find a precise expression of the singular dignity of the human person, "the only creature that God has wanted for its own sake" [emphasis in the original].⁵⁷

The Sanctity of Life

Life is either sacred or it isn't. It cannot be both. Whether or not life is sacred derives from the origin of life, the source from which life springs. If God exists, by definition, and by nature, God is the Creator of everything, including, and especially, human life. If God, who is holy, is the source of all creation, then created human beings are blessed with some measure of God's holiness – however imperfect human nature may be. To be "made in God's own image" means that human beings have a sacred identity. Kevin O'Rourke's definition of the sanctity of life (which he wrote in 1973) indicates a certain transcendent value because of the human's relationship to God, as it transcends and subsumes legal realm of "right to life" and puts the value of a person's life into the realm of personal, intimate relationship. O'Rourke states that:

"Sanctity of life" implies that God has touched man in a personal and lasting manner by reason of the fact that He gave him life. He gives man something of Himself, something holy, something sacred, something of His own being, and thus man is in the image of God...The Sanctity of life is not dependent upon the quality of life. Indeed, we sometimes see the beauty of the human spirit more clearly in those who are "useless" than we do in the so-called normal people.⁵⁸

Sharon Gretz, a parent of a child with a disability and a well-known

advocate for people with disabilities, shared an analogy in relation to her son Luke that makes the concept of "made in the image of God" tangible and real. Luke has a disability in which part of his brain is underdeveloped – a kind of disability that would lead some women to "terminate a pregnancy."

Luke is a very delightful, engaging, vivacious six-vear-old boy who has brought incredible joy to our family. I truly look at Luke and I think he's perfect. People have a hard time with that - even other parents who have children with disabilities. I don't see him as "defective" in any way, even though he's got problems. I think he's perfect. Imagine a famous pianist, who is performing at a concert hall and the pianist begins to play, and the notes come out all wrong. The piano hasn't been tuned, or maybe there's a key missing, or it's broken somehow. The audience wouldn't say the pianist was "defective." They'd say his instrument needed some work. It's a good analogy. I don't see Luke as being "broken", or "deficient." He does have a body that doesn't do what he wants it to do all the time. There's a real distinction in my mind about who Luke is in his essence, which is perfect...God doesn't make mistakes. Luke is no mistake. He's not a "problem," or a "burden," or whatever. He is a joy in my life. 59

Concluding Reflections

Why should people with disabilities live? Who would want to live with disabilities – especially with severe and multiple disabilities? Why is it not better to kill them so as to prevent a "burden of suffering"? The essence of this entire study rests on one fundamental point: people with disabilities are human beings. As human beings, people with disabilities have imperfections, just as all human beings are imperfect in one way or another. As human beings, their lives are sacred.

I have known many people with disabilities in my lifetime. I have yet to meet a person with a disability who wished that he or she had never been born. I have met a few people with disabilities who at one point or another wished they could die – but that is true of people without disabilities as well. It is natural to wonder why disability exists. Why do some babies have healthy bodies and some do not? Since we are not God, we do not have all the answers. Moreover, I do know people with disabilities who have helped me understand that there is more to life than having a fully functioning body – or mind. There are more important things in life, like love, courage, kindness, gentleness, hope, and striving

together in the face of suffering and death. Indeed, knowing people with disabilities has made me *more* human, and if I live long enough, I will likely become "disabled" myself.

The gift of life is a gift from God. Indeed, God is life. If a little baby with severe and multiple disabilities feels the warmth of sunshine on its face, or feels a breeze coming through a window, or enjoys the gentle caress from another human being, that is life for that child. Who are we to deny that child life? The presence of people with disabilities in the world can therefore bring us to a deeper understanding of what it means to be human. The presence of disability can help us recognize that all people have certain vulnerabilities, disabled or not. In our human weakness, we can find a hidden strength, a strength that is given to us by the source of all that is good, our Lord God. Love of God and love of neighbor must then include everyone. Gerald Kelly has noted that Pius XII eloquently addressed the inestimable value of every member of the Body of Christ in his encyclical letter, Acta Apostolicae Sedis:

For the Apostle [Paul] with good reason admonishes us: "Much more those that seem to be the more feeble members of the Body are more necessary, and such as we think to be the less honourable members of the Body, about these we put more abundant honour." Conscious of the obligations of Our High Office We deem it necessary to reiterate this grave statement today, when to Our profound grief We see at times the deformed, the insane, and those suffering from hereditary disease deprived of their lives, as though they were a useless burden to society; and this procedure is hailed by some as a manifestation of human progress, and as something that is entirely in accordance with the common good. Yet who that is possessed of sound judgment does not recognize that this not only violates the natural and divine law written in the heart of every man, but that it outrages the noblest instincts of humanity."

Unborn children with disabilities, unseen by the naked eye, perhaps even unwanted or "undesirable" by their own mothers and fathers, in the eyes of the world are among the "least of the least." Yet in the eyes of God, they are His children. They are our brothers and sisters.

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