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REEXAMINING MODELS OF DISABILITY AND APPLYING RATIONALITY, MORALITY, AND ETHICS TO SUPPORT DISABILITY RIGHTS IN CONTEXT OF GENETICS¹

Gary C. Norman, Esq.*

“I do not feel obliged to believe that the same God who has endowed us with sense, reason, and intellect has intended us to forgo their use.”²

I. Introduction

The “brave new world”³ of genetic and assistive reproduction science and technology provides unrivaled opportunities like no other in history for individuals, either with or without disabilities, to engage in fundamental decisions of procreation, disease prevention and management, and child rearing. Procedures and therapies found in this brave new world are, *inter alia*: prenatal genetic testing diagnosis;⁴ trait selection, which includes germ line modification; and such therapies as stem cell research and Pharmacogenomics.⁵ Likewise, personalized medicine, which is narrowly targeting therapies based on genetics to address disease, constitutes a revolutionary advancement for medicine.⁶ These advancements outpace cultural, ethical, and legal structures and norms, and implicate a dichotomy between the better spirits and the woeful nature of civic society. Advocates, ethicists, legal professionals, and scholars possess concerns about the misuse of science and technology, especially inclusive of medicine, to sterilize, eradicate, and eliminate, or segregate and exclude, so-called undesirables.⁷ Persons with disabilities have all too often been considered as one of these categories of undesirable individuals, and have historically been prey to the nefarious eugenic agenda of some in society.⁸ Additionally, for many, parental choice not to procreate humans with disabilities, or to terminate pregnancies once a disability is detected, constitutes an alarming outgrowth because, even if this falls short of a eugenics agenda, stereotypes are perpetuated.⁹ In sum, should genetic and reproduction science and technology be applied to determine the human genome of fetal life?

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In the view of myriad people with disabilities, the negative outgrowth of such application would include a host of actions from further segregation and discrimination to outright forced eradication.¹⁰ As such, the reemergence of the abhorrent period of history known as eugenics constitutes a concern.¹¹ Conversely, people with or without disabilities have, and should have, a fundamental civil and human right of biological autonomy including private, personal decisions about the circumstances of procreation.¹²

This article will discuss the brave new world of science and technology in light of its impact on people with disabilities. Specifically, the discussion in this article will focus on the prism of the models through which disability is recognized. If applied in a manner such that the best facets of both models of disability can bear forth, then the position of this author, a person with a vision disability, is that my colleagues in the disability civil rights movement should not reflexively excoriate genetic and assisted reproduction science and technology. However, safeguarding people with disabilities, who are a discrete and insular minority across the globe,¹³ against the negative potentialities of science and technology requires more than laudatory pronouncements. Two proposed prescriptions may have the affect of positively influencing the application of genetic and assisted reproduction science and technology within the United States, a world leader with respect to the rights of the disabled community.¹⁴ They are: (1) model legislation that sets a framework for this brave new world of science and technology in a pro-life, pro-disability rights context. A waiting period, such that individuals will subsequently engage in informed decision-making regarding an embryo or fetus with a disability or future possible disabling condition constitutes an integral component of this model legislation. And (2) measures to further evolve further cultural notions and attitudes about disability.

II. Review of Genetics and Assisted Reproduction

A wondrous “blue-print” can be discovered in each human being.¹⁵ Genotypes and phenotypes constitute

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key components of the make-up of people.¹⁶ In the 1990s, the federal government¹⁷ initiated an undertaking of historic proportions, the Human Genome Project, which private industries in competition joined, to identify this blueprint or “map.”¹⁸ The Human Genome Project, and the applications that have been developed and will continue to be developed from it, including the ability to control and manipulate the blueprint, is earth shattering, as it reveals intimate details about medical condition, disease, the predisposition for disease, identity, and family ancestry and history.¹⁹

The project is estimated to have cost three billion dollars.²⁰ Optimism about the ability of mapping the human genome and its applications abounded as the project spiraled forward at a startling tempo.²¹ At the conclusion of the Clinton administration, when the Human Genome Project approached its goal of mapping the genome, scientists and government and private leaders glowed with the potentiality for the new field of gene therapy, which is the treatment of a disease by introducing a corrective gene.²² The hope exclaimed by the White House was that the Human Genome Project would result in cures for some five thousand known hereditary conditions.²³ Furthermore, in 2003, the concomitant occurrences of “finalizing the sequencing of the DNA of the human genome” and the anniversary of the discovery of DNA took place.²⁴

Dr. Francis S. Collins, Director of the National Human Genome Research Institute and now head of the National Institutes of Health, exuded optimism in his testimony before a United States Senate subcommittee on the progress of the Human Genome Project and of its implications for society.²⁵ His testimony expressed that by 2010, “predictive genetic tests will exist for many common conditions where interventions can alleviate inherited risk.”²⁶ Likewise, by 2020, “gene-based designer drugs are likely to be available for conditions like diabetes [and] Alzheimer’s disease.”²⁷

As recently as 2003, sequencing genes cost exponential sums.²⁸ However, the goal is that within five years, sequencing and testing a gene in order to provide personalized medical therapies will cost only \$1,000, thereby spurring further development of genomics.²⁹ The tests, treatments, therapies, and applications, which are presently available in genetics and assisted reproduction, delineate into categories of pre-conception and post-conception.

Specifically, “[m]ost genetic testing does not diagnose physical injury or disease; rather, it...provides information about the possibility of a latent condition in an otherwise healthy person.”³⁰ Regarding pre-conception, genetic counseling constitutes a powerful option for parents, with or without disabilities, to detect disabilities or potential disabling conditions. Genetic counseling constitutes a health service utilized by families and performed by certified health professionals, such as specially trained nurses, the purpose of which, includes, enhanced knowledge of inheritable traits.³¹ Conditions may be observed in utero through such post-conception procedures as targeted blood testing and sampling, e.g., amniocentesis and ultrasound. These means can detect disabilities, such as intellectual disabilities.

For instance, “[i]n 2007, the American College of Obstetricians and Gynecologists recommended that all women be offered screening tests for Down syndrome, which causes...[developmental disabilities, i.e., substantially restricted cognitive functioning] and other health problems.

The current tests consist of a combination of blood tests and ultrasounds.”³² Preimplantation Genetic Diagnosis (PGD) constitutes another example of procedures utilized to control the traits of offspring.³³ As PGD involves the removal and genetic analysis of a single cell from each available embryo, a particular gene can be tested for, (e.g., the gene for Huntington’s disease) and selected for or against implantation.³⁴ Additional procedures include, once again, amniocentesis, chorionic villus sampling, and other methods.³⁵

Finally, advancements in knowledge about genetics will enable screening and testing of “embryos for the presence of gene variants, known as alleles, associated with a range of conditions through the use of a DNA microarray, a testing device that can screen for thousands of alleles at one time.”³⁶ As such, “[c]ombining these genetic advances with ART procedures will permit parents to select embryos based upon their potential future traits.”³⁷

Therefore, the ethical and legal issues caused by genetics strain the mind to be sure. The “newly acquired ability to map and understand...genetic traits” is a discovery that has “transform[ed] both science and society.”³⁸ As Judith Daar, a noted ethicist and scholar, has written, “[a]ssisted conception... is axiomatically complicated by its necessary introduction of third parties into the reproductive process.”³⁹ As such, the traditional two-party process has the issue of increased complexity.⁴⁰ Arguably, bias may be inserted into the process of procreation therefore.⁴¹ In sum, genetic and assisted reproduction science and technology can transform society in a way that either improves the human condition or that worsens bias, discrimination, and exclusion.

III. Medical Model versus Social Model of Disability

Arguably, disability originates from the effect of differing models – the medical and the social models.⁴² This article will discuss the models of disability as well as their historical milieu.⁴³

A. Medical Model

The medical model of disability dates back to the nineteenth and twentieth centuries, which experienced the rapid development of medicine and advancements in medical diagnosis, procedures, and technology.⁴⁴ These centuries also witnessed the corresponding emergence of the physician as a powerful actor in society.⁴⁵ Logically, a biological component exists at the core of this model.⁴⁶ People with disabilities constitute poor suffering patients, afflicted with impaired parts and disease.⁴⁷ Outcomes of the disabled are to be governed by diagnosis, prognosis, and therapeutics.⁴⁸ Arguably, eugenics constitutes the malevolent expression of this medical model of disability.⁴⁹

At this point, it is worth emphasizing that cultural stereotypes of the disabled abound. These stereotypes, many of which implicate the medical model, include the following:

- The disabled person as pitiable and pathetic (e.g., Tiny Tim in Charles Dickens’ *A Christmas Carol* and Porgy in George Gershwin’s *Porgy & Bess*).
- The disabled person as an object of violence (e.g., Joan Crawford in *Whatever Happened to Baby Jane?* and Audrey Hepburn in *Wait until Dark*).

- The disabled person as sinister and evil (e.g., Shakespeare's Richard III, and also Black Dog, Blind Pew and Long John Silver in Stephenson's *Treasure Island*).
- The disabled person as atmosphere or curio (e.g., the characters of Merrick in *The Elephant Man* and Half Soldier in *the Good, the Bad, and the Ugly*).
- The disabled person as super cripple (e.g. the central characters in *My Left Foot* and *Reach for the Sky*).
- The disabled person as an object of ridicule (e.g. the cartoon *Mr. Magoo* and Harpo Marx of the Marx Brothers).
- The disabled person as his or her own worst and only enemy (e.g. the central characters in *Coming Home* and *Born on the Fourth of July* and Lt. Dan, a newly wounded soldier, in *Forrest Gump*).
- The disabled person as a burden (e.g. in the recent British television drama *Keeping Tom Nice*).
- The disabled person as sexually abnormal (e.g. Hephaestus in Homer's *The Odyssey* and Lady Chatterley's husband in D.H. Lawrence's novel).⁵⁰

Additionally, ignorance imbued jocularity reinforces these stereotypes. For instance, a piece published in *Maxim*⁵¹ possessed the seeming intention of using the disabled as a punch line. These representations in mass media reflect that bias, discrimination, and prejudice are prevalent within the intimate, private contexts of courtship and marriage, sexual intercourse, and procreation.⁵² Women with disabilities disproportionately encounter discrimination and prejudice on these issues.⁵³ Disability law and policy scholars seem to accept summarily that the medical model, and its corollary the rehabilitation model,⁵⁴ constitute the reason for these continued notions and stereotypes.⁵⁵

Since the medical model focuses on the physical condition of the disabled, the argument posited against this model holds that it "relies on normative categories of 'disabled' and 'non-disabled,' and presumes that a person's disability . . . is 'a personal, medical problem, requiring but an individualized medical solution.' . . . The medical model views the physiological condition itself as the problem."⁵⁶ As far as this model might categorize individuals as the sum of their anatomical parts and impairments, instead of autonomous actors endowed with dignity, a concern exists about the reemergence of the eugenics movement. Before providing further discussion about the models of disability, exploring the topic of eugenics may prove helpful.

1. Eugenics

As one court explained, "[e]ugenics is defined as the science of improving the qualities of the human race by the careful selection of parents."⁵⁷ There is even so called "positive" and "negative" eugenics.⁵⁸

Additionally, contemplations of eugenics implicate automatically the specter of 1930's and 1940's Germany. Flashing in the mind therefore is: (1) torch ignited parades, (2) Kristallnacht, and (3) guards rounding up fellow human beings, inclusive of women and children, for mass slaughter.⁵⁹ Humans would be remiss to forget this history, as not doing so might cause a repeat of such terror. While the brothers and sisters of people

with disabilities, e.g., Jews, were the subject of horrific acts of evil and prejudice in Germany under the *Das Dritte Reich* or Third Empire, many forget that people with disabilities ostensibly constituted a training module for the Nazi regime even before there were organized concentration camps of terror and death – The Final Solution.⁶⁰

The article entitled, *Bioethics and Disability Rights: Conflicting Values and Perspectives*,⁶¹ in discussing the concern of people with disabilities about the application of genetic and assisted reproduction science and technology, provides a good and concise review of eugenics as it was first utilized to eradicate the disabled. Unfortunately, medical professionals who pledged to "do no harm," participated in the Nazi Action T-4 program, in which up to 100,000 children and adults with disabilities were euthanized.⁶² Arguably, people with disabilities met this horrific consequence because Germans thought them to be feeble, anatomically unworthy burdens on the state.⁶³

Today, a linkage exists among historical eugenics and pre-conception and post-conception genetic testing procedures.⁶⁴ The medical model, and its corollary, the rehabilitation model,⁶⁵ bear forth, especially in the context of sex and procreation.⁶⁶ As such, "[t]he eugenics legacy continues to linger as a cautionary note to the application of a public health model [i.e., a medical model] to advances in reprogenic medicine."⁶⁷ Hence, one can understand that disability advocates typically criticize the medical model of disability because the focus of that model is of the disabled as ill and in need of patronage⁶⁸ and because of its potentiality to reinvigorate eugenics.⁶⁹

2. Counterpoint

However, medical intervention, even as facilitated by the brave new world of genetic and assisted reproduction science and technology, might conceivably aide the future life of people with disabilities. Notably, one morning when at a bed and breakfast in Pennsylvania, a couple recounted how their friend was able to utilize applications that have been derived from genetics to address a life-threatening kidney disease of her fetus that, if present after birth, would have had a high probability of mortality. The fetus, now a grown adult, has a distended kidney. In that circumstance, the medical procedure resulted in a positive outcome—the birth of a contributing human—whose in utero condition might be considered a disability. Moreover, as one author argued:

"Curing cancer; reversing paralysis; eliminating tuberculosis, leprosy, and malaria; and correcting the organic causes of many mental health conditions, for example, would seem to be achievements that nearly everyone would applaud enthusiastically. The elimination of polio, now found in only 4 countries in the world, is well within reach; why would anyone lament its final eradication?"⁷⁰

Furthermore, if comprehensive early intervention services funnel to infants as early on as possible, successful outcomes in rehabilitation and education increase in likelihood.⁷¹ Therefore, by detecting disabilities or the predisposition for disabilities early on, specifically when a fetus is in utero, parents with or without disabilities and society as a whole can engage in critical decisions and planning, to the consequential impact of all. Contrary to the accepted position of some,⁷² the medical paradigm can benefit people with disabilities.

B. Social Model

The belief that discrimination emerges not from disabilities as a medical condition or disease in their own degree but rather from societal attitudes and stereotypes, a belief that emerged during the twentieth century, constitutes the preferred construct of disability held by myriad scholars – the social model.⁷³ The author, Adam M. Samaha, provides a good description of the social model. He expresses that the definition of disability contained within the social model focuses on the “disadvantage” of people with disabilities and the root causes, which include, “architectural, social, and economic,” causes of such disadvantage.⁷⁴ Another definition of disability incorporated in this model is that people with disabilities constitute not the sum of their conditions and diseases but rather, in a certain sense, the victims of an environment that lacks reasonable accommodations.⁷⁵ In sum, whether people with disabilities are abnormal and must adhere to society, or whether a just and equal society should engage in affirmative actions to maximize the potential of such individuals, is a question that the social model addresses.⁷⁶

Additionally, the critical and on-going quest of realizing the noble concepts of equal civil and human rights set forth in the Declaration of Independence, which became a tour de force during the twentieth century, spurred the national and international disability civil rights movement.⁷⁷ Furthermore, the civil rights movements of the late 20th Century arguably caused people with disabilities to “recognize[] that their social positioning was strongly correlated with their exclusion from existing, legal, social, cultural, political, economic and structural arrangements . . . In this sense disabled and non-disabled people emerged as two distinct categories of citizens,”⁷⁸ each deserving protections. The philosophy of this model of disability is that, “analyzed limbs may not particularly limit a person’s mobility as much as attitudinal and societal barriers.”⁷⁹ Consequently, persons with disabilities, if provided the appropriate accommodations, modifications, or supports, can contribute equally to the collective.⁸⁰ In the United States, a panoply of statutes arguably embodies the social model of disability.

The Rehabilitation Act of 1973 (Rehabilitation Act), as amended,⁸¹ and the Americans with Disabilities Act of 1990 (ADA),⁸² as amended,⁸³ as well as other statutes, are argued to embody the social model of disability.⁸⁴ Additionally, the Genetic Information Nondiscrimination Act of 2008⁸⁵ (Genetic Act) can be considered to embody the social model of disability. These statutory schemes seek to establish an inclusive society for all.⁸⁶ Finally, the Convention on the Rights

and Dignity of Persons with Disabilities⁸⁷ and its optional protocol⁸⁸ constitute a reflection of the paradigm shift from the medical to the social model of disability.⁸⁹

1. Social Model: Domestic and International Protections

Equal access to and affordability of healthcare and rehabilitation services constitute critical components of the integration of people with disabilities.⁹⁰ In May 2009, the Secretary of the U.S. Department of Health and Human Services (HHS) announced,⁹¹ in commemoration of the landmark decision of the United States Supreme Court in *Olmstead v. L.C.*,⁹² that 2009 would constitute the “Year of Community Living.” Genetic testing and counseling arguably equals an important community-based support. Additionally, as insurance is a key reimbursement vehicle for healthcare, including genetics, civil rights protections against discrimination have been supplemented, if imperfectly, with the provisions of the Genetic Act.⁹³

Genetic disorders, which are either singular or multifactorial,⁹⁴ obviously result in impairments.⁹⁵ These impairments, if active or even potentially dormant but laden may, depending on their severity, qualify affected individuals as disabled.⁹⁶ Under the Rehabilitation Act,⁹⁷ and the ADA,⁹⁸ as originally enacted, “the ability to reproduce and bear children is a ‘major life activity’ that if substantially limited, may constitute a disability.”⁹⁹ Furthermore, as former Equal Employment Opportunity Commission (EEOC) Commissioner and Endowed Chair of Law, Paul Steven Miller, stated, “[c]early, the ADA covers people who have a manifested genetically related illness or disability that impairs a major life activity as well as those who have a record of a genetically related disability (e.g., someone who has recovered from cancer). The more challenging question is whether the ADA prohibits discrimination based on a diagnosed but asymptomatic genetic condition that does not substantially limit a major life activity.”¹⁰⁰ However, under the expansive provisions of the ADA Amendments Act of 2008, asymptomatic conditions or disorders may be disabilities.¹⁰¹

Scholars and advocates proclaim this set of amendments to the original ADA as a victory for the disabled.¹⁰² In advance of promulgating updated regulations to the ADA, the EEOC will acquire public input by means of town hall meetings hosted across the United States in 2009.¹⁰³ If impairment meets the definition of disability, then certain affirmative obligations protect the individual with those impairments.

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In short, the Rehabilitation Act and the ADA translate the goal of creating a more decent, inclusive society for the disabled by imposing affirmative prohibitions against discrimination and by requiring rights of access and modification or accommodation on private and public actors. The ADA expands on the principles and protections of the Rehabilitation Act into the non-federal public and private sectors. As such, principles under both the Rehabilitation Act and the ADA involve the same matter.¹⁰⁴

Medical offices, institutions, and facilities, which do not receive federal or state financial assistance, comprise places of public accommodation, covered by the provisions of Title III of the ADA.¹⁰⁵ If a state or local government or instrumentality thereof, operates them, then they constitute a public entity and are subject to the provisions of Title II of the ADA.¹⁰⁶ Furthermore, services and programs furnished or operated by a public entity in the context of healthcare can include, for example, state Medicaid programs.¹⁰⁷ A covered party, (i.e., a place of public accommodation or a public entity) must refrain from discrimination. In furtherance of this requirement, the covered party must provide reasonable accommodations or modifications to services, programs, policies and procedures, or provide auxiliary aides and services.¹⁰⁸ Additionally, the Rehabilitation Act, as well as Title II of the ADA, require that programs and activities receiving federal financial assistance, or that are part of state or local government must be administered “in the most integrated setting appropriate.”¹⁰⁹ The purpose behind this so-called “integration mandate,” is that a public entity or place of public accommodation may not deny a qualified person with a disability the opportunity to participate in programs or activities that are as equal to the able-bodied as possible, even if separate programs or activities would be, in the view of such public entity or place of public accommodation, best suited to the disabled. However, despite the passage of the ADA nineteen years ago, and the passage of the Rehabilitation Act before that, people with disabilities, especially women, continue to confront unawareness on the part of providers, programmatic and policy barriers (including, equal access to medical equipment and services, financing, and supports and assistance), and outright discrimination.¹¹⁰

Examples of inaccessible services, programs, and procedures, which women with disabilities confront, include: (1) inaccessible mammography and pelvic exam equipment, (2) overall inaccessible medical equipment, and (3) a lack of fertility and sexual health information.¹¹¹ Clearly, women with disabilities suffer health disparities because of their immutable

characteristics. The problem of health disparities originates from a myriad of root issues.

The 2004 symposium report on the health of women with disabilities, hosted by HHS, indicates that awareness about disabilities among providers is limited. The report states, “despite the increased awareness of women’s health, research to date has not adequately addressed the health concerns of women with disabilities.”¹¹² Moreover, providers typically receive no school or clinical-based training about people with disabilities, either as a whole or as related to sub-fields of medicine, such as women’s health.¹¹³ Medical and allied health schools simply do not possess curricula about disability, except as a reflection of illness and impairment to be cured.¹¹⁴ Consequently, attitudes among providers about disability generally range on the spectrum from the discriminatory to the patronizing.¹¹⁵ For instance, providers can sometimes be surprised that women with disabilities would be sexually active or would desire to procreate.¹¹⁶

Providers, who are generally concerned about the costs and time of regulatory compliance consequently fail to adhere to accessibility mandates because of these underlying beliefs and attitudes.¹¹⁷ A lack of appropriate communication by physicians causes access gaps to a range of minority populations, especially inclusive of women with disabilities.¹¹⁸ Inadequate communication causes these gaps because providers must be vigilant with their patients if they are to avoid errors or to provide meaningful consent.¹¹⁹ By having myopia about people with disabilities, providers are less likely to engage in appropriate communication.¹²⁰ This worsens the consequential power imbalance between the patient with a disability and a provider.¹²¹ Once again, providers, concerned with issues of time and profit margins, tend to limit focus on communication to patients, with or without disabilities.¹²² Inadequate communication, coupled with unequal coverage in the public and private insurance systems, punctuate health disparities.

Reimbursement schemes, especially those furnished through Medicare and Medicaid, are a continued barrier that inhibits broad access to genetic testing and counseling for people with disabilities.¹²³ The HHS Advisory Committee on Genetics, Health, and Society urged action on prior recommendations, namely its 2006 report,¹²⁴ concerning gaps in reimbursement.¹²⁵ Additionally, the United States is a multi-payer based health insurance system, which many Americans cannot afford.¹²⁶ The problem of access disparities worsens under such a multi-payer system when chronic conditions rise to the level of a

disability.¹²⁷ Moreover, a lack of robust community support and services for persons with disabilities and their families compounds the issue of health disparities.¹²⁸ Disability activists lobby Congress on the principle that people with disabilities receive due attention during the reform of American healthcare.¹²⁹ Namely, they advocate the need for better access to community-based supports, coverage parity, and accessibility of Durable Medical Equipment and medical facilities.¹³⁰

Despite these issues, hope exists as regulatory and legislative approaches have been initiated to address discrimination based on the genetic code. In 2000, President Clinton issued Executive Order No. 13145 to prohibit discrimination against federal employees based on genetic information.¹³¹ In 2008, Congress passed and President Bush signed the Genetic Act to address actual or possible gaps in the coverage of statutory schemes, such as the ADA, as to health insurance.¹³²

The Genetic Act seeks to protect individuals from discrimination based on information derived from genetics, namely, genetic tests and counseling, and family medical history. It covers only asymptomatic individuals amending several statutory schemes, including the Social Security Act (Medicare supplemental policies), the Health Insurance Accountability and Portability Act of 1996 and Title VII of the Civil Rights Act.¹³³ The Genetic Act prohibits insurers and employers from excluding eligibility, limiting, or increasing premiums for group insurance, based on preexisting conditions or as a matter of underwriting, and employers, labor unions, or joint management and labor committees from rendering adverse employment decisions based on the genetic code.¹³⁴ The Genetic Act deserves criticism as its provisions fail to address genetic discrimination in life, disability, and long-term care insurance.¹³⁵ Nor do its provisions address other issues, where affirmative language would have been helpful in safeguarding civil rights. For instance, section 208 of the Genetic Act specifically precludes the critical cause of action of disparate impact with which to remedy violations.¹³⁶ In sum, litigation and various forms of alternative dispute resolution will test if the Genetic Act will be effective in combating discrimination.

The new international framework of the Convention on the Rights of Persons with Disabilities and its Optional Protocol, which builds on the positive protections of the ADA, will prove critical globally as civic societies seek to promote the benefits of science and technology while striving against negative applications of science and technology, such as the reemergence of eugenics for the more than 650,000,000 people with disabilities on the planet.¹³⁷ In 2006, the United Nations General Assembly adopted these historic covenants. Scholars Lord and Stein describe that the Convention possesses several general principles and articles, including, “articles of universal application, articles addressing substantive rights, and articles establishing implementation and monitoring schemes.”¹³⁸ The Convention is a comprehensive human rights covenant with affirmative civil, political, and social rights mandates on state parties, or governments.¹³⁹ Specifically, Articles 25 and 26 of the Convention require state parties to engage in actions, such that people with disabilities enjoy equal access to healthcare and rehabilitation services.¹⁴⁰ Explicitly, Article 25 provides that state parties will ensure equal, accessible, and affordable healthcare services, reimbursement systems, and insurance to persons with disabilities, “including in the area of sexual and reproductive health and population-based public health programs”.¹⁴¹ An optional protocol

fortifies the Convention, and that serves as an implementation vehicle with communication and complaint processes to redress the rights set forth in the covenant.¹⁴²

In light of the foregoing, women with disabilities are less likely to receive appropriate gynecological and other health services and examinations.¹⁴³ Therefore, women with disabilities sustain rates of poorer health, especially in terms of reproductive health.¹⁴⁴ Clear inadequacies, as they relate to the protection of people with disabilities, in the brave new world of genetics penetrate existing civil rights frameworks. Consequently, protections in such statutory schemes as the ADA¹⁴⁵ and the Genetic Act¹⁴⁶ constitute starting points which should serve as bulwarks against the negatives of genetic and assisted reproduction science and technology. Moreover, the Convention, which is influenced by the ADA, may be a helpful galvanizer of dialogue, if not substantive legislation, on these issues.¹⁴⁷

C. Criticizing The Social Model: Both Models Have A Role

Clearly, the social paradigm of disability operates with a pro-disability focus. The normative orientation of this paradigm is that people with disabilities deserve equal rights, and the above-mentioned civil rights panoply embodies this orientation. To the extent that this paradigm integrates the historically excluded into civic society, we should applaud the same. However, the review of the models of disability cannot stop here.

The article, *What Good Is the Social Model of Disability?*,¹⁴⁸ provides a refreshing insight into, even perhaps critique of, the social model of disability or the application thereof. The article expresses that the social model is a way to describe disability, but falls short of an actual policy response.¹⁴⁹ Therefore, qualitatively categorizing the medical model and its corollary, the rehabilitation model,¹⁵⁰ as deleterious, and praising the social model of disability, is simplistic. Much more exists to the issue.

When the medical and social model are juxtaposed, condemning the medical paradigm while praising the social paradigm falls short of a workable basis for explaining disability based discrimination. Even the medical paradigm can result in positive outcomes, that is, children – a laudatory magical experience whether disabilities are implicated or not. As pro-disability rights as the social paradigm may be, especially in the inclusion and integration mandates of positive legislation, people with disabilities continue to encounter bias, discrimination, and prejudice in society. Moreover, there is an inherent flaw with qualitatively categorizing these paradigms as such, because neither of them possess measures of goodness or wrongfulness – they are mere explanations and constructs.

Disability, on the one hand, possesses a medical facet, which may necessitate medical attention and even cure. On the other hand, disability implicates the manner in which civic society upholds its better spirits and normative imperatives of the equality of individuals, even if such individuals may not be able to walk up the stairs or see the film screen at the drive-in on a Saturday night. Therefore, society ultimately determines the potential either for the implementation of the morally positive, or for the detriment of the historically excluded and marginalized.

Consequently, merging these models in a way that incorporates each of their better components in furtherance of civil rights of people with disabilities should constitute the searching review and weighty task of scholars and policy-makers. Profound injustice will occur if science and

technology lacks a pro-disability and pro-life perspective.¹⁵¹ Obviously, the eugenics fad of the twentieth century is a clear example of how science and technology can punctuate prejudice.¹⁵² The question that remains is what ultimate course of conduct or remedial measures should be undertaken, such that society advances scientifically but also progressively.

IV. Analysis

The Minnesota Supreme Court indicated, in resolving whether malpractice should be extended to circumstances involving genetic diagnosis and counseling, that the “practical reality of the field of genetic testing and counseling” is that it “not affect[s] only the patient. Both the patient and her family can benefit from accurate testing and diagnosis. And conversely, both the patient and her family can be harmed by. . . testing and diagnosis.”¹⁵³ Parents with or without disabilities increasingly confront, and must respond to, the dilemmas posed by procreation. The choices presented to such parents include: (1) avoid pregnancy in the fear that offspring will be born with active or future disabling conditions or disorders, (2) conceive utilizing donor egg or sperm from an individual who is not a carrier, (3) proceed with a pregnancy, but undergo a prenatal diagnostic test (possibly terminating the pregnancy if it reveals a gene mutation), or (4) accept the possibility that offspring could be born with a disability.¹⁵⁴

Determinations from an array of options increasingly enabled by genetic and assisted reproduction science and technology must be executed in light of underlying societal moral norms, legal systems, and ethical considerations. In this regard, several options clearly fall within the positive side or are morally noteworthy, while arguably at least one option, (as described below), falls within the negative. In the words of one author, “[I]aw probably should not make . . . intimate decisions [about such issues as procreation], but it can shape the social world in which intimate decisions are made.”¹⁵⁵ The ethos, which must consequently govern any discussion about genetics, is that all life, disabled or not, is precious and demands reverence.

People with disabilities need not, and should not, as a matter of reflex, excoriate this brave new world of science and technology. Conversely, people with disabilities are justified to denounce issues posed by genetic and assisted reproduction science and technology, when such science and technology have the impact of hindering their social inclusion and civil rights. In light of this divergence of approaches, options provided by genetic and assisted reproduction science and technology may be proper as long as parents, with or without disabilities, are better equipped by such options to engage in informed decision-making regarding the procreation of a potential child with a disability. However, terminating a pregnancy after which a condition or disorder is identified through genetic testing is repugnant.¹⁵⁶

In the United States, ethical decisions regarding procreation often fall within the context of the rights based framework.¹⁵⁷ Many condemn the choice to terminate a pregnancy because of the detection of a disability or the predisposition for a disability as selective abortion.¹⁵⁸ As such, the better view is that any of the religious,¹⁵⁹ natural law,¹⁶⁰ or Kantian¹⁶¹ frameworks found in bioethics should be applied especially when it means balancing the rights of the person on the one hand, while on the other, safeguarding against continued societal discrimination.

As the Maryland Court of Appeals correctly implied in *Kassama v. Magat*,¹⁶² it is human nature to crave life, not to extinguish such life, even if there are arguably burdens imposed by disabilities. For all that, life offers, it cannot be stated that a life without disabilities is any more socially benevolent than one with disabilities.¹⁶³ Furthermore, attempting to determine the relative value of a life, based on a query of “what is the best life or the best child” is “fraught with bias and ambiguity.”¹⁶⁴ Notably, the late Pontiff, Pope John Paul II, aptly expressed as long ago as 1991 the need for science and religion, morality, and ethics to be interconnected in human advancement. Pope John Paul II expressed, when confronting the dilemmas posed by advancements in science and technology,¹⁶⁵ “progress, particularly in the field of genetics, keeps conscience on the alert and stimulates ethical reflection. This progress cannot be limited to technical aspects which one could consider morally neutral, because it directly concerns the human person in regard to his most valuable possession: his very structure as a person.”¹⁶⁶ Therefore, science has a role to play in improving the quality of life of our species. Human existence is, however, more than the blueprint of life. “Science considers the world and the human person on the horizontal level, the level of physical/chemical processes and of quantifiable matter. Religious faith, on the other hand, considers the vertical level: the level of the human person’s transcendent origin, dignity, and destiny: the level of the . . . person in [a] . . . relationship with God.”¹⁶⁷ In specific regard to science and technology, Kathy McReynolds, Ph.D., offered a noteworthy position paper, which indicates that scientific applications can be consistent with moral and religious imperatives. Namely, by acquiring wisdom about the blueprint of life, this enables parents to prepare for a child with a disability or future disabling condition.¹⁶⁸ Therefore, religion, moral philosophy, and ethics must provide conscience to our scientific and technological advancements.¹⁶⁹ In practical terms, the input and contributions of theologians and leaders of differing faiths, such as Pope John Paul II, as well as moral philosophers, and ethicists, are critical.

Proponents of the enduring legacy of *Roe v. Wade*,¹⁷⁰ as affirmed and refined by *Planned Parenthood of Pennsylvania v. Casey*,¹⁷¹ hold that, as abortion falls within the right to privacy, such right should not be curtailed by the state — no matter what the circumstances.¹⁷² If upholding the principles of *Roe*, even as refined in *Casey*, is at stake, then the proponent of the rights based framework would argue that the potential for human life must relinquish to that of the individual, i.e., the woman seeking an abortion.¹⁷³ As the Tennessee Supreme Court wrote in *Davis v. Davis*,¹⁷⁴ “[a]s embryos develop; they are accorded more respect than mere human cells because of their burgeoning potential for life. But, even after viability, they are not given legal status equivalent to that of a person . . . born.”¹⁷⁵ In the view of feminists, however, embryos and fetuses, even if they deserve heightened status, do not ultimately arise to the level of a life. Abortions are protected, and this is a right that is not to be infringed—even in the context of partial birth abortion, a post-viability procedure. Arguably, the rights based point of view would seem to implicate that somehow rights have no minimum thresholds, and no upper limits. Rights, even in the context of abortion, have reasonable limits that must give way to the compelling interest of the state in protecting the potentiality for human life.¹⁷⁶ Consequently, abortion, recognized as a right, will erode other rights if unregulated.¹⁷⁷

The problem occurs when humans are treated as the mere flotsam of the rights based framework. When humans, even at the stage of pre-viability,

do not receive the reverence they deserve, then our species as a whole reduces to a commodity, rather than as a gift of the creator. The reduction of humans to the level of widgets constitutes the practical outgrowth of this lack of respect.¹⁷⁸ That is clearly unfortunate, no matter how one defines and describes the deity-inspired origins of our species. Even if one does not accept the existence of a creator, one would need to acknowledge that a rational actor, not all rights-based expressions, such as abortion, is morally appropriate if they diminish the equality of others. Specifically, proponents of abortion are unlikely to have had the experience of living with a disability and confronting the ubiquitous bias, discrimination, and prejudice buffeted by an array of actors in society. Proponents must consider how, on the one hand, protecting what they interpret as a right protected under the United States Constitution, might at the same time winnow away at other hard-won achievements in civil, political and social rights.

Scholars in disability law and policy, even those who hail from the feminist perspective, increasingly propound questions about abortions that target embryos or fetuses that have the potentiality for disabilities. As one such scholar noted:

“[W]hat did perturb me was the way in which my serious objections to abortion on the grounds of fetal abnormality were interpreted as an assault on choice, rather than seen for what they really are — an engagement with the ethical questions surrounding such abortions, and a vital challenge leveled against social prejudices about disability.”¹⁷⁹

The author poignantly expresses that, “so long as selective abortion exists,” “prejudices [will be given] legitimacy.”¹⁸⁰ Additionally, commentators argue that, while precise data may be non-existent, rates of abortions are higher when prenatal genetic testing is utilized to detect disabilities or the predisposition for disabilities.¹⁸¹ Selective abortions appear to be encouraged particularly by medical professionals at the stage of pre-viability.¹⁸² Selective abortions thusly cause concern among disability advocates and scholars that people with disabilities, as a fetal populace, will be preemptively screened for and terminated.¹⁸³ Clearly, this punctuates rather than eliminates bias, discrimination, and prejudice held by such powerful actors in civic society as medical professionals.¹⁸⁴ Notably, “[t]his selective elimination of fetuses and embryos with disability-related traits is seen as the ultimate expression of prejudice, the elimination of an undesirable social trait through science and medicine.”¹⁸⁵ As far as this implements the malevolent facet of the medical model, this is an arguable expression of eugenics.¹⁸⁶

Likewise, disability advocates and scholars have posited certain noteworthy arguments, the ‘disability critique,’ against selective abortions. They are in pertinent part:

1. Expressivity,
2. Traits versus Persons, and
3. Disability Identity.¹⁸⁷

Another argument is that, by degrading the value and identity of persons with disabilities, people with disabilities will fall prey to healthcare rationing.¹⁸⁸ That is, because accommodating people with disabilities and addressing their underlying diseases may cost more to society than able-

bodied individuals cost, and because genetic tests can screen-out these suppose burdensome individuals; people with disabilities will be summarily rationed out of the equation.¹⁸⁹

In some circumstances, however, parents may not be in the position to afford a child with special needs. Bias and prejudice, especially as fostered by the medical profession engender this reaction.¹⁹⁰ However, procreating and rearing all children, regardless of disabilities or the potential for future disabling conditions, constitutes an expensive endeavor. In 2006, when declining to extend consequential damages in the law of negligence to genetic counseling and testing, the Ohio Supreme Court wrote that, regardless of disabilities, “significant expense is associated with rearing any child.”¹⁹¹

Finally, people with disabilities may be labeled as possessing a culture which stems from shared experiences in combating discrimination and encountering environments that often lack reasonable accommodations.¹⁹² To the extent there is a disability culture, this does not logically equate to altering offspring in utero to increase disorders or conditions, or the predisposition for disorders or conditions in furtherance of the social model of disability. Any subpopulation of disabilities might seek to apply genetic and assisted reproduction science and technology to augment the likelihood of a future disability in offspring. For instance, “[a] survey published in 2006 indicates that at least a few IVF [in vitro fertilization] centers have assisted in selecting for a ‘disability’ such as deafness or dwarfism.”¹⁹³ Specifically, a documented segment of the deaf, who view themselves as holding a distinct culture, are noted for their desire to apply genetic and assisted science and technology to ensure the viability of their community.¹⁹⁴

The rights of the individual must relinquish, in some instances, to the state, such as its enactment or promulgation of positive moral or religious influenced regulation. Judith F. Daar points out, when it concerns the “procreative liberty,”¹⁹⁵ “[t]he question for constitutional purposes is whether any . . . barriers [to such liberty] rise to the level of state action and if so whether they pose an undue burden on procreation.”¹⁹⁶ On the one hand, where state action is implicated in the process of protecting classes of historically excluded and marginalized individuals, and on the other, is not very intrusive to a liberty interest, who can legitimately argue that such state action fails the test of strict scrutiny?¹⁹⁷ Furthermore, legislative pronouncements do not transition from the page to substantive action by a whim. Thusly, Policy or other measures often spur a change in the culture of citizens, such that compliance with substantive legislation is achieved. In the award-winning fictional television series of *The West Wing*, President Jed Bartlett recognizes this principle when he expressed at a campaign stop in Iowa that the American people have changed their laws and must change their hearts.¹⁹⁸ In sum, this article discusses model legislation and a set of policy measures.

V. Remedies

Draft “model” legislation and a set of policy measures are proposed below.

A. Legislative Remedy

*The Model Defense of the Disabled Fetus Act*¹⁹⁹

A. Preamble

The policy of this state is that all life, whether at its earliest development, its quickening or during gestation, or after birth, inclusive of children and older adults, with or without disabilities, has, and is and ought to be endowed with, sanctity, respect, and dignity.²⁰⁰ The fetus, either with or without known, detectable impairments, defects, disabilities, now or prospectively existing, can rightly be contemplated as possessing potential sentience.²⁰¹

Technology and science are not value-neutral.²⁰² Wondrous, magnanimous intentions, but also evil proclivities of humans imbue technology and science.²⁰³ Particularly, the milieu of technological and scientific advancements in genetics and assisted reproduction seemingly offers a false sense of omniscience, power, and control.²⁰⁴ Serious religious, moral, legal and ethical questions for civic society, including, but not limited to, eugenics, emanates when humans, imperfect creatures, utilize the profound to alter the blueprint of life.²⁰⁵

Women perceive that they receive encouraged, or in some instances counseled to undergo abortions.²⁰⁶ This is especially true in the circumstance of disabilities.²⁰⁷ The policy of this state is to realize the benefits of genetic and reproductive technology and science while, at the same time, safeguarding against, and as applicable, forbidding outcomes, practices, procedures, services, or therapies, which may worsen societal prejudice, exclusion, discrimination, and bias.

Genetic and assisted reproductive technology and science are encouraged, funded, and incentivized as far as they are utilized, developed, and applied to address, if possible, cure, or alleviate the medical facets of impairments, defects, deficiencies, or conditions, which, now or in the future, may rise to the level of a disability. At no time, however, will science and technology be utilized, developed, or applied in a way such that the affects of historical social, political, and cultural prejudice, exclusion, discrimination, and bias are worsened, promoted, and enhanced. Finally, the policy of this state is that the movement, as far as it acts lawfully, to support human life, inclusive of opposition to abortion and selective abortion, is commendable.²⁰⁸

B. In accordance with the compelling interest of the state in protecting the potentiality for human life²⁰⁹ — either with or without disabilities

1. There shall be a right of conscience; neither liability as a cause of action, nor discrimination, disqualification, coercion, for any person, acting individually or in association, in this state, for a failure to suggest, sell, mention, propose, proscribe, recommend or refer for, or discuss an abortion, (including a late tri-semester “partial birth abortion”), especially where wondrous advancements in science and technology, peering into the body, disclose a disability or potentially future disabling condition will attach.²¹⁰
2. There shall be a prohibition to abortions, where such abortions, (including a late tri-semester “partial birth abortion”), are

specifically administered, proscribed, recommended or referred, or sold to prevent, cure, or ameliorate any impairment, disease, defect, deficiency, or condition, which may or may not presently or in the future, rise to the level of a disability as defined under federal law and the laws of this state.²¹¹

3. However, abortions may be performed by a properly licensed medical professional, and in an appropriately accredited and licensed medical facility, institution or hospital,²¹² if they are:
 - a. To save, protect, or preserve the life of a woman experiencing a medical crisis or emergency situation, or
 - b. To remedy an incident or criminal offense of sexual abuse, incest, or rape as defined under the laws of this state.
 - c. However, under subsection “a” providers shall make reasonable medical efforts under the circumstances to preserve both the life of the mother and her unborn fetus in a manner consistent with conventional medical practice.²¹³
 - d. And in the circumstance of subsection “b,” providers shall only perform an abortion, once such provider has referred such pregnant patient to a medical social worker or other allied healthcare professional where the option for and the services related to adoption is discussed and counseled.

C. Causes of Action Or Claims

1. The cause of action or claim of wrongful birth is prohibited,²¹⁴ and
2. The cause of action or claim of wrongful life is prohibited; but,²¹⁵
3. This subsection shall not preclude causes of action based on arguments that, but for a wrongful act or omission, maternal death or injury would not have occurred, or that impairment, disease, defect, deficiency, disability, or condition of an individual, prior to birth, would have been prevented, cured or ameliorated in a manner that preserved the health and life of the affected individual.²¹⁶

D. Additional Prohibitions

The following additional actions respecting genetics and assisted reproduction are prohibited under this Act:

1. Create a human being, perform any procedure or provide, prescribe or administer any therapy, service, or medication that would ensure or increase the probability that an embryo will be of a particular sex, or that would identify the sex of an in vitro embryo, except to treat, diagnose, or address a sex-linked disorder or disease²¹⁷
2. Alter the genome of a cell of a human being or in vitro embryo such that the alteration is capable of being transmitted to descendants²¹⁸
3. Utilize the rapidly developing applications of genetics and assisted reproduction, (e.g., IVF), specifically to create or caused to be created a fertilized oosite for the purpose of treating the impairments, disabilities, disease, defects, or conditions of another child, or for the purpose of perpetuating disabilities or disability culture.²¹⁹

E. Encouraged, Incentivized, And Required Mandatory Actions

To ensure that abortions are truly informed, contemplated, and are the last option in all general circumstances, especially where the developing advancements in genetics, inclusive of genetic counseling and testing, and assisted reproduction, may discover or may cause the discovery of impairments, defects, deficiencies, or conditions, which may now or in the future rise to the level of a disability, the following actions, in the compelling interest of protecting human life, are encouraged, incentivized, and required:

1. Any woman, before she undergoes an abortion with respect to the existence or future existence of a disability of the unborn embryo or fetus, except where such abortion is necessary to preserve her health or safety, will be required to wait a period of one week for such an abortion.²²⁰ During this period, all medical professionals involved with the abortion are required to:
 - a. Provide the woman with information and examples about and of successful people with disabilities. A roster containing the contact information for area non-profits and agencies of and for people with disabilities is to be kept on file at the facility, institution, or hospital.²²¹
 - b. In addition to the passive roster above, which staff at the institution, hospital, or facility, is to provide, a confidential meeting by such woman with a family with disabilities is to be facilitated promptly. A disability liaison at the institution, hospital, or facility, which is to work in tandem with the medical staff, will be established for this purpose.
 - c. The scope of the position of disability liaison will include:
 - i. Providing the woman with information, contacts, and resources or referrals to support services, such as respite care, parent education and training, parent-to-parent counseling, homemaker services, and other services that enables families to maintain and provide quality care to children in their homes.²²²
 - ii. Informing the pregnant woman of the numerous public and private agencies, (inclusive of medical assistance), and services, which are available to assist her during her pregnancy and after the birth of her child, if she chooses not to have an abortion.²²³

F.

The woman, if she wishes to keep her child but is fearful of rearing a child with then or future existing disabilities, must be provided with information, resources, and referral to adoption or foster care, agencies, options, and programs therewith, before an abortion may be performed.²²⁴

G.

Who so ever seeks genetic counseling and testing in order to detect or diagnose a currently or prospectively existing impairment, defect, deficiency, or condition that may rise to a disability, for the purposes of, planning, designing, or acquiring early intervention services, including

developmental training and specialized social or medical therapies, is allowed a tax credit annually to account for the added costs of rearing a child with a disability.

B. Cultural Measures

Correspondence conveyed during the transition to the administration of President Obama suggested continued dialogue on these issues through a national summit on the impact of genetics on the disabled.²²⁵ To this end, it is critical to note that the National Council on Disability will host a national summit on disability policy in July 2010.²²⁶ At this summit, delegates will discuss healthcare services, systems, and technology.²²⁷ Additionally, recommendations which could potentially advance the better aspects of the models of disability in the context of this brave new world of science and technology, are as follows: (1) Congress needs to ratify²²⁸ the Convention²²⁹ and its Optional Protocol,²³⁰ (2) applicable federal agencies and departments should expand on the provisions of the Genetic Act by promulgating regulations and policies that, to the fullest extent possible, without being arbitrary and capricious,²³¹ are broader than the statute, and (3) Congress should pass, with the assistance and input of activists and scholars, a joint resolution indicating support for evidence-based and ethical-based genetic and assisted reproduction science and technology, on the one hand, but that, on the other, equally denounces its negative implications, namely, eugenics. Furthermore, HHS can engage in the vital task of consciousness enhancement of providers about people with disabilities, through increased training about and enforcement of civil rights provisions. Finally, HHS, possibly in partnership with organizations such as the American Medical Association, should utilize its full range of policy options to encourage the design and to mandate curriculum at medical schools for medical students as well as professional development for providers on disability.²³²

VI. Conclusion

Society must consequently grapple with, and will continue to grapple with, the ethical, legal, and moral issues implicated by genetic and assisted reproduction science and technology long into the future.²³³ Particularly, one class of individuals who are likely either to benefit or be negatively affected by this new world posed by science and technology are people with disabilities. A science-based dystopia, where some are equal, but those who have the correct genetic make-up are more equal,²³⁴ will occur if society is not to engage in affirmative actions. In an Orwellian sense, where such dystopia exists, “one who has the genetic code for four legs is good, but one who has the code for two legs is better.”²³⁵ However, when developed in a regime of appropriate regulatory promulgation, based on public negotiation and input, involving all segments of civic society secular leaders and institutions as well as ethical, moral, and religious leaders and institutions—science and technology has the power to enable the better facets of each of the models of disability to improve the quality of life and equality of opportunity of people with disabilities.

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² See DR. GABRIEL ROBINS, GOOD QUOTATIONS BY FAMOUS PEOPLE (1994-2009), <http://www.cs.virginia.edu/~robins/quotes.html> (last visited Mar. 21, 2010) (quoting Galileo Galilei).

³ See WILLIAM SHAKESPEARE, THE TEMPEST, Act 5, Scene 1 (1611), available at www.william-shakespeare.info/script-text-the-tempest.htm.

⁴ See UNITED METHODIST CHURCH TASKFORCE, SPIRITUAL DISCERNMENT: A GUIDE FOR GENETIC AND REPRODUCTIVE TECHNOLOGIES, 18 (2008) (providing a good explanation of science in terms of the laity to this field, setting forth ethical and religious issues, and providing recommendations for Methodists that seek to balance the fruits that could be derived from genetics while safeguarding the dignity of humans).

⁵ See Human Genome Project, Pharmacogenomics: Medicine and the New Genetics, http://www.ornl.gov/sci/techresources/Human_Genome/medicine/pharma.shtml (last visited Mar. 21, 2010) (Pharmacogenomics is the study of how the genetic makeup (genotype) affects how the body responds to medication. In my view, this is probably one of the promising outgrowths of genetics, which can improve the health of people with disabilities without necessarily jeopardizing the civil rights of such persons). www.ornl.gov/sci/techresources/Human_genome/medicine/medicine.shtml (last visited July 7, 2009).

⁶ See Robert S. Boyd, *Genome Advances Promise Personalized Medical Treatment*, MCCCLATCHY NEWSPAPERS, Nov. 16, 2009, available at <http://www.mcclatchydc.com/2009/11/16/78960/genome-advances-promise-personalized.html>; Meredith Simons, *Medicine Tailored to Your Genes*, SEATTLE POST-INTELLIGENCER, Nov. 16, 2009, available at http://www.seattlepi.com/health/412335_tailoredmeds1116.html.

⁷ See, e.g., Denise Avar, Ph.D., HUMAN GENETICS RESEARCH AND PRACTICE: IMPLICATIONS FOR PEOPLE WITH DISABILITIES, Jan. 14, 2002, available at <http://www.un.org/esa/socdev/enable/disid2001e.htm> (stating “[t]here is the potential for this impact to be positive, providing new treatments and supporting people’s choices about their health and reproduction. However, in light of the widespread discrimination faced by people with disabilities, there is danger that these developments could be used in ways that restrict rather than enhance the rights and choices of people with disabilities and their families.”); Edward J. Larson, *The Meaning of Human Gene Testing for Disability Rights*, 70 U. CIN. L. REV. 913 (2002).

⁸ See *Buck v. Bell*, 274 U.S. 200, 207 (1927) (Holmes, J., opinion) (upholding the constitutionality of the compulsory sterilization of a person with a developmental disability, stating “...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. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.... Three generations of imbeciles are enough.”). See generally, Roberta L. Cepko, *Involuntary Sterilization of Women*, 8 BERKELEY’S WOMEN’S L.J. 122 (1993); Posting of Theresa Walsh Giarrusso to <http://www.ajc.com/health/content/shared-blogs/ajc/parenting/entries/20> (In 2001, as a sign of social evolution by Americans, the Virginia General Assembly expressed its regrets for playing a part in the eugenics movement).

⁹ But see *In re Romero*, 790 P.2d. 819, 822 (Colo. 1990) (stating “...The decision whether to bear or beget a child is a constitutionally protected choice...,” (questioning *Buck v. Bell*)).

¹⁰ Larson, *supra* note 7, at 914-15.

¹¹ *Id.* at 915-19, 932-33. (The author describes the awful role of the United States in the eugenics movement with respect to persons with disabilities and

the period propaganda that extolled the benefits of non-creation or even death for the disabled).

¹² See *Roe v. Wade*, 410 U.S. 113 (1973); *Romero*, 790 P.2d at 821 (reasoning that women have a level of autonomy concerning their body and the decision to procreate).

¹³ See Convention on the Rights of Persons with Disabilities, opened for signature (Mar. 30, 2007), 46 I.L.M. 433.

¹⁴ E.g., Posting of Gary C. Norman to <http://blog.gmfus.org/author/gnorman/> (Jul. 29, 2008, 15:49 EST).

¹⁵ See Amy Adams, M.S., Genetics 101: Overview of Genetics, www.genetichealth.com/G101_Genetics_Demystified.shtml (Last visited Mar. 21, 2010) (noting that the building blocks of life can be contemplated as part of a descending litany. There are: 1. chromosomes, 2. genes, and 3. Deoxyribonucleic Acid or DNA, and 4. nucleotides. DNA, which is composed of four types of bases, designated A (adenine), T (thymine), G (guanine), and C (cytosine), plus proteins, equal a chromosome. In each chromosome, there are genes).

¹⁶ See RICHARD LEWONTIN, THE GENOTYPE/PHENOTYPE DISTINCTION, *Stanford Encyclopedia of Philosophy* (Edward N. Zalta ed., 2008), available at <http://plato.stanford.edu/archives/fall2008/entries/genotype-phenotype/>.

¹⁷ Namely the National Institutes of Health and the Department of Energy, as well as a myriad of international partners, such as, the United Kingdom.

¹⁸ See Adams, *supra* note 15; see also Larson, *supra* note 7, at 913; Patricia Alten, *GINA: a Genetic Information Nondiscrimination Solution In Search Of a Problem*, 61 FLA. L. REV. 379, 382 (2009).

¹⁹ See The Future of Genomics, Hearing before Subcomm. on Health, of the H. Comm. on Energy & Commerce, 108th Cong. (2003) (statement of Francis S. Collins, M.D., Ph.D., Director of the National Human Genome Research Institute, National Institutes of Health, Department of Health & Human Services), available at <http://www.genome.gov/11007447> [hereinafter *Future of Genomics*].

²⁰ Alexander Van Voorhees, Note, *Truth in Testing Laws: A Shot in the Arm For designer Gene Tests*, HEALTH MATRIX J. OF L. & MED. 797, 797 (2006).

²¹ Alten, *supra* note 18, at 382-83 (citing S. Rep. No. 110-48, at 5 (2007)).

²² Press Release, The White House, President Clinton Announces the Completion of the First Survey of the Entire Human Genome, Hails Public and Private Efforts Leading to the Historic Achievements (June 25, 2000), http://www.ornl.gov/sci/techresources/Human_Genome/project/clinton1.shtml (last visited June 29, 2009).

²³ See *id.*

²⁴ See *Future of Genomics*, *supra* note 19.

²⁵ See *id.*

²⁶ See *id.*

²⁷ See *id.*

²⁸ See Boyd, *supra* note 6, at 2.

²⁹ See *id.*

³⁰ See Voorhees, *supra* note 20, at 816.

³¹ See Nancy Arnott, *Genetic Counseling, Every day new discoveries unlock medical mysteries. How does this affect your family?*, CHILD BIRTH SOLUTIONS, INC, <http://www.childbirthsolutions.com/articles/preconception/geneticcounseling/index.php> (last visited Mar. 21, 2010).

³² See Rob Stein, *New Safety, New Concerns in Tests for Down Syndrome*, WASH. POST, Feb. 23, 2009, at A1, available at <http://www.washingtonpost.com/wp-dyn/content/article/2009/02/23/AR2009022302837.html>.

³³ See Janet Malek, *Symposium, Disabilities and the Duties of Potential Parents*, 2 ST. LOUIS J. OF HEALTH L. & POL’Y. 119, 121 (2008).

³⁴ See *id.* at 121.

³⁵ See *id.*

³⁶ See Jaime King, *Predicting Probability: Regulating the Future of Preimplantation Genetic Screening*, 8 YALE J. HEALTH POL’Y. L. & ETHICS 283, 286 (2008).

³⁷ See *id.*

³⁸ See Alten, *supra* note 18, at 382 (stating the project “supported an Ethical, Legal and Social Implications research program to address the many complex issues that might arise from this science”).

³⁹ Judith F. Daar, *Accessing Reproductive Technologies: Invisible Barriers, Indelible Harms*, 23 BERKELEY J. GENDER L. & JUST. 18, 21 (2008).

⁴⁰ See *id.*

- ⁴¹ See *id.*
- ⁴² See e.g., Janet E. Lord & Michael Ashley Stein, *Social Rights and the Relational Value of the Rights to Participate in Sport, Recreation, and Play*, 27 B. U. INT'L. L. J. 249, 252-56 (2009); see also Debra Kaplan, THE DEFINITION OF DISABILITY – PERSPECTIVE OF THE DISABILITY COMMUNITY, The Center for an Accessible Society, <http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm> (last visited June 24, 2009).
- ⁴³ See Lord & Stein, *supra* note 42, at 254-55.
- ⁴⁴ See Kaplan, *supra* note 42.
- ⁴⁵ See *id.*
- ⁴⁶ See Bradley A. Areheart, *When Disability Isn't "Just Right": The Entrenchment of the Medical Model of Disability and the Goldilocks Dilemma*, 83 IND. L. J. 181, 186-87 (2008) (stating “[A]dherence to the notion of disability as biological inability is precisely what enables the conclusion that accommodations push the market’s balance beyond equilibrium. More generally, adherence to the medical model encourages the view that disability rights are ‘special,’ akin to some form of charity for biological losers. In short, under the medical model, a person’s disability is her own personal misfortune-devoid of social cause or responsibility. From this perspective, the medical model has the...capacity to fragment the disability community by stressing the individual physiological traits that differentiate disabled persons, rather than the common societal obstacles that unite them.”).
- ⁴⁷ See Lord & Stein, *supra* note 42, at 254-55; Kaplan, *supra* note 42.
- ⁴⁸ *Id.*
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- ⁵⁴ See Nicholas A. Dorsey, Note, *Mandatory Reassignment Under the ADA: The Circuit Split And Need For A Socio-Political Understanding Of Disability*, 94 CORNELL L. REV. 443, 455 (2009) (stating, “[t]he rehabilitation model is essentially a modern application of the medical model. Like the medical model, the rehabilitation model locates the difficulties faced by a disabled person within the disabled individual — rehabilitation is needed to cure the individual’s defects.”).
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- ⁸⁸ Optional Protocol to the Convention on the Rights and Dignity of Persons with Disabilities opened for signature (Mar. 30, 2007), 46 I.L.M. 433.
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- ⁹² 527 U.S. 581 (1999) (holding that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination, based on disability under Title II of the ADA. The Court concluded that, under Title II of the ADA, unnecessary institutional segregation constitutes discrimination *per se*, which cannot be justified by a lack of funding. States may be required to provide community-based services, rather than, institutional placements as a consequence of the integration mandate. The Court remanded the decision to the lower courts for further proceedings.).
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- ²¹⁰ E.g., Okla. Stat. Ann. §1-568 West (2006 and Supp. 2009); PA. CONS. STAT. ANN. §3202(d) (West 1982 and Supp. 2009).
- ²¹¹ MINNS. ST. ANN. §145.424(3) (West 1982).
- ²¹² *Roe v. Wade*, 410 U.S. 113, at 163-64 (“Examples of permissible state regulation in this area are requirements as to the qualifications of the person who is to perform the abortion; as to the licensure of that person; as to the facility in which the procedure is to be performed, that is, whether it must be a hospital or may be a clinic . . . ; as to the licensing of the facility”).
- ²¹³ Women’s Health and Life Protection Act, §4, H.B. 1215, 81st Leg., 1st Spec. Sess. (S.D. 2006), available at <http://news.findlaw.com/cnn/docs/abortion/sdabortionlaw06.html>.
- ²¹⁴ ME. REV. STAT. ANN. tit. x, §2931 (2009).
- ²¹⁵ *Id.*
- ²¹⁶ *Id.*
- ²¹⁷ Assisted Human Reproduction Act 2004, available at <http://laws.justice.gc.ca/en/ShowFullDoc/cs/A-13.4/20090818/en?noCookie>.
- ²¹⁸ *Id.*
- ²¹⁹ *Id.*
- ²²⁰ Some courts have upheld waiting periods. See, e.g., *Cincinnati Women’s Serv., Inc. v. Taft*, 468 F.3d 361, 372-74 (6th Cir. 2006); *Fargo Women’s Health Org. v. Schafer*, 18 F.3d 526, 532-34 (N.D. 1994), February 10, 1994); *Utah Women’s Clinic, Inc. v. Leavitt*, 844 F. Supp. 1482 (D. Utah, 1994); *Woman’s Choice-East Side Women’s Clinic v. Newman*, 305 F.3d 684, 684 (Ind. 2002) (“*Casey* also found the twenty-four hour waiting period was not an undue burden, reasoning that ‘important decisions will be more informed and deliberate’ if made after some period of reflection Again, the Court looked to the exception for medical emergencies and record evidence that in the vast majority of cases a twenty-four hour delay does not create an appreciable health risk. Recognizing that in practice there is a substantial obstacle in a mandatory twenty-four hour waiting period, the Court found a closer question was whether the waiting period will increase the exposure of women seeking abortions to harassment and hostility of anti-abortion protesters. *Casey* held that these findings, while troublesome, did not demonstrate that the waiting period constituted an undue burden.”). Admittedly, no court has been presented with the question of a waiting period of one week, however.
- ²²¹ See generally, FLA. STAT. ANN. §393.064 (2009).
- ²²² *Id.* at 393.064(2).
- ²²³ See generally, TENN. CODE ANN. §39-15-202(b)(5) (West 2009); WIS. STAT. ANN. §253.10(L)(2)(c) (West 2009).
- ²²⁴ *Id.*
- ²²⁵ Letter from American Association of People with Disabilities et al to Melody Barnes, Assistant to the President for Domestic Policy, Presidential Transition Team and Lisa Brown, Staff Secretary, Presidential Transition Team (Dec. 23, 2008), available at <http://jfactivist.typepad.com/jfactivist/2008/12/index.html>.
- ²²⁶ National Council on Disability, *NCD National Summit on Disability Policy 2010: ADA 1990-2010 Retrospective and Future Policy Directions*, available at <http://www.neweditions.net/ncd2010/index.html> (Last visited Oct. 23, 2009).
- ²²⁷ *Id.*
- ²²⁸ In the summer of 2009, President Obama pledged that his administration would sign, and his Ambassador to the United Nations, Ms. Susan Rice, Ph.D. signed, the Convention at a ceremony. Myriad members of the disability community attended; among them, were the President of the Am. Foundation for the Blind. Congress must next ratify the Convention by a super majority. As the Senate is controlled by Democrats, this is anticipated. See, Remarks of Susan Rice, Ambassador to the United States Mission to the United Nations & White House Senior Advisor Valerie Garrett at U.N. Headquarters (Jul. 2009), available at www.usunewyork.usmission.gov/press.../20090730_156.html.
- ²²⁹ Convention, *supra* note 87.
- ²³⁰ Protocol, *supra* note 88.
- ²³¹ See, e.g., *Thomas Jefferson University v. Shalala*, 512 U.S. 504 (1994) (discussing the standard, as applied in the context of regulatory promulgation of the HHS).
- ²³² E.g., Disability Rights and Education Defense Fund, Healthcare Outcomes for People with Disabilities, Healthcare Access Br., available at http://www.dredf.org/healthcare/Access_Brief.pdf (Last visited Jul. 8, 2009).
- ²³³ Donald Elliott, *Symposium, The Genome and the Law: Should Increased Genetic Law Change the Law?* 25 HARV. L. J. & PUB. POL’Y. 61, 61 (2001) (“[H]ow should our law change in light of increasing knowledge of the human genome? That will be a central question occupying legal thought in coming decades as progress in genetic changes not only our understanding of human nature but, also our ability to manipulate human nature.”).
- ²³⁴ See, Michael Schmid, *The Orwellian Language of Big Government*, Pol’y. Paper No. 152 (June 22, 2004), <http://www.ntu.org/main/press.php?PressID=604>.
- ²³⁵ *Id.*; see also, *George Orwell’s Animal Farm: Lessons for Today* (Oct. 2006), available at <http://www.stentorian.com/animfarm.html>.