Born Blind: The Ethics of Accepting Disabilities in an Age of Genetic Intervention

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I. Introduction

His disciples asked him, "Rabbi, who sinned, this man or his parents, that he was born blind?" Jesus answered, "Neither he nor his parents sinned; it is so that the works of God might be made visible through him." Hermeneutical interpretations of John's Gospel reveal that the man's disability ought not to be considered a punishment, or a sentence to be served, but rather as a theophany, a manifestation of God's power. However, few but the most theologically learned scholars are likely to accept without question that those suffering with debilitating disease or disability are expected to merely accept their condition as reflecting God's grace, without considering the possibility of a cruel, potentially avoidable genetic punishment.²

Genetics, as well as enhanced medical and reproductive technologies, have empowered humans not only with the ability to detect diseases in infants which may result in disabilities before symptoms are present, but to do so even before the embryo implants within a mother's womb. While these methods can serve laudable purposes by improving the overall life of a child, genetic screening and selective reproductive processes can also create unnecessary worry, stigma and other kinds of potentially irreparable harm.³ While not delving into all those harms, this paper will argue that society's obligation to improve the human condition through alleviating human suffering and disease does not presuppose the total elimination of human disability through genetic intervention. This stands in contrast to a seeming fixation with and self-appointed obligation to perfect the human species fostered by advances in technology and genetic research.

II. Striving to Improve the Human Condition

Understanding what it means to be human and to possess those characteristics and traits which are uniquely and typically human has been an endeavor of philosophers, anthropologists, politicians and theologians practically since the beginning of time. Humanity's ongoing search to define itself is further complicated by its own desire to improve itself—a self not even fully understood through biomedicine and genetics. In its quest to improve the human condition, humanity wrestles with the attraction of eliminating all unacceptable characteristics and traits not deemed typically human. To say that someone is disabled or that they carry some genetic defect presupposes that there exist criteria for what it means to be non-disabled-to be a "normal"

human. Accepting persons with disabilities, and even rejecting them, requires societal introspection and at least some recognition of what it means to be human.⁴

A. The Meaning of Being Human and the Human Condition.

Possessing ideal human characteristics is largely an ambiguous, social construct. From an evolutionary perspective, humans and their embodied nature are distinguished from other animals and are studied according to how they live in relation to their environment, as well as in terms of particular characteristics of human biology.⁵ According to Allen Buchanan, humans possess good and bad, common and natural characteristics and dispositions that are impervious to change and external influences, such as the ability to make moral decisions and engage one another socially. As such, without these and other impervious and constant characteristics, a being would not be human.6

In addition to reason and reflective capacities, the Judeo-Christian tradition, which has greatly influenced Western thought, holds that what makes human animals *human* is the fact that they are made in the image and likeness of God. This implies that human beings are in special relationship with God and serve as co-creators and stewards for humanity. As stewards, humans have divinely bestowed dominion and are responsible for overseeing things produced for the good of humanity as well for the persons producing them.⁷ This dominion presupposes the duty to change and improve life for the rest of humanity.

Hence, both secular and theological perspectives of what it means to be human underscore the need for humans to change and to improve. Both agree that a fundamental human characteristic is the aspiration to become transformed into healthier, more enlightened beings, though there is a lack of normative rules dictating when and which parts of human beings can be changed or even destroyed in its pursuit of self-improvement.⁸ What is clear is that human life is challenged and even limited by a host of complex variables, what Walter Doefler refers to as the *human condition*.⁹

The human condition is generally seen, in varying degrees, as broken and flawed. Accordingly, human beings, from the beginning, have been striving to eliminate limitations, alleviate suffering and improve the quality of human life toward greater human fulfillment. An examination of the concepts of human flourishing and the good life will help shed light on the extent to which human beings will go in order to reduce or eliminate limitations—particularly those perceived limitations associated with human disability.¹⁰

B. Human Flourishing and the Good Life.

What constitutes a good life and the quest for selecting qualities of human nature which ought to be preserved are questions as old as humanity itself. This paper will not explore the many dimensions of these questions, but will accept for the sake of brevity that those qualities attributed to a good life depend upon what a good life is considered to be. One approach to this question is that a good life is one that promotes and allows for human flourishing.¹¹

As with a good life, there is no single view or generally accepted idea of what it means to flourish. Glover aptly states that much of human flourishing relies upon the innate differences attributed to each human and their unique circumstances and environments. With respect to human disability, Glover contends that while all human disabilities involve some functional limitations, the mere presence of a functional limitation does not create a disability, but rather the real disabling quality is found in the impairments or obstacles to human flourishing. Moreover, much of the ability to flourish depends upon the person's reactions and responses to the circumstances and settings that confront them.¹² A flourishing life is not devoid of flaws or limitations, but is rather one that respects those limits and learns to live alongside rather than beneath them.¹³

Throughout most of history, the idea of disability was a medical one. However, the ability for persons with some physical or cognitive limitations to flourish is often impeded by deficient societal settings and negative perceptions of the idea of disability more than by mere biology. The absence of wheelchair ramps, poorly designed transportation systems, and the lack of education and understanding of how to interact with persons having limited functionality impairs human flourishing oftentimes more than the limitation itself. The ability to flourish is further hampered by cultural assumptions of what is *normal*, and society's frequent intolerance, discriminatory practices and preconceived opinions about persons with disabilities and their limitations.¹⁴ Often persons with disabilities, particularly cognitive impairments, function at a level that is often above that of typical or *normal* persons and yet, they are still considered to have a disability.

This presumes that living with a disability or with a person who has a disability is somehow a denial of life's goodness. Persons with disabilities can flourish on their own, because what constitutes flourishing is dependent largely on preferences.¹⁵ A disability which renders someone unable to engage in a particular activity may not be a disability at all if the person would not value that activity or want to engage in it even if they could.¹⁶ Most persons with disabilities along with their families and loved ones express a sincere appreciation for the lives they live. The joy that someone with a disability experiences in the ordinary course of their lives-the joy they appreciate-is markedly different from that which the able-bodied experience. Hence, they are misunderstood or ignored altogether. The negative views and social responses to those with disabilities are based upon prejudice and ignorance.¹⁷ People rarely talk about the positive, relational life experiences of persons with disabilities, but rather, persons with disabilities are often referred to in relation to their perceived deficiencies. In addition to the importance of human flourishing, the

good life ought to be defined in terms of the health of human relationships.

The relationships between persons with disabilities and their families, the persons they choose as friends, and the communities within which they live can enhance and enrich the ability to flourish beyond any biological characteristic or quality. Martina Holder-Franz warns that society must guard against creating a myth of normality that values people excessively for their biological characteristics and qualities. She contends, instead, that life is vulnerable and relational, and persons with disabilities ought not to be judged by their *ability*, but rather by their *availability* for relationships. Personhood is sustained by relationship, and what sustains relationship is love.¹⁸

Christian theology teaches that humans are to live in communion with each other. to share with one another and to serve one another. The Great Commandment is about humans and their loving relationship to their neighbor.¹⁹ Human flourishing demands loving relationships that promote dignity, friendship and caring. Rather than adhering to attitudinal barriers which create roadblocks to flourishing, humans must be motivated by a belief in the goodness of creation and the image of a God that is present in everyone in order to reveal God's face and to allow His grace to emerge.²⁰ The grace that appears allows humanity to witness the truth that each person is limited and broken in some manner and is need of others. This enables persons with disabilities (and all persons) to live what Matt Edmonds calls a graceful life.²¹ This

togetherness promotes interdependence that welcomes the presence of God, and helps to eliminate the fear that often pervades the willingness to get to know a person with a disability. Christian interdependence honors the value of all individuals-despite their limitationsnot by what they can or can't do, but by simply being who they are.²² Interdependence means persons are dependent upon God and each other, but it also acknowledges God's dependence upon everyone to be agents for God's healing throughout the world.²³ The idea of healing and curing are seminal objectives often employed when supporters seek to justify improvements to the human condition, particularly when those genetic improvements seek to eliminate disease and suffering associated with perceived disabilities.

III. Perspectives on Improving the Human Condition

Although there are inherent cultural and societal difficulties in determining which human characteristics render a person able-bodied or disabled, or normal versus abnormal, applying a medical model that relies on the human genetic code will at least presuppose a prescribed, predictable baseline of acceptable and healthy genetic characteristics. Influenced by the bioethical principles of beneficence, autonomy, justice and non-maleficence, genetic technology and medicine undergird the duty to improve the human condition by preventing mortality, morbidity, and disability.²⁴ The concepts of healing and cure seem to undergird these efforts to improve, and often run

parallel to or intersect with the history of eugenics.

A. To Heal Or To Cure.

The distinction between curing and healing is rarely clear, and, in fact, it is frequently blurred. When the word *cure* appears in the English language, it typically refers to the eradication of a disease and its symptoms such that a person is restored to the same health and physical condition as before the disease appeared, or as if it hadn't appeared at all.²⁵ If a cure seeks to eliminate disease and suffering, it must be distinguished from *healing* which, as Nancy Lane asserts, is a *process* of integration and wholeness and not simply being free from illness, and does not necessarily manifest physically. According to Lane, healing is freedom from false and unrealistic expectations.²⁶ Healing brings about grace, peace and well-being, and often involves finding a sense of meaning and purpose-a spiritual wholeness, but not necessarily a cure.²⁷ A healing may or may not include a cure, and, clearly, a cure may or may not include a healing.

Understanding the nebulous demarcation line between these two words is critical to the discussion of genetic interventions and their effect on human disabilities. Because society traditionally perceives healing very narrowly and typically recognizes it only in the physical improvements and manifestations of those persons with an easily detectable disorder or disability, its inclination is to focus on only the physical effects of the healing or cure. This tendency severely limits how society ought to see the collateral impact to the ablebodied as well as disabled persons who are spiritually healed, even in the absence of a cure.²⁸

To find a cure, society turns to the medical arts. Exercising prudence, religious traditions advocate and approve of the view that humans can intervene as stewards of life and co-creators to cure and heal, seeing medical professionals as God's agents on earth.²⁹ However, as St. Basil the Great warned, there are limits to the effectiveness of the medical arts and persons cannot turn the pursuit of health and cure, or even longer life, into an allconsuming idol. Medicine as a healing art gives glory to God, but if fails to help, all hope for relief cannot be placed in this art. Humans must look to God's will.³⁰ This is a critical warning, because while the New Testament is filled with accounts of Jesus' curative miracles as divine revelation, not everyone who was sick was cured, and yet many were inwardly healed.³¹

It is in society's best interest to place a high value on health and well-being, to value good health over ill-health, and to reduce morbidity and improve overall health. However, as Wilkinson contends, placing a high value on good health ought not to imply that those who are ill or disabled are valued less. Similarly, while most people would prefer being ablebodied to being disabled, and healthy rather than unhealthy, the fact of the matter is that much of what is considered normal and able are subject to normative beliefs,³² and even the most robust members of society are only temporarily able. In time, all are broken to some

degree.³³ So a principle issue for those who seek to improve the human condition is whether it is in the purview of society to decide the state of any future person by eliminating disability through genetic intervention. The notion of choosing who and what constitutes an appropriate human life has many very deep roots in eugenics.³⁴

B. The Impact of Eugenics.

The term *eugenics* was coined in the late 19th century by Sir Francis Galton to refer to those who were "well born" and was applied to the study of heredity to improve the genetic makeup of the human race by removing undesirable individuals from the societal gene pool. Later, the U.S. Supreme Court decision in 1927 upholding the eradication of all "imbeciles" bolstered and fortified this movement.³⁵ During this period in history, it became an obligation and reproductive duty of all good citizens who were the "right type" to leave behind their blood in the world through procreation and to prevent the "wrong type" of person from procreating. Forced sterilization laws mandated that prisoners, residents of mental facilities and paupers-those deemed manifestly unfit-be irreversibly prohibited from reproducing.³⁶

It wasn't until Adolf Hitler's perverse and notorious world of eugenics, genocide, and mass murder resulted in the systematic execution of those persons classified as "defective" that the American eugenics movement began to die. Any association with Nazi eugenics was shunned. Genetic advances today are resurrecting eugenic-like conduct and reintroducing it into American culture largely through prenatal testing, and the killing of embryos and abortion of fetuses with genetic disorders. However, termination of these unfit lives is performed without any honest acknowledgement of the eugenic nature of the activity.³⁷

Today eugenics is typically characterized as a study of the conditions under which the human condition or the biological character of the human race and its offspring can be improved. Often influenced by political and social controls, positive eugenics occurs when the goal of a eugenic activity is to produce humans of high quality by increasing the "good" gene pool in order to enhance the human condition. Negative eugenics seeks to reduce undesirable genes that cause disease and disability in order to prevent harm to the human race by minimizing the number of sick babies born.³⁸ The positive and negative aspects of eugenics and the purpose of each type determine whether disability is seen as a defect requiring enhancement or elimination, a disability that seeks healing, or as an illness seeking a cure.

The connection between genetics and historical eugenic philosophies, which associated social ills with the prevalence of mental and physical defects, undergirds much of contemporary thinking concerning treatment of persons with disabilities.³⁹ Ethicists who argue against eliminating disability through both positive or negative eugenics properly contend that genetically screening out and deselecting disability, or even attempting to correct characteristics of disability in the absence of a diagnosis, expresses discriminatory views that the person is unfit. And even those ethicists who support negative eugenics admit that continued efforts to reduce the number of sick babies will merely increase the list of characteristics, qualities, and conditions to be eliminated, adding to the discriminatory effect.

Since the primary goal of eugenics is the identification, manipulation and perhaps elimination of certain prescribed human characteristics, those who possess certain disabilities are once again viewed as having lives that are less meaningful, have less purpose, and are deemed unworthy to live.⁴⁰ Consequently, eugenicists would support deselecting embryos believed to carry a disabling condition because it would avoid creating a low-quality life. This is a preposterous belief, and as Wilkinson asserts, the happiest person with a disability will likely experience a better quality of life than the most miserable able-bodied person.⁴¹ Similarly, Paul Ramsey considered all forms of genetic control unethical arguing that positive eugenics suffered from cultural influences determining normalcy and defect, and instead favored very limited negative eugenics through voluntary childlessness and reducing the number of pregnancies if a known genetic predisposition existed. Some ethicists see eugenics as genetics in the absence of Christian thought.⁴² Although many do, clearly not all methods employed to improve the human condition through

genetic interventions carry the indicia of questionable eugenics. IV. Methods of Improving the Human Condition

There are many ways to improve the human condition and create opportunities for humans to flourish that do not entail biological interventions. Nevertheless, disease avoidance typically involves some physical interventions. Some of these will now be briefly considered.

A. Newborn Screening and Prenatal Testing.

Today, state-sponsored newborn screening tests are administered to more than 4 million infants per year.⁴³ By acting on the screening results, presymptomatic identification and diagnosis can help to establish early treatments—including dietary modifications—to avert a serious disability, moderate the effects of a disease and improve prognosis, and assist parents in their future reproductive planning.⁴⁴

Policymakers favor screening only for serious disorders with effects that can be mitigated or even reversed before clinical onset. There is an overwhelming acceptance of mandatory newborn screening initiatives for those conditions where morbidity is reduced, disabilities are avoided and beneficial treatments and protocols exist.⁴⁵ As such, newborn screening provides a mechanism for human flourishing which serves to avoid needless suffering for newborn children and their families in order to improve the human condition without controversy. Carrier and prenatal testing can determine the risk of having a child with a rare congenital condition if both parents carry the same gene—oftentimes ahead of pregnancy, but always before the child is born. Information from carrier testing can assist parents in making informed, proactive, reproductive and even lifestyle choices which may reduce the prevalence of a disease. In addition, testing may afford parents the opportunity to prepare financially as well as psychologically for the arrival of a child with special needs if they decide to have their own biological child.⁴⁶

Carrier and prenatal testing shift the parental decision away from deciding which early intervention or treatment is most appropriate to having a healthy baby as in the case of newborn screening, to deciding whether to have *any* baby at all. It is this *selective* quality that carries both ethical and theological implications.

B. Selective Reproduction.

While most genetic intervention is seen as a positive method of promoting flourishing for both existing and future children, selective reproduction makes it possible for parents to literally choose to have one desirable child instead of another child with perceived undesirable characteristics and disabilities, thereby allowing one person to come into being while another may die.⁴⁷ Reducing the conflict that selective reproduction techniques create between flourishing and negative eugenics requires some examination of what parents really owe to their children.⁴⁸ Most parents want what is best for their child and accept the obligation to provide for them according to their ability. However, it is not clear whether the duty to provide what is best includes genetic interventions to eliminate a disability, or to choose not to have a child with a known disability all together. Since a good life entails the ability to flourish, then it logically follows that parents have a duty to provide opportunities for their children to flourish, and any intercession beyond that, such as genetic interventions to correct or eliminate conditions that do not clearly threaten human flourishing, may go too far and represent nothing more than parental hubris.49

Certain prenatal testing procedures call into question the parental duty to facilitate flourishing. Procedures such as amniocentesis can result in the prenatal diagnosis of Down-syndrome and other congenital defects that cannot be treated and reversed in utero. As a result, termination of the pregnancy is often viewed as the only "therapy" for these conditions. In addition, pre-implantation genetic diagnosis (PGD), which occurs prior to the embryo entering the womb, forces parents to decide which embryo to implant and which one to destroy.⁵⁰ Wilkinson aptly contends that selective reproduction such as PGD and prenatal testing accompanied by selective termination present the opportunity for present and future children to be discarded and replaced with a more desirable variety.⁵¹ Thus, the ability to choose future children through selective reproduction is vastly different from

providing opportunities for human flourishing by improving the condition of children who currently exist through newborn screening, preventive medicine, and treatment.

Inherited genetic modification (IGM) or somatic gene therapy makes it possible to modify the state of a baby's genetic blueprint from what the baby *would* have become to what it will become.⁵² While it has been developed as a treatment because it can affect inheritable gene material, it also possesses all of the critical components of an enhancement that seeks to improve the human condition rather than only treat a human being.⁵³

V. Ethical and Theological Dimensions of Deselecting Disability.

Deselecting children and denying them life in an attempt to improve the human condition and minimize suffering by reducing the number of persons with disabilities threatens, among other things, the notion of uniqueness. It further conveys the message that the world would be "improved" and better off if persons with disabilities were never born.⁵⁴ The presumption that a person with a disability experiences human suffering, that all suffering is bad, and that suffering eclipses human flourishing ought to cause humanity to reconsider its view of what it means to suffer.

Human flourishing does not entail genetic perfection through the absence of disability. Rather, it entails embracing all life as a gift through acceptance and tolerance. Just as it would be unconscionable to abandon a child who becomes disabled, rejecting a possible future child with a disability is equally so.⁵⁵ Pervasive negative images of persons with disabilities and the abhorrent notion that they impose burdens on the human condition that should be eliminated through genetic interventions must be examined through ethical and theological lenses.

A. The Gift of Life and Human Suffering.

To say that a human life is only as good as the person's ability to flourish implies that much of the good turns on the choices available to that person. Hans Reinders considers human goodness and asserts, instead, that what accounts for having a good life is not whether a person would choose to live their life again, if given the choice, but rather the recognition that life is good because it simply is good. The goodness of life is a gift of divine goodness—a donum—a gift and giftedness that has a divine purpose.⁵⁶ Life as a gift is received from God who intended it to be good and is grounded in God's act of giving.57

Nevertheless, God's gifting of the good life does not vitiate humanity's free will and choice. As with any gift, humans have the choice to accept the gift. The goodness of life turns on humanity's willingness to learn how to receive His gift, respond to Him, and find peace with Him. God's gift of life does not come with a voucher; it cannot be returned if it isn't exactly what was desired or doesn't fit quite right. Gracious recipients of gifts know that the highest compliment a person can pay the giver is to thoroughly enjoy and love the gift. So it is that the highest recognition a human can give God is to thoroughly love their good life.⁵⁸

Writing in a more secular vein, William May refers to parenthood as the 'openness to the unbidden' in that the ethic of giftedness includes the notion that parents ought to appreciate children as gifts and accept them as they are given. The gift of life is not as an object of design to pick and choose as a person might pick and choose the color scheme of a newly built home or office. Parental love cannot be contingent on the desirability of the attributes and talents of the child. Flourishing requires love-two types of parental love according to Mayaccepting love and transforming love. Accepting love affirms the goodness within the gift of life and transforming love seeks the well-being of the child.⁵⁹

Transforming love speaks to the obligation to heal and strive for curative measures as necessary and to advance medical treatments for the sake of the health of the child, but not as an attempt at boundless mastery or domination over the giftedness of the child. The obligation to heal or help cure a sick child now does not equate to rejection of the future gifts of life of later born children, nor does it grant a parent authority to change the genetic makeup of this gift.

But humanity struggles with the idea of expressing authentic appreciation for an arguably good gift of life that brings with it physical and/or emotional pain and suffering.⁶⁰ Even though the presumption that persons with disabilities experience suffering that is desperate for relief is shaped by society's understanding of normalcy and individuals' perception of personal flourishing, reducing suffering and preventing impairment are still primary goals of humanity. As is often the case with those who have a disability or are different in some apparent way, the greatest suffering one can experience is the pain of isolation and rejection, or the pain from the knowledge that one belongs to a class that is not welcomed or valued. Yet, the truth is, only those with disabilities know whether or not they suffer.⁶¹ Theological concepts of suffering can help to shape patterns of interaction and understanding between those with disabilities and those without.⁶²

Biblical support of virtuous suffering—the idea that impairment and disability are signs of divine election, as reflected in the passage from St. John's Gospel at the beginning of this paper—may help to sanction acceptance among persons with disabilities, but does little to foster acceptance between the community and even the parents of those with disabilities.⁶³ What needs to happen is a universal acceptance and recognition that those with disabilities, especially those who are perceived to suffer greatly, are divine gifts and, as St. Augustine claimed, humans are not defined by their mental and physical perfection or the degree to which those capacities are painfully deformed and disabled, but rather are grounded in their decent from Adam. As

such, they should not be shunned, but rather seen as God's special works. By fixating only on the perceived deficiencies and limitations of those with disabilities, society's adherence to artificial normative constructs of what constitutes avoidable pain and suffering fails to recognize a significant value and gracefilled opportunity that those with disabilities bring to living. As the footwashing scene in the New Testament emphasizes, the essence of Christian life is one of community and service to one another. This service does not define one person as superior or inferior to the other, but rather establishes a mode of service involving the sharing of gifts between friends-bundling the notions of love of neighbor and Christian friendship.⁶⁴ The theological concept of suffering creates an opportunity for Christian service and friendship, not for genetic intervention and eugenic eradication.

Nothing is more unimaginable than the broken and disabled Christ as described by Isaiah. Unable to move or speak, he was profoundly and grotesquely disabled, and like many who suffer stigmatization from their afflictions, he was avoided, spurned and accustomed to infirmity. Like the fear that many have for those with disability, people hid their faces from him.65 And despite being dispossessed of his power and abandoned by nearly everyone, he was restored to greatness through his suffering. For those who struggle to understand the role that pain and suffering play in Christian life, it is often understood best when someone lives through their most painful and challenging experiences. It is then that

they find God, somewhere in the pain. The pain is used for some transformed good. Richard Rohr teaches that pain is counterintuitive. People must go down before they can know the joy that is above.⁶⁶ It is in this transformation that pain and suffering take on a deeper meaning. It is through the integration of the giftedness of life, living in service of others, and the grace that comes from human suffering that Christianity emerges to embrace human disability as a divine blessing, not as a loathsome disease.

B. Christian Acceptance of Disabilities.

Conservative and liberal Christian theologians differ considerably as to whether or not the duty to improve the human condition and promote human flourishing includes genetic interventions that interfere with human disability and, if so, what amount and type is appropriate. The spectrum ranges from the view that humans are co-creators and that the call of the faithful is to work for the most desirable future for humankind measured by God's destiny, to the thought that genetic technology and the ability to provide for a better future is justified through brotherly love and beneficence, and to the view that technological advances do not permit humans to *play* God,⁶⁷ but rather to play human as God intended. This means humans have a stewardship duty to restore, change, and sustain the world.⁶⁸ In addition, it is critical to understand that for most Christian perspectives, particularly Roman Catholic, attempting to improve the human condition by deselecting an

embryo likely to have a genetic defect is the functional equivalent of killing a disabled person.⁶⁹

As discussed earlier, life is a not a matter of chance, it is a gift, and human procreation is not a game where the winner takes all and parents who give birth to a child with a congenital disorder or who learn of a genetic defect are forced to become gracious losers.⁷⁰ Rather, since all human life is a gift from God and parents who receive God's gift cannot lament the fact that the child lacks certain characteristics, or ideal traits, or that the child has a serious disability.⁷¹

Since humans are in fact God's co-creators through the gift of procreation, then perhaps the goal of humans is to move away from wanting supremacy over nature and to move instead towards the ultimate good and human flourishing considering the eschatological dimension that Aquinas suggested. However, the Catholic Church does approve genetic interventions that do not contradict Catholic reproductive norms provided that their principle aim is curative, palliative or preventive, and possibly even geared towards elimination of a genetic disorder from a family line, without harming human integrity or worsening a person's life condition.⁷²

The Magisterium of the Catholic Church professes to hold science and research in positive esteem and urges that harmony between science and indispensable human values be established. It sees science as an expression of man's dominion over creation, according to the *Catechism of the Catholic Church*.⁷³ However, the Church warns that from the moment of conception, every living embryo must be respected as if it were human in an absolute way because humans are the only creature that God wished for himself and no one has the right to destroy that life.74 In addition, the Catechism of the Catholic Church further teaches that it is morally unacceptable to put an end to the lives of the disabled or handicapped, regardless of the means or motives.⁷⁵ Hence, genetic interventions that seek to eradicate human disability through de-selection or other means are prohibited. All human life that is affected by disability or handicap is to be treated with special respect.⁷⁶

As already mentioned, the Catholic Church and other Christian faiths recognize the duty to be stewards of creation and to improve the human condition through activities that demonstrate a continual respect for human life. By applying the gifts of wisdom and prudence, humans can come to understand the future that God intended for creation, the scope of human flourishing, and the appropriateness of human actions toward that end.77 Deanne-Drummond correctly suggests that moral justification for improving the human condition through genetic technology can find guidance within the theological framework of virtue ethics. Prudence (recognized as experiential reasoning), justice (balancing equality with good), fortitude (the strength to do what is right), and temperance (selfrestraint in the face of impulse) are gifts of the Holy Spirit that are infused by God. Applying these theologically informed virtues is necessary to moral decisionmaking vis-à-vis genetics and the implications for those with disabilities.⁷⁸ Prudence and wisdom will open the eyes blinded by eugenic notions of perfection to see that the human condition is *unconditional* and acceptance of God's gift is not conditioned on achieving human perfection.⁷⁹

The concept of eschatology underscores the notion that humans cannot, and should not attempt, to make themselves perfect on their own. Death will always eclipse confidence in genetic technology and interventions.⁸⁰ The Babel Principle, according to Nigel Cameron and Amy DeBaets, warns the human race against such arrogant attempts to circumvent God and achieve perfection on its own.⁸¹

The Christian community must remain committed to the gifts of the Holy Spirit and to acting in ways that are welcoming and accepting of all persons with disabilities along with their families.⁸² When society welcomes these, they welcome God. According to Deanne-Drummond, Stanley Hauerwas and other disability theologians echo that the presence of God is in everyone – especially the disabled, and when they are accepted, welcomed and sustained, God is similarly affected. God's being is the being of the disabled.⁸³

VI. Conclusion

Human beings have long pondered the existence of pain and suffering in the world, and considered the presence of disability to be someone's punishment or curse.⁸⁴ The desire to eradicate suffering and transform the human condition has motivated society, science, and medicine throughout the centuries and appears to have found its culmination in genetic technology. Humanity's interest, however, in improving the human condition and alleviating suffering appears to have stretched beyond what is morally acceptable insofar as genetic interventions and modifications seek to eliminate human suffering by presupposing the elimination of those with disability.

Accepting and embracing human disabilities requires a shift away from a culture that pursues perfection at all costs and requires recognition that the beauty found in the person with a disability is not dependent upon human perfection, but rather, divine grace.85 Human perfection ought not to be a human aspiration, but rather an exclusive entitlement belonging to the one true holder of Divine sovereignty. Prudence allows those who seek perfection by eliminating the imperfect to see that there is much to learn from those with disabilities and the tendency to render them worthless or unfit is wrong.

The Creator of the human condition is indeed a God of and for the broken and disabled in all of humankind. And in fact, Jesus reminded his disciples that God's ultimate power and presence was reflected in the man born blind. His blindness, like the myriad of disabilities present in contemporary society, did not emanate from his sin or the sin of his parents, and was not something to be de-selected and destroyed. Rather, his healing and the lessons learned from that healing were

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signs of God's preeminence. Human limitations and sinfulness resulting from the Fall can disable human senses and prevent persons from seeing and hearing God's tender voice, not a vengeful voice, that whispers to his people in a sound of fine silence.⁸⁶ These same limitations can be overcome whenever people set aside their prejudices and see with the eyes of the disabled, and listen with their ears to God' divine message.

^{1.} John 9:2-3.

 ^{2.} (Rohr, Things Hidden: Scripture as Spirituality, 9-12-25).
^{3.} (Baily and Murray, Ethics and Newborn Genetic Screening, 160-169, 206, 260-266).
^{4.} (Black, The Healing Homiletic, 43-47).
^{5.} (Kraebnick, The Idea of Nature. Debates About Biotechnology and the Environment, 49-56).
^{6.} (Buchanan, Beyond Humanity, 143-152).
^{7.} Genesis 1:26-29.
^{8.} (Buchanan, 115-139).
^{9.} (Swinton and Brock, Theology, Disability and the New Genetics. Why Science Needs the

Church, 117-130).

^{10.} (Buchanan, 130-139).

^{11.} (Glover, *Choosing Children. Genes*,

Disability and Design, 87-99).

^{12.} (Glover, 4-18).

^{13.} (Cole-Turner, *Transhumanism and Transcendence*, *52*-59).

^{14.} (Swinton and Brock, 44-54).

^{15.} (Eiesland, *The Disabled God*, 49-67).

^{16.} (Wilkinson, *Choosing Tomorrow's Children*, 63-75).

^{17.} (Swinton and Brock, 163, 165, 205);

(Eiesland, Human Disability, 206-208).

^{18.} (Swinton and Brock, 57-64).

^{19.} Matthew 22:34-40.

^{20.} (Au, *By Way of the Heart*, 41-48).

^{21.} (Matt Edmonds, A Theological Diagnosis. A New Direction on Genetic Therapy, 'Disability' and the Ethics of Healing, 29-42, 130). ^{22.} (Eiesland, 19, 36-40, 52-63). ^{23.} (Black, 32-42). ^{24.} (Deanne-Drummond, 1-5, 140-148). ^{25.} (Edmonds, 153-168). ^{26.} (Edmonds, 42-43, 160-161). ^{27.} (Black, 50-56). ^{28.} (Eiesland, 105-122). ^{29.} (Glover, 171-179). ^{30.} (Cole-Turner, Design and Destiny, 2, 11, 83-88). ^{31.} (Martos, Doors to the Sacred. A Historical Introduction to the Sacraments in the Catholic Church, 328-343). ^{32.} (Wilkinson, Choosing Tomorrow's Children, 159-166); (Baily and Murray, 299-302). ^{33.} (Eisland, Human Disability and the Service of God, 123-140). ^{34.} (Deanne-Drummond, Genetics and Christian Ethics, 55-75). ^{35.} <u>Buck v. Bell</u>, 274 U.S. 200 (1927). ^{36.} (Sandel, The Case Against Perfection in Ethics in the Age of Genetic Engineering, 63-68); (Edmonds, A Theological Diagnosis, 50-51). ^{37.} (Swinton and Brock, 96-106). ^{38.} (Wilkinson, 149-163); (Deanne-Drummond, Genetics and Christian Ethics, 60-74). ^{39.} (Brownlee, *Disability and Disadvantage*, 319-320). ^{40.} (Wilkinson, 149-185). ^{41.} (Wilkinson, 58-70). 42. (Wilkinson, 170-173); (Deanne-Drummond, Genetics and Christian Ethics, 55-67). 43. (Baily and Murray, 1-30, 100, 212-214). ^{44.} (Baily and Murray, 93-116); (Deanne-Drummond, Genetics and Christian Ethics, 77-

88)

^{45.} (Baily and Murray, 129-130,223-224,

264); (Deanne-Drummond, 81-84).

^{46.} (Baily and Murray, 292-303).

47. (Wilkinson, 5-7, 177); (Deanne-Drummond, 5-8). ^{48.} (Glover, 14-18, 39-51). ^{49.} (Glover, 14-18, 39-74). ^{50.} (Deanne-Drummond, Genetics and Christian Ethics, 86-88, 108-110, 116). ^{51.} (Wilkinson, 129-141). ^{53.} (Deanne-Drummond, Genetics and Christian Ethics, 125-138); (Wilkinson, 186-196); (Green, Babies by Design, 33-42). ^{54.} (Wilkinson, 166-179). ^{55.} (Wilkinson, 29-40). ^{56.} (Swinton and Brock, 30, 163-178); (Cole-Turner, Design and Destiny, 85-88). ^{57.} Genesis 1:1-31. ^{58.} (Rolheiser, Against an Infinite Horizon. The Finger of God in Our Everyday Lives, 78-81). ^{59.} (Sandel, 45-62). 60. (Black, 19-26). 61. (Black, 19-32). 62. (Eiesland, Human Disability and the Service of God, 105-122). 63. (Eiesland, The Disabled God, 69-86). 64. (Au, 153-167). ^{65.} Isaiah 53: 2-5. 66. (Rohr, 12-25). ^{67.} (Green, Babies by Design, The Ethics of Genetic Choice, 171-196). ^{68.} (Deanne-Drummond, Genetics and Christian Ethics, 30-45). 69. (Wilkinson, 13-15, 173-179); (Deanne-Drummond, Genetics and Christian Ethics, 86-88). ^{70.} (Wilkinson, 134-146). ^{71.} (Wilkinson, 37-47). 72. (Glover, 172-191); (Cole-Turner, Design and Destiny, 12-15, 60-65). ^{73.} Catechism of the Catholic Church, n.2293, n. 2294, p.552; (Cole-Turner, Design and Destiny, 83-84). ^{74.} (Cole-Turner, Design and Destiny, 52-65, 98). ^{75.} Catechism of the Catholic Church, n.2277, p.549.

^{76.} Catechism of the Catholic Church, n.2276, p.549. ^{77.} (Deanne-Drummond, *Genetics and* Christian Ethics, 44-54, 149-150). ^{78.} (Deanne-Drummond, Genetics and Christian Ethics, 1-26). ^{79.} (Wilkinson, 21-35). ^{80.} (Cole-Turner, Design and Destiny, 99-105). ^{81.} (Cole-Turner, Design and Destiny, 1-6, 106-107). 82. (Deanne-Drummond, Genetics and Christian Ethics, 41-54). ^{83.} (Deanne-Drummond, Genetics and Christian Ethics, 112-124). ^{84.} (Eiesland, *The Disabled God*, 67-71, 83-84, 92). 85. (Deanne-Drummond, Genetics and Christian Ethics, 85-86, 101-115). ^{86.} 1Kings 19:11-13.